

Impact Report 2024

The Crohn's in Childhood Research Association (CICRA) raises funds for vital research into Crohn's disease, Ulcerative Colitis, IBDU and VEOIBD, collectively known as Inflammatory Bowel Disease (IBD), a less well-known but very complex, debilitating disease affecting children.

Research

2024 saw the start of three new CICRA research projects and two very successful 'in person' Family Information Days:

A three year CICRA Research Fellowship at Southampton Children Hospital:

"Research Fellow **Dr Zachary Green** has settled in well. He is working with the group using large-language models to structure medical reports, aiming to utilise these clinical data in a variety of research projects. He is currently working with these data to explore how blood tests taken at IBD diagnosis might predict disease outcomes. Supervised by Dr James Ashton he has published an editorial piece titled 'Prediction in Inflammatory Bowel Disease – Do the Answers Lie in Big Clinical Data?' and worked with Mick Cullen, a paediatric gastroenterology clinical nurse specialist, to submit a service evaluation on the use of pre-medication in IV Infliximab infusions.



A three year PhD Studentship at Dundee University under the direction of **Dr Mairi Mclean**:

"I'm delighted to be awarded a PhD studentship for my lab.

We are using cutting edge experimental models of the cells lining the gut called organoids, created from human IBD tissue samples. In health, these cells lining the gut create a barrier between the gut contents and the underlying tissues. This barrier changes in active IBD and becomes 'leaky', and allows gut contents such as bacteria to interact with underlying immune cells..

This project will define ways in which gut barrier cells are injured and the cell mechanisms they use to repair. This will create new knowledge on the underlying cell biology in IBD with the aim of identifying new treatment targets for future development. **Billie Nuth**, the appointed PhD student, is enthusiastic and dynamic and is making great progress. It's great to be given the opportunity to supervise and mentor the next generation of scientists within the IBD field. Thank you once again to CICRA for this funding award."



A 1 year Project under the direction of **Professor David Wilson** for the novel use of nationwide administrative health data and data-linkage to define UK paediatric IBD epidemiology, early life associations, course and educational attainment.



Research Highlights

As we moved through 2024, we put the financial help we have received into further scientific research, and support for families of children affected by any form of Inflammatory Bowel Disease - the two reasons for CICRA's existence since its formation in 1978. Over £10 million has got us to where we are today with huge improvements in the understanding, treatment and management of children with IBD. Here are a few highlights from previously CICRA funded research.

- Confirming the involvement of T cells in paediatric Crohn's disease
- Identifying the benefits of enteral nutrition as a component of paediatric Crohn's treatment strategies
- Profiling the inflammatory mediators responsible for chronic bowel damage in paediatric IBD
- Broadening our knowledge of the commensal bacteria associated with paediatric IBD
- Understanding links between body composition, nutritional status & likely disease outcomes
- Pinpointing key genetic traits associated with paediatric IBD

Research is expensive, and slow, but without it we won't find the answers we all want, to give children with IBD a better quality of life and hope of a healthy future

And for the future...

With your help we will continue to raise the profile of childhood IBD and ensure that with advice from our Medical Advisors we fund only high-quality research, helping to ensure children with IBD have as good a childhood as possible, despite their lifelong illness. **We are truly grateful for all donations given during 2024**



Research Fellowships

Good management throughout childhood is essential for these children and part of CICRA's research programme has been to fund, the three-year training of young qualified doctors wishing to specialise in Paediatric Gastroenterology. This training scheme helps to ensure that all children affected by IBD can be treated throughout their childhood by a specialist. As there has been a huge increase in the amount of children affected, from babies through to adolescents, it is important to continue funding future specialists.

Support

One very successful form of support for the whole family are the informal 'CICRA IBD Information Days' held in differing parts of the UK. Talks from medical professionals and a young person, or a parent, are followed by small discussion groups, led by professionals, covering all aspects of IBD. Entertainment is laid on for the young ones and a special session for teenagers only, allowing them to have a very open discussion on any aspect of their condition with the doctors and each other.

Events for families in 2024

July Family Information Day in Manchester

October Family Information Day at The Royal School of Medicine, London



In 2024

**We supported
4,213 families** who have a child
affected by the condition



1,470 Parent packs
and Support Cards sent to
hospitals in the UK



67 hospitals
in the UK gave out CICRA
information and literature

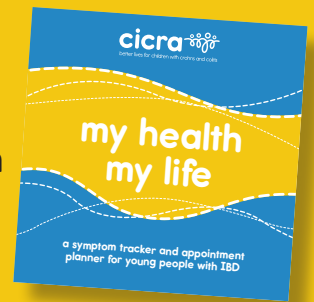
4,747 families and medical
professionals
received a copy
of our bi-annual
'Insider' newsletter



433 families joined the
CICRA membership scheme
without cost to the family

326 children received a
Can't Wait card and Radar key to
help explain their condition quickly
and without questioning if they
need to use the toilet urgently

531 children
received a Symptom
Impact Tracker
to keep a record
of how they felt
between hospital appointments
and to feel more confident in
managing their condition



**1,924 emails, calls
and messages**
seeking guidance,
information and support

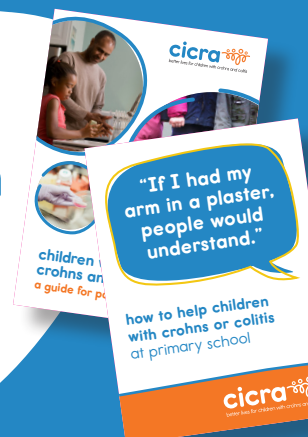


60 children
took part in the e-pal
scheme and chatted to
other children with IBD



3,507 school booklets
were provided for parents,
teachers and support staff to
explain IBD, school responsibilities
and how the school can help

**37,399 support
and information
leaflets**
distributed in total



Fundraising

As with many other charities the Crohn's in childhood Research Association (CICRA) was formed, in 1978, by two sets of parents – brought together at Barts Hospital in London by having the same problem – a child with an illness that few had heard of and less knew anything about. The children had Crohn's disease and although seen in adults since the turn of the century, it was seen for the first time in children in the 1970's, so it was very rare.

At the formation of CICRA, the aim was to raise £8,000 to fund a doctor for a year, on a private grant, to care for this small but growing number of children with Crohn's and learn how to recognise and treat this complex condition. With a sudden dramatic increase in children being diagnosed with Crohn's, and other forms of Inflammatory Bowel Disease, more parents joined CICRA to help raise funds and give support to each other. Some of those parents and families are still donating to CICRA to this day.

With no government funding we rely on applications to Trusts and the generosity of our supporters but welcome donations from anybody sympathetic to our aims of preventing children's lives being so dramatically affected.

Over £10 million has now been raised and spent on support, research and three year training for doctors wishing to specialise in paediatric gastroenterology. In doing so it has helped to give children with all forms of Inflammatory Bowel Disease chance of a healthier childhood. However, we cannot stop now and need to increase our annual income to fund further research and support programmes. There has been a huge increase in cases over the 45 years and never more so than over the last few years, particularly the very early onset cases of babies and toddlers.

CICRA's aims are not achieved easily or cheaply. Research is expensive and often painfully slow, but projects funded by CICRA have added a wealth of knowledge towards better treatments and the eventual cure. Continuation of this research is vital to give children with IBD a chance of a healthier future.



Thank you

We would like to thank everybody who donated to our cause in 2024.

Amongst many these included Pippa growing her hair, marathon runners Ben in Manchester and Tom in Berlin, the Gurney Family music festival, plant sales, 9 year old Esme climbing Snowden, Sarah walking 5km with her dog every day for 2 months and Alison's line dancing classes.

We also thank all the schools, clubs, youth associations, who have held sales, non-uniform days and even a doughnut sale.

Every event and donation, big or small, makes a difference.

