



the insider



Spring 2021

Family Days – We will be back!

CICRA Family Days are a very big part of what we do as a Charity, and please be assured that just as soon as it is safe for us to do so, and Government restrictions allow, we will be aiming to get arrangements in place to resume regional Family Day events. Please keep a look out on our website and Social Media for further announcements.

Inside >

Page 3 – Introducing our new ‘Dynamic Duo’ Medical Directors

Page 5 – Everything you need to know about Oral Crohn’s

Page 8 – Exciting News from the Paediatric Gastro Team at Cambridge

cicra 

better lives for children with crohns and colitis

Contents

Medical Director Duo	3
Ask the Doctor	4
Oral Crohn's disease	5
DAD'S Despair	6
Exciting news from Cambridge	8
inspirational stories	10
200+ Club	11
Wonderful fundraisers	12
AGM highlights	14

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CICRA Finances 2020



Can I thank you all you for the fantastic support we received from you in 2020. Our income fell by between 23% and 59% compared with each of the preceding 6 years. Like all other charities this was due to trusts and corporates diverting their funding to causes directly linked to COVID with sponsored and community events ceasing completely.

However, your support in maintaining donations and 200 club memberships, supporting our COVID appeal and our raffles and Christmas Card sale ensured that not only were we able to maintain our support services but the trustees felt confident enough about our finances to commission two new research projects mid-year.

We cut out all non-essential spend and with research projects having to be put on hold by the hospitals we were able to break even.

With the fundraising landscape so unclear we have set an income budget for 2021 similar to our 2020 outcome. We have set our expense budget to match this which requires us to continue to avoid all non-essential spend and not replace staff who have left. Family support will continue throughout but

we are budgeting it at 60k less than our original 2020 plans. More positively we are committed to 120k of research spend in 2021 for which we will need to raise extra funds for or use our limited reserves.

The Trustees have agreed that we will monitor income during 2021 at each trustee meeting and hopefully if we can start to rebuild income levels this will allow us to release funds for further research.

2020 could so easily have been the year that CICRA had to use all income to maintain its existence as has been the case for so many other charities. With the essential continued support of our membership, we have ensured that a high percentage of our income continues to be spent on our charitable support and research activities.

We face a number of challenges to rebuild our income to our prior year levels but in a year, we really needed your support you truly stepped up – Thank You!

Simon Coleman
Treasurer.

CICRA Videos

In 2018 we were fortunate to receive funding from Amgen to cover the cost of producing information videos about childhood IBD. We have interviews with consultants and health professionals covering almost all topics from diagnosis to treatments to wellbeing. We also have interviews with young people on how the condition has affected them and how they manage symptoms, procedures and treatment. These videos can be seen throughout the CICRA website and on Youtube.

Medical Director Duo



If it had been any other year when our Medical Director, Dr Richard Hansen was due to hand over to his successors it would have been at our AGM as part of a Family Information Day. This would have given us the opportunity to thank him personally and to welcome his successors Dr Kate Blakeley and Dr Jenny Epstein. The best we could do in 2020 was to make the formal announcement at our virtual AGM. We take this opportunity to thank them publicly now.

We have been very fortunate to have had Dr Hansen, Consultant Paediatric Gastroenterologist at Glasgow Children's Hospital as our Medical Director for the last three years. As a consultant in a very busy unit, we are extremely grateful for all the help, advice and time he has given us. Many members will have seen Dr Hansen at our Family Days and appreciated him sharing his knowledge in a way that we could understand, especially about research on the microbiome and his involvement with the research on the CD Treat. We wish him well and feel sure that we won't have lost him for good and hope to see him again when we get back to having some form of Family Days.

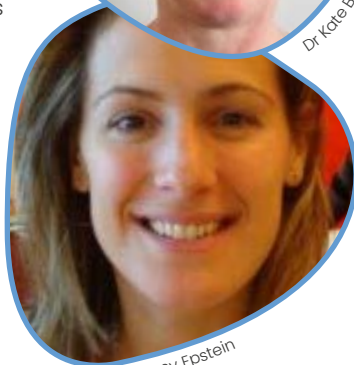
We are pleased to announce that Dr Kate Blakeley, Consultant Psychologist at the Royal London Hospital and Dr Jenny Epstein, Consultant Paediatric Gastroenterologist at Chelsea & Westminster Hospital, and former CICRA Fellow, have agreed to become joint Medical Directors, a first for CICRA.

Dr Blakeley has been attending our Family Days for years now, giving presentations, and advice on psychological issues in the Living and Coping sessions. This has been greatly appreciated by all the families who have attended these sessions. Dr Jenny Epstein was a former CICRA Fellow who received her training under the guidance of another well-known name, Professor Ian Sanderson, and currently serves on our Medical Advisory Panel reviewing our research. Dr Epstein will be able to advise on all our clinical aspects of Inflammatory Bowel Disease.

With Kate as our 'go to' person if we have any coping and psychological queries and Jenny for any clinical problems, we are delighted to have them join our team. We look forward to seeing them when we do get to hold Family Information Days again.



Dr Kate Blakeley



Dr Jenny Epstein



Working together for everyone affected by inflammatory bowel disease

IBD UK

IBD UK was formed as a group by CCUK to raise the standards of care for patients with IBD. CICRA have always been represented even though, obviously, children are a small percentage of the total number of patients. In 2009 Trustee Rod Mitchell and I were pleased to be invited to be at the launch of the first set of Standards for IBD at the House of Lords, The Welsh Assembly, Stormont and Holyrood Parliament. Over the last three years a lot of work has gone into updating these standards and they will be launched in the coming months.

This group is still led by CCUK and we thank CCUK's CEO Sarah Sleet and Jackie Glatter for all the work they do as Chair and Secretariat. We are grateful to Trustee Nicola Pitney-Hall who has taken over from Nick Posford as CICRA's representative and we look forward to continuing as the voice of the children.

Margaret Lee



Ask the Doctor

How can IBD affect your mental health in relation to your feelings and mood in general? Are there any links between IBD and depression?

Any long-term health condition can affect our mental health especially if there is no 'end' to the illness as there is with IBD. There are certain stages of IBD which are more likely to have a significant impact on mental health and these are diagnosis, frequent relapses, difficulty getting the disease under control, with loss of confidence in medical treatment and need for escalation of treatment. These are all good reasons to involve someone with knowledge of IBD who can give psychological support such as your IBD Nurse Specialist who might suggest referral to a Paediatric Clinical Psychologist who works with the IBD team where available.

Of the referrals I get from The Royal London Children's Hospital Paediatric Gastroenterology team by far the most are in relation to low mood and depression in children and teenagers who have IBD. This is often around the period of diagnosis when the child or teenager is feeling very unwell, tired, in a lot of pain and often undernourished as a result of their inflammatory bowel disease. Reassuringly 90% of the time their mood improves as their health and general physical wellbeing improves. It is very difficult to formally diagnose depression with active IBD as the physical behaviours of tiredness, lack of motivation, loss of appetite etc are difficult to identify as being caused by exclusively by either physical or mental health. However, if there are more specific mental health symptoms of suicidal thoughts and the child is acting on them in any way this should always be managed by an appropriate mental health professional and may need referral to the local Child and Adolescent Mental Health Team.

An extended period of illness with IBD or difficulty getting the IBD under control can lead to low mood and frustration that nothing is working. Depending on the child's age this can be expressed in behavioural ways such as not participating in the usual daily routines or expressing a wish to die in frustration rather than wanting to do this. It would be important to have a formal assessment of mood if the child or teenager is taking Steroid medication as these can cause mood and behaviour changes.

Dr Kate Blakeley
Consultant Paediatric Psychologist
CICRA Medical Director



My son, 9yrs, has recently been diagnosed with IBD and OFG so has to follow a cinnamon and benzoate free diet. Could you recommend a liquid paracetamol with no benzoates in that I can give him please? I cannot give him Calpol or Calprofen.

We do not know of any liquid paracetamol preparation that doesn't contain benzoate. Effervescent (dissolving) paracetamol tablets are benzoate-free but only come in 500mg, so your son would need to weigh at least 33kg to safely take that dose. Or you could use paracetamol suppositories (insert into the bottom), which do come in smaller doses. Ibuprofen (eg Calprofen) should be avoided in general in IBD.

Dr Jenny Epstein
Consultant
Paediatric Gastroenterologist
CICRA Medical Director

Although, my son was diagnosed with UC 4 years ago, no GP, consultant, nurse has ever told me not to give him certain pain/fever relief. I've been told no aspirin, no ibuprofen etc by another mother whose child has UC. Can you please advise, what pain/fever relief is recommend for a 17 yr old with UC. Many thanks.

Paracetamol is safe and should be the starting point. We generally advise people with IBD to avoid ibuprofen, because there is a possibility it can trigger bowel inflammation and it can cause stomach irritation / bleeding / ulceration. If paracetamol is inadequate and on balance you feel the symptoms are bad enough to warrant it, then the odd dose of ibuprofen here and there is likely to be fine, especially if the colitis isn't active, but it shouldn't be used on any kind of regular basis. Aspirin is no longer recommended as a pain killer for any child. Unfortunately, most pain killers (other than paracetamol) are not very kind on the gut, plus, they tend not to work very well for tummy ache in general.

Dr Jenny Epstein
Consultant Paediatric Gastroenterologist
CICRA Medical Director



Oral Crohn's disease

A rare form of Crohn's disease, more common in children than adults. Can be very painful and disfiguring

Crohn's disease is a chronic inflammatory disease of any part of the gastrointestinal tract. In Oral Crohn's the affected site is the face and mouth. Oral Crohn's disease is one of a number of conditions sometimes known as Orofacial Granulomatosis (OFG)

Clinical Features

- Common features of the disease are facial and lip swelling with soreness and cracking at the corners of the mouth (called angular stomatitis)
- The cheeks and lips, and occasionally the palate, can be seen to have a cobblestone appearance
- Mucosal tags inside the mouth
- Mouth ulcers
- Gum swelling (hyperplasia) and redness
- Under the microscope (histology)
- Oral Crohn's looks exactly like gut Crohn's

Will my child get gut disease?

- Not necessarily
- Oral Crohn's can occur on its own
- More than 60% on first presentation do not have gut disease
- A few will go on to develop gut symptoms (30% over 10 years)
- Some patients develop oral Crohn's after gut disease (80%)

Who can I go to for advice?

- Ask your doctor to refer you to the nearest teaching hospital
- Most oral medicine consultants deal with oral Crohn's

What will they do?

- They will ask you questions about your child's mouth and gut and also take a dietary history
- They will take a biopsy to make a diagnosis
- They will also do patch testing to exclude allergy to common foods or additives

What is the most common worry?

- Most children and teenagers are worried by the appearance

Can Oral Crohn's be treated?

- Yes
- Whether you have gut lesions or not some treatment can be given

What treatment is available?

- Exclusion diet - this tries to reduce the intake of food which may make the swelling worse. Some centres are very strict while others try and exclude specific components in the diet only.
- A mouthwash or paste for mouth ulcers
- Injections into the swelling on lips or cheeks to try to improve the appearance. This usually results in a good cosmetic result.
- It is not a good idea to have cosmetic surgery as the swelling returns quickly and lots of scarring may occur. Surgery may sometimes be necessary but should always be done in conjunction with a physician's input.



DAD'S Despair

We print below the journey that Ben, 17, made, supported by his close family, and told by his Dad, Stefan, who, went from despair while watching Ben suffer, to contentment once he received the correct treatment.

Ben's diagnosis came in September 2019 at Queens Medical Centre Nottingham after what seemed like nearly five years of appointments with GPs and Gastro specialists locally resulted in misdiagnosis ranging from constipation to toilet anxiety.

My wife Suzanne and I had started to notice Ben was spending longer and longer on the toilet daily before school to the point where he was cutting it fine in making it to school on time. Eventually Ben started to miss the start of the school day and when he was in school, he was missing lessons due to being on the toilet with a constant discomfort and never feeling complete. We also noticed Ben's reluctance to want to go out from home more and more and his socialising with friends became either online or they would come to our house.

In the build up to Ben's GCSEs Suzanne and I along with Ben spoke to his Head of year about the difficulties and anxieties Ben was facing daily and thankfully his school were so understanding and made it clear that Ben would never be penalised for late attendance or missing lessons and any work could be completed at home if necessary. Additionally, Ben was offered the use of a student support centre, a safe place he could work in school if feeling he could not attend lessons along with pastoral care.

A family holiday

In August 2019 we booked a last-minute family holiday to Crete at a seafront complex making sure everything was in place to make it as easy as possible for Ben to enjoy without the stress of leaving the hotel daily. It was one morning when I checked on Ben and he told me what was really going on. He showed me the

blood and what seemed like a mucus on the loo roll and in the toilet. On returning home from our holiday, I went to see Ben's GP with photos of what we had seen and thankfully Ben was referred to the children's Gastro team at QMC pretty much straight away, quite soon after that Ben received an appointment for a Colonoscopy and Endoscopy. Finally, we thought we would get some answers to what was going on.

A diagnosis at last

On the day before Ben was due to go into hospital, he took the preparation prescribed to clear his bowel which was uncomfortable and most of the day was spent on and off the toilet.

Next morning and an uncomfortable journey to Nottingham of around 45 mins to have his Colonoscopy resulted in a clear diagnosis of Ulcerative Colitis (Proctitis) Inflammatory Bowel Disease. We had heard of Crohn's and Colitis but didn't really know much about it at this point and Ben was discharged with Salofalk Enemas to be administered daily along with Mesalazine tablets to be dissolved in water daily.

Suzanne and I thought this would be the start of Ben learning to manage his IBD with the right medication but after only 3 days of Ben trying to take an enema, he couldn't cope with it and was refusing to take medication in this style.

I spent many hours writing emails and having conversations with

the IBD nurses at QMC explaining how this was affecting Ben mentally and his toilet time was now increasing to 3-4 hours at a time, but they always told us they couldn't help with the psychological impact of IBD.

Ben tried a course of oral steroids around November 2019 and although these helped Ben gain weight and start to look healthier they had no effect on his symptoms or the length of time he was spending on the toilet. Ben was now pretty much homeschooling with full support of his teachers due to his condition worsening.

Tears of hopelessness

Finally, I'd hit rock bottom and after everyday consumed conversations with IBD, which looking back didn't help Ben at all, it just increased his stress levels. I often spent days alone in a Royal Mail van getting





more and more frustrated, sometimes reduced to tears of helplessness, that is when I decided to reach out to CICRA.

I spoke to Jayne who put me in touch with the CICRA family support worker Laura. After around an hour and a half talking to her about not only how Ben was affected but how I felt and how it was putting such a strain on us all I felt like I'd offloaded all my worries and concerns about what we were going through as a family.

It wasn't long before I spoke to Laura again and she linked us to a lovely parent Jen who has exactly the same colitis as Ben and we arranged to have a conversation with her to see if she could offer any advice.

We spoke to Jen very soon who was so understanding of how Ben was feeling and also how Suzanne and I were coping as parents, she made us feel like we had been friends for ages.

Jen connected us to Seb who works closely with the NHS and Dr Rob Heuschkel at Addenbrookes Hospital Cambridge where we were invited to take Ben for a second opinion.

Hope at last

The journey itself was traumatic for Ben with limited toilet availability on dual carriageways resulting in a panic attack which was a new experience for us all.

On arriving at

Addenbrookes Jen had agreed to meet us for support as she was familiar with the hospital and also got to see first-hand what Ben was going through when he missed the first half of his appointment due to being on the toilet.

Dr Heuschkel recognised straight away and explained to us that Ben's Proctitis shouldn't be controlling his life in the manner it was. He removed all the stress of medications related to IBD saying "we needed to get Ben back" before thinking of more medical intervention for his Colitis.

Appointments were arranged with Sally and Sri in the children's psychology and psychiatry department and Ben started (due to COVID-19 restrictions) video meetings to work on his anxiety and insecurities related to living with IBD.

Sri recognised that Ben required medication to help him with his anxiety and after around a month of being on his new medication and weekly chats with Sally, Ben's outlook and condition started to become greatly improved so much so that when school reopened after summer holidays Ben returned to all his lessons arriving on time with no interruptions to his day to use the toilet.

Help from CICRA's Epal scheme

Ben now manages his Colitis very well and with full support of his close family and girlfriend continues to make substantial progress and is working well from home during the current COVID-19

restrictions.

Ben is a key member of CICRA E-pal program helping children and teenagers connect with each other, so they don't feel so alone living with IBD. He also helps Seb Tucknott where he can with research for his company IBDRelief.

Personally, I can't thank CICRA enough, especially Laura, the family support worker, for all the hours she spent listening to my worries and concerns and helping us make the right connections to get Ben the help he so needed. We no longer feel alone living with IBD and urge any family to reach out to CICRA.

If you would like your story published in a future newsletter please send this together with a photograph to support@cicra.org



Exciting news from Cambridge

In 1998 Dr Rob Heuschkel became one of CICRA's Research Fellows under the guidance of Professor John Walker-Smith at The Royal Free Hospital, London. Who could have guessed that from those early days of training, a dedicated gastroenterology service for children in the East of England would emerge some years later. CICRA have been pleased to have been part of this extraordinary success story. Our thanks to Rob Heuschkel, Dr Matt Zilbauer, Mary Brennan and many others who have joined them at Addenbrookes. And special thanks to Rob for developing this leading clinical gastroenterology service. Not only are the East of England fortunate to have such a dedicated team but all children with IBD will benefit in the future from their excellent research.

12 years of Paediatric Gastro in Cambridge – care and research for children with IBD (2008–20)

In 2008 there was no dedicated gastroenterology service for children in the East of England. Outreach to Addenbrookes had long been provided by London centres until efforts by clinicians and commissioners in the East of England secured funding for a Consultant post at Addenbrookes. In January 2008 Rob Heuschkel (CICRA fellow 1998–2000), together with Mary Brennan (Paediatric IBD Nurse & long-standing CICRA Meeting faculty member) moved to Addenbrookes from the Royal Free Hospital in London to develop a clinical paediatric gastroenterology service for the region.

Since then, the East of England Paediatric Gastroenterology Network (EPPGN) has been strengthened, with regular meetings and closer links between the 17 hospitals in the region. The service in Cambridge provides access to timely endoscopy, management of complex patients and established a clinical IBD service. The regional demand was significant, especially in the number of children and young people with IBD.

In 2010, there was a significant expansion of the clinical service, with the appointment of former consultant colleagues from the Royal Free Hospital, Drs. Camilla Salvestrini and Franco Torrente, both bringing experience and commitment to the rapidly growing in- and out-patient service, especially important in the absence of dedicated trainees at that time. We also appointed key roles for a regional service, including in psychology, speech therapy, as well as more specialist nutrition nursing and dietetic time.

That same year we were also able to appoint Dr Matt Zilbauer, previously a Lecturer at the Royal Free, as a temporary Clinical Lecturer in Paediatric Gastroenterology to complete his clinical training and aim to develop a sustainable research theme. Our vision was to develop a fully integrated translational research program within the growing clinical service, similar to the successful model started by Professor John Walker-Smith (lifetime CICRA President) many years ago at St Barts.

Initially it was in fact the Dept of Medicine that provided the all-important funding, space and academic oversight. This gave us valuable time to build the case for a longer-term future for academic paediatric gastroenterology in Cambridge.

Following some good early research output, then with support from the Dept of Paediatrics, Matt was appointed as a substantive University Lecturer in 2013. During this time, we began attracting small amounts of grant support for our early research efforts, benefiting from key CICRA seed funding to establish our own laboratory space and begin building the foundations of a sustainable research program through high quality research output.

In 2012 we began our overseas clinical fellowship program, attracting committed and excellent trainees, largely from Europe, to our offer of clinical and research opportunities. Mostly self-funded, these outstanding individuals supported our rising clinical activity, but also delivered clinical and laboratory research output. Of note was Marco Gasparetto, who joined in 2012 as a visiting fellow, obtained a CICRA fellowship (2015–2017), finally leaving us in 2018 with the Cambridge University prize for best MD, a first author paper in Gastroenterology, and a Consultant Paediatric Gastroenterology post at the Royal London Hospital. We have been fortunate enough to continue attracting excellent fellows from around the world, learning from them just as much as they create the energy and critical mass to drive out training and education efforts.

At present the paediatric IBD service led by Dr Torrente cares for over 300 children with IBD, much of the care delivered in various shared care arrangements closer to home. Over 50% of outpatient contacts are now taking place by video or telephone. From the very outset, the IBD service for children received outstanding support from Mr Justin Davies, an adult colorectal surgeon, later joined by Mr Michael Powar, whose dedication and expertise continues to benefit children and young people with IBD across the region.

With the support of our excellent fulltime research nurse, Claire Glemas, we have been able to continue recruiting children for research samples throughout the pandemic, with over 90% of



patients and families undergoing endoscopy consenting to provide biopsies for our studies. Our translational program now recruits an average of 150 children / year, with well over 1000 blood and 3000 tissue samples now collected for research.

We have recently completed 4 years as members of the US-based ImproveCareNow program, something we hoped would help manage our patient population more effectively and proactively, and in fact led us to now develop our own IBD dashboard within the EPIC system, linking in with a growing transition program to adult gastroenterology. We will also launch on March 1st, the first UK based, comprehensive online educational program for children and families. This resource – IBDmate – developed in collaboration with IBDrelief, will provide children, young people and families with access to over 150 videos on subjects on and around IBD – insights and information from members of the clinical team, as well as from patients and families.

Building an International Centre for Research in Paediatric Gastroenterology

During the last 10 years we have established a broad and productive translational research programme investigating intestinal health and disease. Taking advantage of our growing patient cohort with access to human gut tissue, we established a network of collaborations with a range of scientists based on the Cambridge Biomedical Research Campus, Cambridge University, the Wellcome Sanger Institute as well as The European Bioinformatics Institute (EBI-EMBL). Supported by this unique, world class research & academic environment over the last decade, we have been fortunate enough to have secured over >£5 million in grants for our laboratory group over the past 3 years, that currently stands at about 10 team members. The lab now caters for post-docs, bioinformaticians, PhD students, research nurses, technicians as well as visiting scientists and undergraduate students.

One of our main areas of focus is the role of epigenetic mechanisms (i.e., DNA methylation) in regulating gene expression and cellular function in the human gut lining. We have been exploring these changes during healthy development as well as in the gut

of children newly diagnosed with IBD. In addition to studying the small biopsies we obtain from consented children during endoscopy (e.g., genome wide multi-omics profiling), our group has also established a human gut 'organoid' model system (Figure 1). This provides us with amazing opportunities to study gut health and disease in a patient's 'mini-gut' in a dish. Results of our work on this advanced technology has highlighted, and is extending, the use of these research tools in IBD.

Cambridge Centre for Clinical and Translational Research in Paediatric Gastroenterology, Hepatology and Nutrition

Based on the growth and expansion of both our clinical and translational research programmes we will be formalising our group as the 'Cambridge Centre for Clinical and Translational Paediatric Gastroenterology, Hepatology & Nutrition'. This centre will coordinate our clinical and research efforts as we focus on areas to develop over the next 10 years. In addition to focussing on research in paediatric IBD, we will continue and further expand on our work in other related areas including gut infection models (e.g., viral and bacterial infection – OrganoVir), cancer development (in collaboration with Cancer Research UK Cambridge) and basic cell biology (e.g., investigation of epimutations during clonal expansion). Teaching and training will form a cornerstone for our centre, building on several core clinical and academic training opportunities – including PhD studentships/fellowships, a University of Cambridge Academic Clinical Lecturer post in Paediatric Gastroenterology (first candidate to be appointed in end 2021), all hoping to attract high quality researchers with an interest in paediatric IBD from around the world.

Whilst initially located within Cambridge University Hospital NHS Trust (Addenbrookes), the Centre will soon be located in the new Cambridge Children's Research Institute, which will form an integral part of the Cambridge Children's Hospital, planned to open in 2025/26.

Our long-term vision is for our Centre to develop into one of the world's leading research institutes for Paediatric Gastroenterology.



We always look for inspirational stories of overcoming IBD and on these pages are two very different, but equally inspirational stories of how Dr Laura Hinchliffe, with 21 years of coping and Noah Bawdon, just 11 and recently diagnosed, not only cope but are helping others by raising funds for CICRA.

Dr Laura Hinchliffe (21 miles for CICRA) £2,126

I was diagnosed with Crohn's disease when I was 10 years old, and spent years trying various medicines and treatment. I found it hard to deal with when I was younger, because at school all you want to do is fit in, and I was "the sick kid". I had to be tube fed on several occasions, and at one point learnt how to pass the nasogastric tube myself, so that I could replace it every day and didn't have to wear it at school during classes.



Most of my healthcare was advised by my consultant at the hospital, but my parents explored every avenue possible to help me get better, paying for things like acupuncture and homeopathic remedies. The weirdest was definitely trying helminth therapy. For those unfamiliar, this is essentially deliberately infecting yourself with the eggs of a parasitic worm, thought to benefit inflammatory diseases.

Although I had periods of being well, these were short-lived and I eventually had life-saving surgery at 15 years old when my bowel perforated, resulting in removal of my colon and a permanent ileostomy. My recovery took a while, so I ended up leaving school for a year to get better.

Although surgery wasn't what I wanted, I was finally able to start living like a normal teenager. I completed my bronze, silver and gold DofE, and Queen's Scout Award. I went to university and got 3 degrees, including a PhD. I learnt how to scuba dive. I ran multiple marathons. I travelled to America, Brazil, Paraguay, Egypt and more. All these things are possible for me now because

of my surgery, and I'm so grateful to all healthcare workers who got me there.

As of now, I've lived with Crohn's for 21 years, so I decided to run 21 miles to fundraise for CICRA on Ostomy Awareness Day. It was wet, windy and fairly miserable, but the motivation of so many people who generously donated was enough to keep me going to the finish line.

Charities like CICRA have helped advance medicines and ostomy supplies over the years, giving people like me a much greater quality of life. The support they provide to families and young people is incredible, and I'm so glad that I can do my bit to help support them.

Noah Bawdon Raised £1,272

Noah was diagnosed with Crohn's disease in December 2019. He started to show signs of being unwell just 3 months before. He had mouth ulcers and tummy pain but after several visits to the doctor we were reassured it was nothing to be concerned about. After losing weight, and further tests, Noah was referred to a specialist at Bristol Children Hospital.

Booked in for a colonoscopy a week before Christmas Noah had to eat a bland diet for 3 days and just liquid for 24 hours before the procedure. The IBD nurse said that they had found ulcers in his colon and, although mild at this stage, it was a clear indicator of Crohn's disease. Myself and my husband were very upset, but Noah was very positive about everything.

To give his body chance to reduce the inflammation and potentially put his Crohn's into remission Noah had to follow a 6-week liquid diet. Being a week before Xmas the nurse suggested Noah start on the 1st of January. He was able to



enjoy his favourite food over the festive period, but we were aware the 6 weeks following would be a challenge! Noah had a goal after the 6 weeks as we were going to Austria and he wanted to have his favourite milk shake in a café we had visited in 2018.

The liquid diet was tough for him. Especially at school and not being able to eat school lunch with his friends. However, we started to see his health improving. His skin was better, and he was getting some energy back. However, I remember a particular day when Noah was tearful because there was a special treat at school where pupils could have sweets after class, but he was not able to take part! He also experienced some bullying about the drink he had at school and teachers not letting him go to the loo when he needed to!

Once his 6 weeks were over, we were hopeful Noah wouldn't need to receive medication and would be in remission, but it wasn't to be! His bloods did improve, and his weight was up but the specialist felt he needed to be on long term medication as, being so young, his growth was at risk. He started on a biologic which had good results and few side effects. It was a fortnightly injection that could be administered at home by us and would impact on his immune system but reducing the inflammation and controlling the Crohn's. It would also mean Noah could eat a normal diet, but he needed to eat a healthy balanced diet. Within a month you could see a visible difference in his health. His tummy pains had gone, and he was full of energy.

Unfortunately, when COVID started in March his regular activities stopped. He decided in October that he wanted to do his run as he was missing football and we suggested he could raise some money for charity. He would run twice a week, once with me and once with my husband and he ran in all weathers! He was very proud



to have got so many sponsors and we are so grateful for all the people who sponsored him and hopefully he is able to help towards the future of treatments for IBD.

It's definitely a journey we are going through and hopefully we can learn to accept and make the most of the situation. It is tough sometimes and in the middle of a pandemic it feels all the more challenging, but Noah has shown resilience and courage and we are very proud of him.



Christmas Cards sales up thanks to Jayne and David

When the first lockdown hit us at the end of March 2020, we were already looking at Christmas Cards. Little did we know what was to come. At this point we had a very generous offer from Jayne Boyd-Bell and her husband David. As David had recently retired and Jayne had cut down her hours, they offered to come into the COVID secure office on a voluntary basis and take over the complete Christmas Card process. Cards for Good Causes struggled to find suitable shops so we had to drop out from this scheme for the first time in about 20 years. However, the good news is that the sale of cards went very smoothly thanks to Jayne and David and sales were up 10%

We thank those who continued to support us, particularly Jean Gooding, who despite the problems, once again managed to sell hundred of pounds worth of cards, all helping to fund our research and support programmes.

200+ Club

Thank you to all supporters of this scheme. This is greatly appreciated and particularly to receive donations from the prize winners in this difficult year. If you would like to join for 50p a week, payable quarterly, half yearly or annually by Standing Order or annually by cheque/website, please email support@icra.org or ring 0208 949 6209 and we will send the forms. For over 20 years this fundraising scheme has helped us support research which has brought about improvements in diagnosis, treatment, and management of IBD and hopefully will eventually lead to discovering the cause and a cure.

200+ Club Winners

July 2020

129	J Parker, Somerset	£50
13	G O'Neill, Gloucestershire	£50

August 2020

26	M Patten, Kent	£50
103	W Dando, Wales	£50

September 2020

93	A Tucker, Devon	£250
149	A Kelly, Gloucestershire	£75
184	C Dickinson, W. Midlands	£75

October 2020

49	T McErlean, W. Sussex	£50
58	M Moore, Bedfordshire	£50

November 2020

116	R Smith, Norfolk	£50
31	T Tweedie, Scotland	£50

December 2020

25	S Anderson, Surrey	£250
78	M Cox, Dorset	£75
55	M Cottrell, Wales	£75



Wonderful fundraisers

Welcome to our Fundraising pages in which we give well deserved thanks to you – our amazing supporters who work so hard to raise money for CICRA.

In common with other Charities, the past 12 months or so have been extremely tough for us as the Covid virus not just wreaked havoc with our everyday lives but also massively reduced the number of charitable events held and thus subsequently led to a big decline in our income.

You have been incredible in the ways you have adapted to try and still hold events and keep the money coming in and for this we offer our sincere thanks. Now more than ever, every penny really does count, and over these pages we take the opportunity to acknowledge just some of our awesome fundraisers.

Christmas Crafts bring festive cheer

Joanne Chilcott is an inspirational fundraiser, and in the run up to Christmas held popular online classes to help people create their own Wreaths. Clearly a winning idea with an amazing £800 raised. Grateful thanks to Joanne and her followers.

'Eyes Down' for fun and funds

Who can resist a fun game of bingo – especially when you are in 'Lockdown' Clearly friends of CICRA supporter Tasha Burney can't as they together raised another £45 towards our ongoing research. Thank you all.

Masks make money

Thant Phway has been working hard again making face masks since March 2020. It has become a hobby but, as her son suffers with IBD, a great way to raise funds for CICRA. Both adult and children's masks are unique and clearly in demand raising £360. Many thanks Thant.

Crafty Cards Create Copious Cash

Its always pleasing to receive a card on that special occasion, and even more so when that card has been handmade. Nathan & Rebekah Arnold (Dad and daughter) spent time together making and selling their cards, and thanks to their

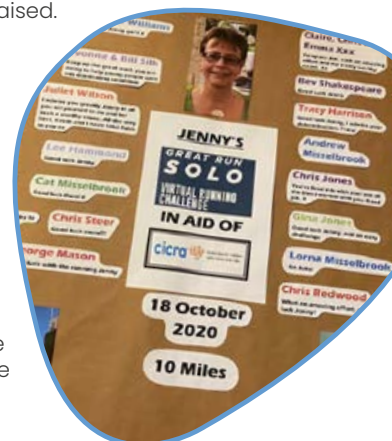
efforts an amazing £210 was raised. Thank you both for your awesome support.

Amelia Streams Success

One of our younger members Amelia Jones was not prepared to let being stuck at home in 'Lockdown' affect her fundraising efforts. Amelia tells us, " I am a small content creator know as Panda GirlMC and I am doing charity live streams and fundraisers for CICRA because I want to help fund research into Crohn's. I have recently been diagnosed with it and I want to help raise awareness of the disease and help fund research into a cure" What a great idea Amelia, and many thanks for the amazing £140 raised.

Jenny's Great 'Solo' South Run

Supporter Jenny Steer was not one to be deterred as she planned her 25 Charity runs of at least 5km An update read: I am running on the treadmill now the weather has turned, and will create a poster to wrap round it with pictures of Portsmouth and names of everyone who has donated, ready for the virtual Great South Run. Update:



I did it. I have run over 101 miles. Thanks to everyone for your unbelievable support and I know CICRA will put this money to good use!" Thank you Jenny for your continuing support with almost another £1000 towards CICRA Research.

The Clayton's Kerbside Shop does roaring trade

With people setting up little stalls on their driveways or in their gardens during lockdown young enterprising CICRA members Lucas & Joanna Clayton did just that to raise money for their favourite Charity, as they set up their 'Kerbside Shop'. With support from Mum Joanna, they did a roaring trade raising £155 to help with our Research. Thank you both very much.

Classic 'Great North' also goes Virtual

The atmosphere at the Great North Run is incredible with true 'Geordie' hospitality and still very popular. Sadly, in 2020 the event fell victim to Covid, but two of our supporters carried on undaunted by taking part virtually.



On 13th September at 10.30am, Simon Burchell started with the virtual GNR mimicking the usual race format with all runners starting at the same time and completing the 13.1 mile distance, but rather than with others around the streets of Newcastle and cheering crowds he ran around the footpaths of Northamptonshire on his own! but as encouragement Simon's young daughters



Martha and Lucy supported his efforts Martha completing a 2 mile run and Lucy a 1 mile course. Well done girls! Thank you for raising £800 shared between us and Prostate Cancer.

Pam Westhead was clear why she was taking on the event: "It's been a challenging year with my son Alfie being diagnosed with Crohn's. We are incredibly proud of his attitude and determination. He loves sport so that is why I signed up for the Virtual Great North Run to help raise funds for CICRA." Pam paced along the streets for the 13.1 miles setting herself a target of £100, but thanks to her generous supporters, raised well over £1000.

Manni's Raffle raises £2,192

A raffle, which included prizes from 26 businesses in Wombourne, raised £2192 for CICRA. The raffle, which took place on Christmas Eve, saw a star prize of an alcohol hamper worth £400. Businessman Manni Massey from GM Home Discounts decided to organise this after speaking to Gail Crompton, mother of schoolgirl Isabelle, 14 who suffers from Crohn's disease. Collection boxes in GM Discounts added £150 to the total. Grateful thanks to Manni, Gail and the businesses around Wombourne who made donations.

Emily's Amazing Cycling Journey

A cycling tour was Emily Brady's way to help two favourite charities. Stage one of the tour was completing a 380km cycle from Dover, along the South coast to



Portsmouth then stage two, a tour around the beautiful Isle of Wight. A massive thanks to Emily for the most welcome sum of over £1600 received as a result of all the peddling.

Play it again 'Ryan'

As Covid hit so many fundraising activities, people have come up with imaginative ways of securing sponsorship. Ryan Wyness did something completely different by playing the Alkaline Trio album 'From Here To Infirmary' in its entirety on his guitar, live on Facebook on Sunday 23rd August 2020. A great bit of entertainment for a Sunday at home, and we applaud him for the amount raised of over £150.



Steve's SJS 3 Peaks Challenge

Stephen Norman and a couple of friends decided to do some fundraising and chose to attempt the 3 Peaks Challenge. This meant climbing the three highest peaks in Scotland, England and Wales (Ben Nevis, Scafell Pike and Snowden), all in 24 hours including travel time. Our intrepid climbers more than doubled their target by raising in excess of £700. Thank you guys so much.

Karen's Big Birthday Bash

Karen's son Tom was diagnosed with Crohn's Disease two years ago years. With care provided by the wonderful team at Birmingham Children's Hospital he is now doing incredibly well. Recalling how scary the diagnosis was Karen kindly acknowledges that CICRA provided invaluable support to the family, and so for her 'Special' Birthday celebrations, her wish was to raise funds for research. We hope she had a lovely Birthday and thank her for the most welcome sum of £180

Nick's Jump for George

Nick Ellis-Gowland had plans for a sponsored tandem skydive, due to take place in June 2020 to raise money for CICRA. Sadly this was another victim of Covid restrictions but Nick will complete his skydive as soon as rules allow. In the meantime we thank all his generous supporters for the sponsorship monies already received in excess of £700. This challenge is in memory of Jill George and her wish to support her young grandson coping with IBD.



Pennies from heaven

Every penny really does help - especially when Charity incomes have fallen so much over the past year, and we send our grateful thanks to Simeon Greig for sending us the amazing amount collected in his penny jar and funds raised through the sale of some beautiful handmade cards made by Grandma Steph Bennett. Thank you to you both for the £152 raised which is very much appreciated.

Thank you to all of you who have worked so hard to raise money and apologies if you have not been mentioned this time. If you are thinking of holding an event please contact us for advice or guidance.



Highlights from the 42nd Annual General Meeting

Last year's AGM was, due to the Coronavirus pandemic, held virtually, on 31 October 2020, and below are a few highlights of the Report & Accounts 2019.

Finance – Total income: £290,505. Spend on Research: £41,178, Support: £202,777. Future commitments to research: £38,534. Following a review research will increase in coming years.

Research – During 2019 we continued to fund 1 Research Fellowship and 2 PhD Studentships. A new psychological research project was approved. Several bursary grants were awarded.

Membership & Fundraising – CICRA continues to offer free membership to parents, family members and those interested in supporting the work of the charity.

Support – Our 'Can't Wait' card and epal scheme continue to help young people cope with their condition. Information Days, were held in Plymouth, Newcastle, and London. Laura Palmer joined our team as Family Support Worker on a two-year grant from Global Make Some Noise.

Governance – The Board of Trustees met every six weeks and were responsible for determining policies, the budget and overall management plans.

Election of Trustees – Two Trustees, Simon Coleman and Paul Cooper stood down and sought re-election. Nicola Pitney-Hall and Chloe Malloy had been co-opted during the year and all four were elected to the Board.

Results of the CICRA Christmas Draw which took place on Tuesday 9th December 2020

Thank you to all who purchased and sold tickets for the Christmas Draw, particularly in such a very difficult year. After taking out prize money and printing of tickets, £5,142 went directly towards research. We thank David-Boyd Bell for coming to our offices in Sutton to make the draw. Some of the prize money was very generously returned as donations and greatly appreciated.

Thank you. Margaret Lee, Promoter



	Ticket No.	Name
1st Prize	035037	K O'Boyl, Worcester
2nd Prize	014629	K White, Bedworth
3rd Prize	012649	J Griffiths, Fareham
4th Prize	015585	P Stevens, Strood
5th Prize	003118	S Durman, Guernsey
6th Prize	007309	M. Street,
7th Prize	014105	A Parris, Selsey
8th Prize	058980	Fran, (Unable to trace)
9th Prize	030369	H Brims, Canisbay
10th Prize	043786	A Stirton, Bloxham
11th Prize	044399	R Ross, Poole
12th Prize	038042	E Rushton,
13th Prize	043823	S Carter, Abingdon



Fundraiser Extraordinaire

In the last newsletter we included an article about the amazing Alan Cresswell, Fundraiser Extraordinaire. We have to report the sad news that Alan passed away at the end of December. He was such a character, very generous and always seeing the positive side of life and in doing so was a joy to be in his company. Alan will not be forgotten in Tewkesbury and certainly not in CICRA. Alan and the 23 volunteers did so much to help families with Crohn's and Colitis in those early days raising funds and helping to create an awareness of this complex condition which was then comparatively unheard of in childhood.

Like so many others this year, Alan's funeral had to be small, but family and friends are hoping to have a memorial service when things get back to normal. R.I.P Alan

Wills and Legacies

Please remember CICRA in your will

Legacies are an extremely valuable source of income for all charities and CICRA is extremely grateful for any that we receive – whether large or small. Some donations come as a direct bequest and others as part of the residue of a will which is distributed to charities by the Executors/Trustees of the Will using their own discretion as to the wishes and desires of the deceased.

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

Making a will is very simple and you can do it yourself, but it may save problems arising later if it is done by a solicitor or with the help of the Citizens' Advice Bureau. Making a will is often spoken about but is something that we all tend to put off but if you die without making a will your estate will be distributed according to the law of intestacy and this might not be in accordance with your wishes.

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

"I give and bequeath the residue of my estate to the Crohn's in Childhood Research Association of Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey, SM2 6AQ and direct that the receipt from a Trustee of CICRA shall be a good discharge to my Executors"

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

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

"I give and bequeath the sum of £.....to the Crohn's in Childhood Research Association, Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey, SM2 6AQ and direct that the receipt from a Trustee of CICRA shall be a good discharge to my Executors"

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

In all cases, of course, the document must be correctly witnessed – not by family members.

How your gift can help

We will ensure that any gift bequeathed to us will be put to the best possible use for bringing improved outcomes for future generations and families. However, if you would like to specify how you want your gift to be used, we will try and ensure that we adhere to your wishes. Much of our world leading research programme has been made possible thanks to the generosity of gifts in wills.



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:

David Allen

Much loved uncle of a Crohn's sufferer, remembered with a smile, donation in lieu of flowers.

William Bines

Memories of happy times spent with Billy 'Dream On'. Margaret, Susan, Ian and families

Doreen Godsall

Mum/Nan will be remembered fondly by all of us and granddaughter Amelia, a Crohn's sufferer. Remembered with love by family and friends

Edward Taylor

Fond memories of a loving father, and grandfather of a Crohn's sufferer. Sadly missed by family, friends and neighbours.

Joyce Holder

Grandmother of two Crohn's sufferers. Remembered with love by all the family and friends

And donations in memory of:

**Matthew Gurney,
Ian Winzar and Katy
Jade Sutton**



4 easy ways to raise funds for children with Crohn's and Colitis while you shop online

From buying your holiday to fundraising on Facebook, it's easy to help children with IBD when you're online.

1

Turn unwanted stuff into charity donations with ZIFFIT

Have you been having a 'lockdown turnout' and don't know what to do with the unwanted goods. If so perhaps Ziffit can help. This is a free web and app service, that instantly values books, games, DVDs and CDs and the trade value can be donated directly to CICRA via Virgin Moneygiving. This is a quick and easy way for you to raise funds in four easy steps without it costing you a penny.

www.ziffit.com

ziffit.com

2



It's easy to create a fundraiser, share it with friends and reach your goal. Why not donate your birthday to children with IBD? You can easily create a fundraiser for CICRA, share it with your friends and encourage them to help you raise money on Facebook. People can donate to your fundraiser in just a few clicks without leaving Facebook

facebook.com/fund/CICRAcharity

3

AmazonSmile is a simple and automatic way for you to support CICRA every time you shop, at no cost to you. When you shop at smile.amazon.co.uk, you'll find the exact same low prices, vast selection and convenient shopping experience as amazon.co.uk, with the added bonus that Amazon will donate a percentage of the purchase price to children with IBD.

www.smile.amazon.co.uk/ch/278212-0

amazon smile
You shop. Amazon gives.

Raised to date
£2,475.45

4

Raised to date
£3,976.34

easyfundraising
feel good shopping

EasyFundraising is the UK's largest charity shopping fundraising site. Thanks to our members, CICRA has benefitted by just under £4,000 with no costs to our members or CICRA. When you do your shopping please remember that easyfundraising is partnered with many of the largest retailers and businesses who give a small percentage of their profit to chosen charities through this simple scheme

www.easyfundraising.org.uk/cicra/

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