



CICRA Family Days
Advice and support for returning to school
Ask the Doctors – Your questions answered

cicra

better lives for children with crohns and colitis

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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



looking to the future

Dear Friends

Although things remain very difficult, we are still hoping to have had a phased return to the office by the time you receive this newsletter. All necessary safety measures are being put in place so let us hope there will be nothing to stop us.

In earlier communications I said that, although reluctant to do so, we had to cut back on funding more research for the time being but that we were really pleased to have been able to fund the collaborative project headed up by Professor Holm Uhlig. I can now tell you that the Trustees have agreed to fund one other project at Nottingham University, led by Assistant Professor Moran (pages 6 and 7). The Oxford project will be pushing paediatric gastroenterology forward towards better and personalised treatments and the Nottingham project will be following up encouraging results on a potential new treatment for Ulcerative Colitis.

Although the outlook looks bleak for many businesses and charities the Trustees are working hard to make sure that CICRA is still here for when things improve, as they must. The world may never be the same again but hopefully we will soon get used to the new normal and work round this. As you will read later, Paul and Jayne are putting in place provisional plans for 2021, hoping that once the government lift the 'large gathering' ban we will be able to have those very popular in-person meetings again.

Not knowing how things will be at Christmas has prompted a few discussions about what to do about Christmas Cards. We are still not sure whether the Cards for Good Causes Shops, where we usually sell some of our cards, will be able to open, due to the size of the shops not allowing for social distancing. We have therefore, had to cut back on the number of designs we have ordered. We enclose the brochure for 2020 and if you choose to buy your cards from us we will be extremely grateful. We will be selling some stock from previous years as sale packs

on the website - www.cicra.org. All are very good value but there is low stock of some.

We wish you a healthy and happy winter season

Margaret Lee Chair of Trustees



words of wisdom from Professor John Walker-Smith. **CICRA's Life President**

At this time of great anxiety, it is so important for everyone to appreciate the need for resilience in this time of the corona pandemic. It has been my experience over many years that children with Crohn's disease and ulcerative colitis do display remarkable resilience as they adjust to the unpredictable burden of inflammatory bowel disease.

In the early days of diagnosis I found that children and their parents often ask the question Why me? This question is more powerful in a society of general good health and improving infant mortality and longevity, as compared to the situation of a child living in a society where poverty and early death are common place. Furthermore, in a society where celebrities are so admired, I found young patients could initially be angry, when they were first diagnosed. But it was my experience that most children developed resilience and hope.

Now hope comes from improved knowledge and the hope for improvement in treatment. This is where CICRA and the vision of the parent founders comes in. These original parent founders realized that research gave hope to their children. I have noticed at the national CICRA open days that child patients are encouraged and even inspired when they hear about the research being done to help them. What we have already learned from the Covid-19 experience, is that the need for research is urgent and vital. This appreciation should be a great encouragement to CICRA and its supporters. We should be encouraged by the general recognition in society, that research is vital.

Since I first began to care for children there have been great advances in chronic inflammatory bowel disease, at first related to more accurate and precise diagnosis and then improvement in management with enteral nutrition and a range of new drug therapies.

So, in this time of corona, we need both resilience and hope. The children of CICRA and their supporters, by their example, can show society at large how important these qualities are. Then I believe the general appreciation of the importance of medical research may inspire you all to even greater activity at a time when charity giving is more generally difficult.

John Walker-Smith is Emeritus Professor of Paediatric Gastroenterology of University of London. He is an Australian graduate whose professional life in Britain was based first at St. Bartholomew's Hospital with Queen Elizabeth Hospital for Children(1973-1995) and then at Royal Free Hospital (1995-2000). He is a pioneer of paediatric gastroenterology in the United Kingdom. He was First President of British Society of Paediatric Gastroenterology and Nutrition. He has a special interest in chronic inflammatory bowel disease in children. He has been Life President of CICRA since 1999.



John was the inspiration for parents to create CICRA and from day one was instrumental in giving sound advice, overseeing our very first information booklets and most importantly giving the best possible treatment and care to the first children diagnosed with IBD. With our funding he was able to pass on his skills to others via the three year CICRA Research Fellowship training scheme. His dedication throughout his career ensured that paediatric gastroenterology became the speciality it is today.

We thank John, on behalf of all parents of children with IBD for his continued interest in the children and their progress. We hope to see him at future CICRA Family Days, once we are able to get back to some sort of normality.

Margaret Lee

CICRA's commitment to research

Research to try and understand the complexities of Inflammatory Bowel Disease, in the hope of finding the cause and eventually a cure, are a very important part of what CICRA does and raises money for. Whilst waiting for the cure we know that the wealth of knowledge gained from CICRA's research has brought about many improvements in the daily lives of children and young people with IBD

"Research often seems

painfully slow and

very expensive but

without it we won't

find the answers we

are hoping for"

At the start of the year the current CICRA medical advisors were busily going through our rigorous peer review, to help prioritise the applications for funding. Then coronavirus threw the whole procedure into a lockdown of its own. University laboratories were closed or transformed into helping with coronavirus. Working from home and not being able to meet was difficult but with much help from the Chairman, Professor Ian Sanderson, and other members of the

MAP, excluding those barred by having a vested interest, we managed to complete the grading. We thank members of the medical profession who helped us complete this procedure so that we were able to be fair in our grading of applications. It became a very long, drawn out complex procedure

At this stage with complete lockdown and fundraising at a standstill, the Trustees had to look closely at how much of the reserves they could sensibly commit, not knowing what the future held. Following virtual meetings, it was decided by the Trustees that at that time, we should fund just the top graded project, led by Professor Holm Uhlig at Oxford University. However I am pleased to say that the Trustees met recently and decided to fund one more project led by Asst. Professor Paloma Moran at Nottingham University.

Although disappointed that we are not able to fund as much new research as we as hoped this year, we will continue to raise funds wherever we can and invest

more in research if possible. We will also be monitoring our situation carefully and by ensuring the longevity of the charity, hopefully, we will be able to fund much more research in the future.

Before gastroenterology charities were large enough to become members of the Association of Medical Research Charites in their own right, CICRA joined with others to form the Association of Gastroenterology Research

> Charities, chaired by the late Professor John Lennard-Jones. We met regularly, exchanged reports on our research and took forward new ideas. Gradually there was an increased interest in these 'cinderella' conditions and eventually we were all accepted into the AMRC as research charities in our own right.

CICRA have been very fortunate to have members of the medical

profession giving their time to advise us. The late Sir Antony Dawson and Professor John Walker-Smith established the first Medical Advisory Panel and we continue to have the support of experts.

This year the coronavirus pandemic has been a distressing time for everybody and we thank all the medical professionals for keeping their young patients safe when attending hospital. We also thank our Medical Director and Medical Advisors for keeping us up to date with the Coronavirus guidance and for answering our endless questions.

Margaret Lee



Transitional Science for Paediatric Inflammatory Bowel Disease



The UK IBD Bioresource

This research to be funded by CICRA is a multi-centre project to establish a UK paediatric IBD Bioresource which will build on the very successful adult IBD Bioresource project. The paediatric project will be led by Professor Holm Uhlig at Oxford University with co applicants already committed to this project from Edinburgh, Cambridge, London, Birmingham and Glasgow. Supported by the professional body of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), representing paediatric gastroenterologists across the UK, this project unites many of the leading specialists in paediatric bowel disease and their centres of excellence. It is hoped that eventually all centres will participate.

Paediatric inflammatory bowel disease (PIBD) is increasing in incidence worldwide. Large cohorts are instrumental in establishing novel diagnostic and therapeutic pathways. The aim is to recruit 800 paediatric patients, including 150 with new onset disease. These will compliment the paediatric onset IBD (now adult) patients in the overall IBD Bioresource to overall 5000 paediatric IBD patients by 2023. A paediatric co-ordinator will work with paediatric centres, with clinical research nurses and the IBD Bioresource team. Genotyping, banking of samples and consent for recall will provide a sample resource for ongoing and future genetic, epigenetic and immunological research. This collaborative project will support UK and international research towards personalised medicine in paediatric IBD.

targeting a Cxcl10-approach in Ulcerative Colitis

The aim of this research project is to improve the lives of IBD patients, especially the children who have to live many years with this disease. To that end Professor Moran at Nottingham University aims to study the response to anti-TNF α therapy in Ulcerative Colitis patients. In this direction Professor Moran has found, from previous studies, a protein that may be at least partly responsible of anti-TNF α resistance because it interferes with the intestinal inflammation process by decreasing stem cell activity and in consequence tissue regeneration. By blocking this protein with specific antibodies they aim to discover a novel approach for treating these children. There have been promising results in IBD mouse models and murine 3D organoids. Human samples will be used to confirm the results. If Professor Moran's concept is confirmed this project will allow her to go to the next level to eventually translate the findings into the clinic.





Paul Cooper, trustee



family days we'll be back!

Our Family Day Events are a very important part of the service we provide to Members, and it was very disappointing that we had to cancel our planned events in Cardiff and Liverpool in the first half of this year, and have now sadly decided not go ahead with the meetings planned for Belfast & Glasgow in the Autumn of this year. We are so very sorry that it will mean that a whole year will go by with no Family Days but in the light of the 'Coronavirus' situation it is clearly the most sensible course of action to ensure everyone's safety.

It is very difficult for anyone to know what the future holds, and restrictions on 'large gatherings' will have to be lifted before we are able to go ahead. Our Cardiff event



was going to take place at the amazing Millenium Stadium, and the management there have recently advised me that the Stadium's current secondment as a 'Nightingale Hospital' has now been extended until at least the end of this year. We also use hotels for many of our events and the major 'Chains' have advised that they are currently limited in the size of events they are allowed to accommodate.

It takes a lot of work and time to organise these events, and also, we very much rely on the help and support of our wonderful medical professionals whom have all been working so hard during the virus . It would be unfair of us to add to their workload until life is back to some sort of normality, hence the decision to cancel the remaining events for this year.

We have though decided to adopt a positive stance with regards to a hopeful end of 'Covid19' and to start putting together plans for 2021.

We are hoping to reschedule the Liverpool Meeting to April of 2021 (provisional date Saturday 24th). This meeting will as usual provide a varied and informal programme. As the teams at Royal Liverpool and Alder Hey Hospitals have been working very hard over a good number of

months to set up a full regional Transition service, the event will have that subject as its focus.

A lot of interest had been shown in the Wales & West of England Family Day planned for Cardiff, and this is now being rescheduled for June 2021. (Provisional date Saturday 26th).

If we are lucky enough to have a virus free 2021, then we also very much hope to include the previously planned Family Days with our friends in Glasgow and Belfast in the latter half of the year.

Family Days will only go ahead if Government rules allow, and we are totally satisfied that the relevant venues we use meet the highest possible standards of cleanliness and safety.

It is always an absolute pleasure to meet so many of you at our Family Days, and we know how much those who attend get from the experience, hence why we are so keen to try and get back to 'Normal'.

Please keep a look out on our website and social media pages for up to date information on these events and we look forward to having the pleasure of welcoming you to a 'Cicra Family Day' in the not too distant future.



what happens at a Family Day?

I am sure many of you will have read reports in 'The Insider' about our 'Family Days' or seen adverts for upcoming ones. You may have wondered what exactly happens at them, or you may have been put off at the thought of spending all day listen to someone talking about something you don't understand. Let me take this opportunity to give you an idea of what goes on at one of our events.

These special days are planned to ensure that Parents, Carers, Grandparents and most importantly the young people get as much out of them as possible. Please do not worry when they are often referred to as meetings. This no doubt conjures up images in your mind of some boring corporate conference – Let me assure you, they are nothing like that at all.

We do concentrate on the major Cities around the United Kingdom. This is because the big cities have the type of facilities we need, and they have good transport links from the surrounding areas. It also enables us to work closely with the IBD teams at the local Hospitals, as these wonderful professionals are an integral part of our Family Days. We do try and plan so that over the course of a year we have events well spread over the country.

So who can come? All members of the Family of a sufferer are most welcome, and we especially love to see siblings of our young patients as they can learn a lot about what their brother or sister has to live with.

The day will traditionally start with a tea or coffee as everyone assembles, and there is the chance to view various fundraising stalls, merchandise and of course buy raffle tickets.

You will then be asked to take your seats as the meeting commences, and where space at the venue permits, we try and arrange seating to create a relaxed & informal atmosphere.

Our guest speakers will then be introduced. These speakers will be a variety of people, Doctors, IBD Nurses, Specialists, and most importantly of all, young people who are given the opportunity to tell their own story of living with IBD. The medical professionals will talk about a variety of subjects but please be assured they will do this in easy to understand terms and will do their very best to avoid complicated medical terms! These people give their time freely to come along to join us and we do thank them most sincerely.

At the end of the talks you will be invited to ask any questions to our panel of experts and they will do their very best to give you clear answers.

Running alongside the medical talks we will often have other activities on offer for young people. These will generally be things like 'Team building' which gives the youngsters a great opportunity to get to know each other and relax.

At the end of the morning session we will usually provide and buffet lunch which gives people the opportunity to chat and meet other families in a similar situation to themselves.

The afternoon will commence with a couple more guest speakers and also some explanations of the work that CICRA does and some helpful guides and information on how you can raise funds for us to ensure that our valuable research and support programmes can continue.

We then reach what is, for a lot of people, the best part of the day, as we hold a number of small breakout sessions covering a variety of different medical topics. Sessions will cover subjects like, Diet & Nutrition, Treatments, Living and coping, and various others. These are rotating groups, hosted by several medical experts. You will have the opportunity to visit several of the groups for the topics that interest you most. A really perfect opportunity to ask all those questions you don't have time for in your 8 minute hospital outpatients appointment!

Alongside these rotating groups, will be other groups one for older teenagers and one for younger teens. These will be run by IBD nurses or doctors who absolutely love being able to chat with their young patients without Mum or Dad interfering. Over the years, some really great friendships have been formed as a result of these groups, and the young people find it really positive to be able to meet others going through the same issues and problems as they are.

For the younger children we provided another space where they will be kept amused by a professional entertainer.

The day will conclude with a few closing words from a CICRA Trustee, and thanks offered to all the medical professionals for giving their time and expertise to support the event.

At our 2019 Family Day at the Oval cricket ground in London, we were privileged to welcome nearly 300 CICRA members and their families, and more than twenty medical professionals from all the top IBD Centres across the London (and elsewhere). A real testament to the high esteem in which these CICRA Family Days are held.

So, why not be brave, and come along and join us at a Family Day in 2021 – We promise it wont hurt one little bit, and hopefully you will end the day wondering why you had never been before.

We look forward to meeting you.





ask the doctors

Here we get experts to answer key questions which you may have about children with IBD.

What is your view on Probiotics?

Probiotics are microorganisms that, when consumed (as in a food or a dietary supplement) maintains or restores beneficial bacteria to the digestive tract. It also refers to a product or preparation that contains such microorganisms

Evidence indicates that the gut microbiota (miro-organisms living in your bowel) and/or interactions between the microbiota and the host immune system, your own immune system, is involved in how IBD happens in your body.

It is important to remember there are thousands of different strains of micro-organisms. A recent study has looked into 11 strains of lactobacilli and bifidobacteria who has anti-inflammatory properties and may help to enhance barrier function in your gut. Data from animal models of IBD have revealed the potential of several bacterial strains to modify the natural history of IBD.

However, though there is some evidence for efficacy in ulcerative colitis and in pouchitis (with VSL#3), in particular, there has been little indication that probiotics exert any benefit in Crohn disease.

Currently, there is lots of research ongoing about the specific topic, at present, we cannot recommend any specific probiotic for IBD.

Should a child with IBD take a multivitamin supplement?

Vitamin and mineral deficiencies are caused by insufficient intake, impaired absorption and increase requirements due to the disease and are relatively common among IBD patients.

Some nutrients like calcium, magnesium, zinc, folate, iron, Vit-B12, fat soluble vitamins (A, D, E and K) and antioxidants can be low when someone has been diagnosed with IBD. It is therefore essential that a child is seen by a paediatric dietitian. The dietitian will tailor your diet to ensure all nutritional requirements are being met. In many children, doses needed to restore normal levels are not consistent with nutritional recommendations for healthy individuals.

In my practice I have found that children with Crohn's disease and terminal ileum involvement, generally have a lower Vit-B12 status. Also, children with Ulcerative colitis often has lower Vit-D concentrations. It is therefore essential that your medical team regularly monitor your bloods for possible vitamin and mineral deficiencies. Routine supplementation for children with IBD is not recommended.

When the disease is in remission it is very important to follow a healthy, balanced diet with fresh fruit and vegetables. Also, be sure to limit processed food!

Questions answered by: Carin Swart, Paediatric Dietitian, Maidstone and Tunbridge Wells NHS Trust





Is it OK to ask for a second opinion from a doctor at another hospital and how do you do this?

The General Medical Council, which regulates doctors, state that all doctors must 'respect the patient's right to seek a second opinion'.

The Department of Health accepts that if a doctor thinks that it is in the best interest of the patient to refer for a second opinion, they should do so. Although you do not have a legal right to a second opinion, a healthcare professional will usually be happy to consider your circumstances and whether a second opinion is needed. There are occasions when a consultant may ask a colleague to provide a second opinion such as in complex cases, or they themselves need to refer a patient to another sub-speciality consultant for their expert advice e.g., surgeon, rheumatologist or ophthalmologist for IBD related problems.

Before asking for a second opinion, it is worth asking your consultant team to go over your diagnosis and explain anything you don't understand. If you're unhappy with your diagnosis or would like to consider a different course of treatment, discuss this with them. Your consultant team will be happy to explain things and in many cases there may be no need for a second opinion.

If you would like a second opinion after seeing a consultant team you should discuss this with them. There are two ways to obtain a second opinion. Your initial consultant team can refer you to another hospital or your GP can refer you again. If your GP or current consultant agrees to refer you to a new consultant, the consultant will be told that this is for a second opinion. They will likely request any relevant test results previously carried out. If you want to be treated by the new consultant, this will need to be arranged with the new consultant and their hospital.

While waiting for your second opinion, I would recommend you discuss or inform your initial consultant team about this. In cases requiring urgent treatment, I would advise that you discuss this with the team and find out whether any delay in starting treatment could affect your child's wellbeing.

It is, in most cases, helpful to share your feelings with your initial consultant team when seeking a second opinion. Most doctors' welcome other doctors' opinions and should not be offended when a patient/parent asks for one.

My son has recently been diagnosed with IBD and is nearly 16, are there any hospitals that offer a clinic/wards dedicated to older teenagers and those in their early 20's? I am worried that his care will be transferred to doctors that look after adults.

There are some hospitals that have dedicated adolescent services in the UK with dedicated wards for young adults, which offer specialist inpatient and day care as well as dedicated outpatient department. However, these hospitals tend to be in the larger units and are still not commonplace.

Many parents have significant concerns about the transition to adult IBD care and can be quite attached to their child's paediatric IBD team. As a parent it is natural to worry about your child's future. As such, it is important that your paediatric IBD team speaks to you about the transition process which will begin long before the actual transfer of care.

All young people should have access to age-appropriate services. Transition is done differently in different places. The number of paediatric units which have a dedicated transition IBD clinic is increasing. These clinics usually have both a paediatric and adult GI consultant with specialist IBD nurses who work together to care for the young person with IBD until their early 20's. For those that do not have a dedicated transition clinic, the paediatric IBD team will usually work jointly with an adult IBD team who will go on to look after the young person with IBD.

It is important to find out about the local protocol in place for transition at the hospital which is looking after your child. Transition can seem daunting, but once it begins most young people and families adapt quickly and find that the change is a positive one. Adult health providers are very experienced in caring for people with IBD.

Questions answered by: Dr Protima Deb, Consultant Paediatric Gastroenterologist, Royal London Hospital





school - what should be in place for your child with IBD?

The new school year under 'normal' circumstances can be an uncertain time for many young people and parents, particularly if this means starting a new school. Given the current situation with Coronavirus and the impact this has had on so many aspects of our lives, the forthcoming school year is perhaps causing increased anxieties and raising more questions than you may otherwise have had.

At CICRA, we know from the contact we have with families that school may be a difficult place for some young people with IBD, if they are not fully supported and their illness not properly understood. We have put together some advice that may be helpful to start thinking about ahead of the new school year, particularly where children are starting at primary school for the first time or moving to a new school. This information is also important when you are familiar with the school, as new year group teachers need to be aware of your child's IBD and how it could impact on them academically, practically and emotionally.

We appreciate that there is a lot of information to take on board and it can be difficult navigating it all. But we are here to help and we have lots of useful resources proven to work and ensure your child can achieve their potential.

Please do not hesitate to contact us if you want to talk anything through in the context of your situation. Laura, our Family Support Worker, will be very happy to talk with you or work alongside you to get the support your child needs at school.

Tel: 020 8949 6209 Email: support@cicra.org

> Contact us for a copy of 'quide to school for parents and carers'. Which offers suggestions to help with:

- what should be in place for your child with IBD?
- individual healthcare plans / school support
- explaining IBD / fatigue
- planning for exams

If I had my arm in a plaster, people would understand.

how to help children with crohns or colitis at primary school

Cicra****

key tips for the start of term

We all know school can be hard for a child with IBD, so here with the new school year fast approaching we take a look at how you can support school and your child to work together.

It is important that key people within the school understand as much relevant information as possible about your child's IBD. Whilst they do not need to know every personal detail, anything that could impact on your child's ability to function day to day should be flagged up so that your child can be supported in the best way possible. If the school have not been told anything, or you don't feel that they have fully taken on board the information you have relayed, it could prevent your child from getting the support they need.

Involve your child in discussions with key teachers (Ideally the Special Educational Needs Coordinator and class/form teacher) This could help your child to build up trust in the school and feel part of a process, rather than perceiving that adults are making decisions for them. It is a good way for your child to have some control over the situation, by encouraging them to talk about what will/will not be helpful to them, rather than parents and teachers second guessing.

Ensure that key teachers who are privy to the information about your child's IBD, have relayed this to all relevant members of staff. This should be an automatic process once an Individual Healthcare Plan

is in place, but it does happen that class teachers are not made aware of a child's diagnosis and this results in unnecessary implications for the child. A subject area that has typically caused conflict is P.E., either because the Teacher is unaware of the diagnosis or in some cases has not understood the impact IBD can have and how this relates to their subject area.

Always be prepared for the unexpected! Whilst some young people will go through their school life with very few IBD flares or none at all, others may experience many. Whilst some people may know when they are starting to flare, for others it may be more 'out of the blue'. It is this unpredictability that many people understandably find difficult. This is also a reason why we recommend so strongly getting an Individual Healthcare Plan in place. If your child is doing well and the plan does not need to be followed, that's brilliant, but it is better to be prepared than having to react suddenly to a situation i.e. sudden prolonged absences, sudden need to rush to the toilet frequently etc. If it is all considered and discussed in advance, it will give you some peace of mind should a flare up occur.

Talk to your child and plan what they want to say if somebody asks them about their IBD, so that they feel confident and comfortable about what their response and not put on the spot. Some young people are very open with friends, others are not and there is no right or wrong, it is down to individual choices. It will of course depend on so many things, particularly age, those diagnosed whilst at secondary school sometimes find it more difficult to talk about their illness to friends. Sometimes the difficulty can be that a young person does not want to be treated differently, which is understandable, but due to the nature of their treatment/IBD status. they are missing lots of school or having to leave the classroom regularly and friends start to ask questions. Have discussions with your child about how to 'manage' the friend situation...do they want to be prepared and upfront with friends, by taking control and telling them about their IBD before questions are asked. Or do they just want to have a response prepared should friends start to ask questions? (See our support cards as one way for young people to start the conversation)





Here is a story compiled from some real life issues we have been contacted about.

Young person, age 15, experiences first IBD flare in 5 years and the first since being at High School, they are suddenly absent from school for a prolonged period and their attendance rapidly drops from 95% to 60%. Whilst school were aware that the young person has a diagnosis of IBD, in practice this was not understood, the young person 'always seemed fine' according to teachers.

After 2 weeks, parents begin receiving e-mails from the welfare officer at school, concerned about the child's attendance.

The family now have additional worries and challenges to contend with from school, at a time when their primary focus needs to be getting their child well again. School are requesting letters from the

Hospital as proof of what is going on and questions are being asked as to when the young person is likely to return to school.

After several weeks' absence from school, the young person is beginning to improve and gain strength. Still a long way from feeling as well as they did before the flare and continuing to undergo intense treatment, the young person is also struggling emotionally and this is compounded by the fact that they are a conscientious student and know only too well how much work they are missing out on and how difficult it will be to catch up.

Despite the young person feeling able to start accessing school on a reduced timetable or do some work from home, School are not forthcoming in supporting this and are keen to know when the young person will return full time again.

Having an Individual Healthcare Plan (IHP) in place is not the answer to everything and additional, unexpected issues may arise. However, in the case study above, having an IHP in place that had discussed and pre-empted all of the above (despite the fact that this young person had not had a flare in so long) could have potentially allowed the whole situation to be better managed. The school would have been more prepared, and the young person/family would not have had additional, unnecessary pressures placed upon them.

For support

Ring: 020 8949 6209 Email: support@cicra.org

Activity log

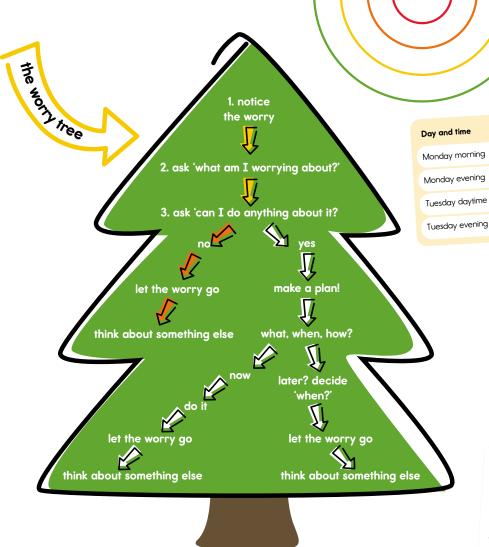
PE at school

After school club

Dinner and TV with the family

Hospital appointment, history lesson

Energy level



tools for talking it through

We know that having IBD can not only have a toll on a child's physical health but also their emotional health, and that of their families.

CICRA launches new emotional wellbeing kits to help young people, parents and carers, and siblings cope with the emotional challenges of IBD.

Our brand new emotional wellbeing kits contain a wealth of resources to help young people, parents and carers, and siblings cope with the emotional challenges of IBD.

Each emotional wellbeing kit has different sections with downloadable information sheets with links to further resources. The packs have been prepared with input from others in similar situations and expert clinical psychologists. Range of topics, including:

- · dealing with diagnosis
- · family interactions
- taking control
- · talking about it
- school





Find out more and download the kits: www.cicra.org/wellbeing

www.cicra.org/blogs/post-adversarial-growth





positive attitude as history repeats itself

Jenny was determined her son wouldn't live with the shame she felt.

I don't remember a time when I went from being well, to unwell. It must have been a gradual change. I remember spending more and more time in the toilet, particularly before school. I think without parental intervention, I would have stayed there (I would sneak a book in if I could!). I felt safe. I was struggling with urgency that never seemed to go away, constant diarrhoea, losing blood (it seemed like gallons to my frightened mind). I was also losing weight, and felt exhausted and drained. I was ten years old.

Memories of my diagnosis are vague; in my defence, we are talking 30 years ago! I was treated in the Gastroenterology department in my local hospital, alongside adults

of all ages. I don't remember seeing any other children there, though there must have been. I recall endless incomprehensible conversations (directed at my Mum), intrusive examinations, blood tests and procedures. I remember feeling frightened, overwhelmed, embarrassed, ashamed and a complete loss of control.

After a time, I was given my diagnosis and was simply aware that it was Ulcerative Colitis. I now know it to be Proctitis and Distal Colitis. I was told after my first colonoscopy that it was mild to moderate UC and that I was 'fortunate'. I didn't feel very fortunate, and the symptoms didn't feel mild to moderate. However, I was a small child being told this by important, highly trained adults, so I didn't question it.

I grew up understanding that bowels, toilet habits and poo are not 'nice' subjects for discussion and

spoken of in hushed tones! This, along with my belief that I was 'fortunate' and shouldn't make a fuss, was the beginning of my almost thirty year journey of embarrassment, shame, endless attempts to downplay or hide my

condition and symptoms. It never occurred to me to admit that my 'normal' was quite different to other peoples 'normal'.

Symptoms were brought under control with steroids but also my first experience of moon face and other associated symptoms; resulting in active avoidance of oral steroid treatment wherever possible in the future!

Memories of my diagnosis are vague; in my defence, we are talking 30 years ago!

I began taking, and have been since (with the odd laziness break), mesalazine (Asacol) and iron tablets for severe anaemia. Things improved, though rarely symptom-free (I wouldn't admit for fear of repeat colonoscopies and steroids). I needed to know at all times there was a toilet available, usually needing quick access, coping with bloating, gas, and the pain from holding gas in!

I became a quietly anxious child, with so much to cope with, but unwilling to share how I was feeling (remember, I was fortunate!). As I grew, I developed painfully low self-esteem, blaming myself for being unwell. I felt I was battling against a body that was letting me down.

High school was really tough. When flaring, which seemed to be most of the time, I would need to make repeated trips to the toilet, something which didn't go down well with my teachers or fellow students (eventually, to my great embarrassment, school were informed of the nature of my condition, after a history lesson where I had to leave to use the toilet twice, and was refused permission a third time).

overwhelming, which didn't connection, or here be experiencing to be experiencing to accepted that this complete in the complete in th

When I reached the toilets, I was often unable to go, but just couldn't shake that feeling of urgency. Sometimes I didn't quite make it, and would have

to set about clearing up accidents. I never admitted this to anyone. On occasions I would return to class without underwear, much to my well-hidden shame. When I did need to go, I would find myself sat for long minutes, holding on until the toilets were empty – my fragile self-esteem couldn't risk someone hearing me. Or smell me!! I vividly remember sitting there, eyes closed, telling myself that I was disgusting, hating that I couldn't control myself like other people. By early afternoon, I would invariably have quite severe stomach pain from the gas that I had been holding in throughout the day. I would always keep this to myself.

School trips, long coach journeys, sleep overs, all the exciting things about school were accompanied by high levels of anxiety. I took part in a French exchange aged fourteen, which involved staying with a lovely French family in their home. My anxiety was high, and I flared. The feelings I experienced, whilst trying to explain, in not even quite GCSE level French (they didn't speak more than few words of English), why I

was in and out of their toilet throughout the night, still comes back with amazing clarity.

It makes me really sad to remember this now, and the hard time I gave myself. I had no one I felt I could talk to, I didn't know anyone else with IBD. And of course, I was fortunate!

As I grew older, and began to have more control over my life, managing my condition was a little easier, although by that time I had developed chronic anxiety, had very low self-worth and was overwhelmingly risk-adverse. It didn't occur to me that any of these might be attributable, at least in part, to my condition. I just saw it as a long list of my own failings. I sought help on various occasions when the anxiety was overwhelming, was prescribed anti-depressants, and a bit of CBT counselling. No one ever made the connection, or helped me to understand why I might be experiencing these difficulties.

Life moved on, I coped with my 'normal', and accepted that this was how life was meant to be.

of a 'bubbly tummy'. And

visiting the toilet more often.

And I knew.

Over the years, I had three beautiful children. A few years later my marriage ended. I knew I was unhappy, and something needed to change, but I didn't know what to do. One day I met a wonderful woman (who is now a very dear friend) who

encouraged me to seek counselling. At this point, I still had no idea that a large proportion of what I was struggling with could be directly connected to my IBD. Gradually, this started to become clear to me.

At the same time, about 2 ½ years ago, my middle child started to become unwell. Max has a diagnosis of Autistic Spectrum Condition (high functioning), and already displayed a range of unusual behaviours. When he started sitting down on the floor at every opportunity – in the shops, out walking, on the playground in the rain, I just thought it was another to add to the list! But then I noticed that he was looking thinner, had developed dark shadows under his eyes, and seemed tired all the time.

He began to complain of a 'bubbly tummy', visiting the toilet more often. I knew.

After a quick appointment with our GP, who accepted that I knew what I was seeing in Max, we were sent to the hospital. The doctor examined Max, then suggested we should give it three months to







see how he got on. I was seriously concerned that three months would be far too long, considering how rapidly Max's condition was deteriorating. Thankfully, we received an unexpected appointment at Addenbrookes Hospital the following week.

The team at Addenbrookes were incredible. Max's situation was assessed and, after a range of tests and his first colonoscopy, he received his diagnosis. Crohn's disease. My heart broke briefly.

I knew what I had to do. I had to make sure that Max would never feel the way I had. Talking about his condition without shame or embarrassment would be the norm. He would never feel alone. Bowels, toilet habits

and poo became a celebrated topic of conversation in our house! Max seemed completely comfortable talking about his condition, and I encouraged this. Trips to Addenbrookes became an enjoyable ritual, Max always happy to see the team. He was incredibly strong. Blood tests, procedures and various medicine changes were dealt with, as were steroids (and moon face!). When his symptoms weren't controlled by steroids and Azathioprine, it was decided that the next step was biologics (Adulimumab). Again, Max adapted to regular injections (he now self-injects) and his symptoms were quickly brought under control. He started growing again!

Max has been doing really well since, and as far as I can tell, his emotional health seems good, with little impact from his IBD journey so far. Addenbrookes, and his school have been extremely supportive,

and last year Max participated in the making of information videos produced for CICRA, talking about his experiences. Watching those videos being shown for the first time at the family's day in London, was an emotional point for me. In that moment, I felt certain that Max would never struggle the same way I did.

A few months ago, I was inspired to focus more upon educating myself about my condition. I began to learn more about how my body works, and what an

Max participated in the making

incredible thing the digestive system is! I've become aware of the impact that

of information videos produced IBD can have on a person's for CICRA, talking about his emotional wellbeing, have learned about, and taken on experiences. positive lifestyle changes, in order for my body to be in the best place it can to deal with the challenges

it faces. I feel that I've stopped fighting against my body, and instead am learning to love it. To take back control of my own health.

I have also been encouraged to see the value in my journey; that perhaps I can use my experiences to help others. I've found the confidence to begin training to become a psychotherapeutic counsellor in order to offer emotional support to newly diagnosed IBD patients and their families. I found my purpose.

Above all, I have begun to appreciate the true power of connection. Of being heard.

I'm not ignoring the possibility that things may get tough again. I'm ready for that should it happen. But would I change my journey? Absolutely not. Now, I truly feel fortunate.

Matt's Personal Everest

Things will get better if you believe they will

Matthew Eames has had Crohn's since he was eight years old. Ten years ago aged 22 he had a sub total colectomy with ileostomy. Prior to the operation he was virtually housebound as he was going to the toilet 20-30 times a day. Matthew said of that time:

"The op changed and saved my life. I wish I had done it earlier."

Fast forward to 2020 and Matthew decided to set himself a major challenge to celebrate 10 years with his stoma bag. He said:

"Since my op I've accomplished things I never thought my disease would allow me to do. I've put on weight and muscle, become confident in myself, got and held a job I love for seven years, married the love of my life and bought a house. So I thought I'd think big with the challenge to match how big I feel these accomplishments are for me."

Behind Matthew's house is Cragg Vale - the longest continual gradient in England which rises from the valleys of Yorkshire to the wild moors on the Lancashire border. He worked out that if he cycled up Cragg Vale 30 times it would be 8850m of vertical height gain - Mount Everest is 8848m.

Having planned his challenge for September, Matthew was furloughed and so decided to bring it forward. On 1 May he set off to ride the hill 30 times in 31 days - a round trip of 19 miles each day. Matthew said the first week was tough:

"Cragg vale isn't a steep hill but it's a long energy-sapping drag. I played about with my fuelling and after the first week I'd worked out that bananas (good for my stoma output too) and Battenberg were my perfect food source whilst on the ride!

"I decided to leave my double run until the last day. It was tough but I managed the 38-mile double run and even had the bonus of an ice cream van being at the top for my final

ascent. I sat having an ice cream at the top having accomplished my own personal Everest and felt blessed that my body enabled me to do it.

"The fact that I managed and enjoyed such a challenge has made me regret not doing it earlier. I think that Crohn's and colitis can be a mental barrier as well as a physical condition. So, if you want to do something but don't think your disease will allow it, just give it a go. You might be surprised"

"I hope this provides some motivation to those struggling with Crohn's and colitis. Things will get better if you believe they will, there is so much support available out there especially from CICRA, a wonderful charity".





fundraiser extraordinaire

raise £20,000 £200,000 £350,000!









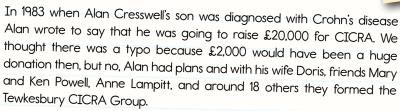












Receiving a £3,000 cheque from them recently reminded me of just how much their efforts in raising over £350,000 have helped CICRA provide consistent research and the training of specialists, leading to better diagnosis, treatments and care to help all children diagnosed with IBD.

We had many CICRA Groups around the UK in 1983, all raising funds to help children and parents cope with the little known conditions of Crohn's and Colitis. Alan, not only came up with wonderful ideas to raise funds and make people aware, but in doing so, gave great pleasure and entertainment to the people of Tewkesbury and beyond.

As the local hairdresser, Alan was well suited to one of his early sponsored events. With volunteers from the local school, Alan got into the Guinness Book of Records by carrying out 100 haircuts in 2 hrs 55mins. He even managed to get international athlete David Moorcroft to join in the Tewkesbury Fun Run.

From car boot sales at the Gupshill Manor Pub to organizing a whole weekend of fun – anything was possible. Alan's enthusiasm was infectious. A 'Raft Race' saw crowds lining the river bank on a Saturday afternoon to see how far teams, on mostly home-made rafts, could travel up the River Avon - nobody came to any harm, just got a bit wet sometimes! This was followed by a real "Country and Western evening" with crowds sitting on bales of hay in a huge marquee. No rest on Sunday though, this was a full day with Tewkesbury's local radio station providing, not only the entertainment for the day, but also the commentary for teams competing in 'It's a Knockout'. Alongside were large marquees with goods for sale, a bouncy castle, a fortune teller. These were huge events, unlike any others seen in the town

In 2006, to show their gratitude, Alan was awarded the freedom of Tewkesbury. Inexplicably 5 years ago he was diagnosed with Crohn's himself. We all owe Alan and his wonderful group so much in bringing CICRA and IBD to the attention of so many, and helping us to push for the specialist service for children that we have today, that wasn't there 40 years ago. With no colonscopes small enough for a child until the end of the 80's and faecal calprotectin only available as a test around 4/5 five years ago, we have a lot to be thankful for.

Thanks Alan for all you have done for CICRA. Keep well. Margaret



2.6 challenge

When the London Marathon was cancelled. UK charities were looking at a substantial drop in income, so the organisers arranged for a 2.6 Challenge – socially distant, lockdown compliant fundraising to raise spirits as well as funds. Well, CICRA supporters showed just how awesome they are, with a whole load of unique and interesting ways to support children with IBD.

marathon man

Inspired by CICRA member Stefan Latter, Chris Limmer ran four marathons in four days and raised £1,030.





Raised £1.638!!

ball skills

Kerrie Stoner's son Jve raised a phenomenal £1638 by doing 26 days of a 2.6 km Run and 26 Keepy - uppys with his football every day.

don't stop them now!

Samantha Bremerkamp let her class of pupils set her 26 challenges and raised £446 - with a great finale rendition of Queen

Raised £446!!



family fitness

The Lemer family raised £1534 by doing a series of challenges across 26 days: 2.6 km runs (Immy), 26 basket ball hoops, 26 sit ups and press ups (Max), 26 cartwheels / 26 shuttle runs (Gracie), 26 sit ups and press ups, together with 2.6 mile runs (David)

Else & Finn's epic 26 day challenge

We were in awe of two amazing young people - Elsie and Finn - who raised more than £1,500 to support our work. Elsie hula hooped continuously for ten minutes every day for 26 days and Finn ran 10 laps of their garden each day in fancy dress. Pop on our Facebook to see some great footage of the costumes and the hooping. A huge THANK YOU to you both!





The Brown Family won our Easter Egg painting competition with these amazing characters.







eggs-tra special

Heather Reid raised £350 by selling eggs at her caravan park.

zoom quizing

Since March we've all had to become more accustomed to socialising via a screen and Emily Fairbrother used this technology as an opportunity to hold an online guiz night which raised £100.



thank you!

to all our amazing fundraisers -YOU make the difference



plant sale

Thank you to the Law family who held a plant sale and raised a fantastic £437 to support children and young people living with IBD. They cultivated over 150 plants to sell and plan to open their garden and sell refreshments again

Raised when Coronavirus is a £437!! distant memory.

The last six months have seen some amazing fundraising by CICRA supporters. They rallied to our cause when the pandemic caused the cancellation of major events such as the London Marathon, Ride London and the Great North Run. Just as crucially, it meant all those wonderful events that CICRA members hold - bake sales, fetes, school stalls etc. - had to be postponed or cancelled. Keeping safe is the most important thing and we completely understand, but it was a sudden hit to our income, around 30% of which comes from events and community fundraising. To everyone who has fundraised, donated or supported in whatever way you can, we say a massive... THANK YOU!



Congratulations and huge thanks to Victoria, Tracy and Jamie who ran the Vitality Big Half marathon before lockdown and raised nearly £3000 to support children and young people living with IBD.

Jamie achieved a personal best of 1:51:02 and Victoria and Tracy said they suffered sore legs afterwards but were delighted to be able to raise awareness as well as funds to support our work.

We're so grateful to all of you for your amazing support - thank you!

We were also privileged to have Dr Marco Gasparetto on our amazing Cambridge Half Marathon team. Marco is a former CICRA Fellow and now works as a consultant at the Royal London Hospital. We are sending our very best wishes to Marco and all medical professionals working to keep us safe during this current crisis.

Jamie Phillips had a special reason for running the Vitality Big Half Marathon for CICRA. As grandson of founder members of CICRA, Rosalyn and Philip Phillips, Jamie ran in memory of his Uncle Andrew, one of the first children diagnosed with IBD. Jamie comes from a very musical family and in 2012 was appointed to the Halle Orchestra as their youngest ever assistant conductor. As quest conductor he has appeared with some of the finest orchestras in the UK and Europe. He spent the 2018/19 season touring Europe and is currently on a Fellowship with Gustavo Dudamel.

Thank you Jamie for finding the time to run for CICRA and we will continue to follow your career with interest.



snip snip

Katie Rolph who was only diagnosed a week before lockdown raised £957 by getting her mum to cut

her hair! Brave young lady in so many ways!

Raised £957!!

two wheels

Bertie Steptoe, at only 6 years old, raised over £2000 for CICRA and CCUK by cycling 20 miles around the local area in order raise awareness and funds



anyone for tennis?

every little bit helps

The children of Claire Beesley's 'Marla Dance School' have been

into promoting healthy eating by

paying 30p for a piece of fruit which

is donated by Claire's Mum, Angela

Wagstaff all in aid of raising funds for

CICRA. This fundraising is helped by 5p being donated for every hairnet that the dancers buy. Thank you all.

Like so many other fundraising events, this year the tennis tournament organised by Jax Martin-Betts in aid of CICRA could not take place and there some very disappointed enthusiasts. However many very generously paid their booking fee to help us and we received from Jax a cheque for £430 plus a donation of £100. Thank you all.

fishing club

Member, Claire Townshend and her husband are members of a fishing club who have supported CICRA for several year organising a fishing competition but this was another cancelled event. Disappointed fisherman came up trumps though when Claire organised a raffle to help fill the gap that the competition would have raised for us. The generosity of this club showed in the payment we received from Claire of £1095. Thank you Claire Raised and all who were involved.

lockdown photoshoots

Toby is a young CICRA supporter who has been fundraising to help other young people with IBD by taking doorstep photographs during lockdown in return for a donation. Aided by his mum, and careful to pace himself to avoid fatigue, the quality of his shots is impressive! As mum Jan says "Lockdown really has been his norm this year, so having a hobby to develop is very handy!"

Thanks, Toby and family, for your support and raising £577, and we look forward to your Vogue cover shoot in the future!



gamers raise over £2000 for children with IBD

We're so grateful for the incredible support we received through two gaming streams. 100hp Gaming did a 24 hour stream and raised over an astonishing £1200 in the first five hours and smashed through £2000 by the end. Casey James also did a couple of charity gaming streams to support CICRA during lockdown. Thanks, both and any budding gamers who would like to fundraise, do pop us an email on fundraising@cicra.org or send a message on Facebook, Twitter or Insta. We know that for some young people, gaming has been important in coping with their health condition and it can be a great way to connect with others.

and not forgetting

Many thanks also to Kate Bryans, Joanne Shaw, Catriona Scott, Tracey Westlake, Heather Bryce, Lucy Machen / Rafferty Cumming, Karen Merrett, Charlotte Merriman, Bertie Steptoe, age 6 UC, Melanie Bell Scott, Richard Shaw

£1,095!!



a fond farewell

Dr Victor Miller

We were saddened to hear of the death of Dr Victor Miller, a pioneer of paediatric gastroenterology and a very caring Doctor to so many children with IBD in the days when it was rare to see this in a child.

Dr Victor Miller was born in London. the son of refugees. He had a hard childhood, but this only made him more determined to believe he could do anything he set his mind to, and he did. He studied medicine at Glasgow University between 1955 and 1961. After qualifying, his clinical rotation meant long gruelling hours at Western Infirmary, the Royal Hospital for Sick Children and Oak Bank Hospital, passing his exam of membership to the Royal College of Physicians and Surgeons in 1965.

At an interview for a position at Gt Ormond St Hospital in 1966, Victor answered 'gastroenterology' in response a question as to what he wished to specialise in. So began a process, alongside colleagues with a similar interest, of opening up a specialist area in paediatrics. Returning from a spell in Philadelphia, Victor became senior registrar, and then Consultant Paediatric Gastroenterologist at Booth Hall Hospital, Manchester. This was the first time the NHS had funded a Consultant Paediatric Gastroenterologist. Earlier positions had been funded by the Universities, so this was a major step in helping to bring paediatric gastroenterology to becoming, in its own right, a sub speciality of paediatrics.

Victor's unit was seeing young patients with inflammatory bowel disease, not only from Manchester but the whole of the NW region. With problems of understaffing CICRA were very pleased in 1988 to support Victor's unit by funding the first of many 3 year Training Fellowships under his direction. After their 3 year training all continued to have young IBD patients under their care. In those early days Booth Hall (now Manchester Children's Hospital) became one of three major centres for the management of Crohn's disease and is now a major centre among twenty-seven. Victor was a kind caring doctor - a true pioneer, dedicated to the advancement of paediatric gastroenterology. R.I.P.

Margaret



Michael Seres

We were very sad to hear that renowned patient advocate and Founder and CEO of 11Health, Michael Seres, has died. Margaret Lee, pays tribute:

Michael was 12 when he was first diagnosed with Crohn's and went on to

become an amazing person who has probably done more to publicise Crohn's than anybody. Although this rarely happens, the Crohn's could not be kept under control and in 2011, now married and with a family of four, Michael decided that 20 bouts of surgery and being on TPN for 18 hours a day was no life. He opted to become the 11th person to receive a small bowel transplant. This was really successful but left him with a stoma. While travelling extensively to speak at patient and medical meetings, he devised a sensor that would clip on to his stoma bag and through the phone create alerts. He set up a company called 11 Health, and produced the sensors.

Despite all his problems, Michael lived life to the full, never complaining or feeling sorry for himself. As an untiring advocate for Crohn's disease, he was always pushing for the patient to have a choice and in doing so giving so much publicity to Crohn's. Michael will be missed by not only his lovely family but by so many others who knew him.

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:

Florence Bines

Flo has left many memories with us all and she will be sadly missed. Margaret, Susan, Ian and families

Ann Burn

Fondest memories from Husband Don, Andrew, family and friends

Jill George

A cherished Grandmother of a young Crohn's sufferer and his two sisters. Missed and loved by her family and friends.

Joyce Cresswell

Fondest memories from family and friends

John 'TERRY' Nock

'Grandad Boats' – much loved and always remembered by Emily Fairbrother, family and friends

bequest

We are grateful to have received a bequest from the Will of the late **Mrs Joyce Haslam**





win with CICRA

You can raise funds for children's IBD research while possibly winning some pocket money for yourself!

00+club

winners list up to June 2020

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.

1011115.		
Jan 103	W.Dando, Caerphilly	£50
183	C Shaw,,I Gt. Manchester .	£50
Feb	O Griaw,, i Gt. Marioriostor.	200
92	C Hougham, Hampshire	£50
21	V Batchelor, Kent	£50
Mar		
218	T Westlake, Chichester	£250
63	T O'Neil, Gloucestershire	£75
147	C McCormick, Bucks	£75
Apr		
57	C Prosser, Cardiff	£50
167	M Khuraijam, Cheshire	£50
May		
45	M Craigie, Devon	£50
94	P. Herman, Worcester	£50
Jun		
91	J. Buchanan, W. Yorkshire	£250
146	L. Hall, London	£75
213	A Gibbs, Hampshire	£75

CICRA Summer Draw 2020

On Monday 15th June 2020, the country was still in lockdown due to the coronavirus so the Draw could not take place in the CICRA office. This was drawn in the home of a CICRA Trustee with two independent witnesses not associated with CICRA. Below are the winners

Prize	Ticket No.	Name
1st Prize	12190	Mrs M Powell
2nd Prize	47589	Mrs N Jones
3rd Prize	31074	Dr P Law*
4th Prize	07329	Mrs S Durman*
5th Prize	47583	Mrs N Jones
6th Prize	38533	Mrs K Fox
7th Prize	49502	Alex Kershaw*
8th Prize	43955	Mr M Hammond
9th Prize	44926	Mr Underwood**
10th Prize	38287	Mrs Brasier
11th Prize	41004	Mrs A Meddes
12th Prize	07770	Mrs R Squire
13th Prize	52567	Mr B McKinney

*Given back as a donation to CICRA **Unable to contact

Many thanks to members who either bought tickets themselves or sold tickets to support this draw during this difficult time of lockdown.

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