

# Impact Report 2023

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 disease affecting children. This can have a devastating effect on young bodies.

At the end of 2023 the Trustees were very pleased to announce that following a rigorous Peer Review by members of the CICRA Medical Advisory Panel and external referees, grants amounting to over **£400,000** were awarded as follows:



A **three year CICRA Fellowship** was awarded to Dr James Ashton and the team at Southampton's Children Hospital with Dr Zachary Green taking up this paediatric clinical and research training in 2024.



A **three year PhD studentship** was awarded to Dr Mairi McLean at Dundee University. A student will be appointed early 2024 to look at injury and leakiness of the epithelial barrier in IBD to identify new knowledge of why IBD develops and identify new ways of treating this condition.



A **one year Project Research Award** was made to Professor David Wilson at Edinburgh University 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



## Support

**“Great news!  
and a testament  
to the critical  
role of CICRA  
in driving IBD  
research.”**

Comment from a medic



# CICRA's Impact over 45 years



Over £10 million has been put into research to improve the lives of children with IBD resulting in:

- **Earlier diagnosis and specialist care** for children with IBD through the funding of 3-year paediatric gastroenterologist training fellowships for **27 doctors** now treating children at specialist units throughout the UK
- **Funding the research which led to a liquid diet**, still the first line of treatment for children with Crohn's
- Providing the funding for staff and equipment for the **first Paediatric Gastroenterology Laboratory in the UK**.
- Funding **24 PhD studentships** to research IBD in childhood, encouraging them to continue researching IBD as a career choice
- **Funding 62 research projects** which has added a wealth of knowledge about the condition, including the discovery of a factor causing gut damage, which led to new therapies, now used world-wide in treating children and adults with severe IBD
- Funding the setting up of the **Paediatric IBD BioResource** – a move toward having personalised medicine for all children with IBD in the future

## 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

Children with IBD have a very unpleasant lifelong condition which does not have the high profile of other conditions such as cancer or cystic fibrosis. It is common that they hide their condition from their friends due to embarrassment making school and socialising a real problem on top of coping with their health issues. Support for the children and families in this often-lonely position is vital to their wellbeing.

In 2023, for the first time since lockdown, we were able to hold two successful Family Information Days for parents and children in Nottingham and Bristol. Over 300 took the opportunity to meet face to face with doctors, nurses, healthcare professionals and other families, learning more about the condition in a very relaxed situation. In 2024 we plan to have at least three of these days in various parts of the UK.



# In 2023

**We supported  
4,531 families** who have a child  
affected by the condition



**2,109 Parent packs**  
and Support Cards sent to  
hospitals in the UK



**67 hospitals**  
in the UK gave out CICRA  
information and literature

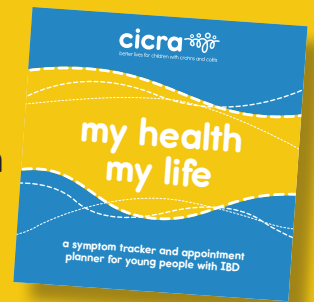
**5,079 families  
and medical  
professionals**  
received a copy  
of our bi-annual  
'Insider' newsletter



**508 families** joined the  
CICRA membership scheme  
without cost to the family

**400 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

**635 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



**1,872 emails, calls  
and messages**  
seeking guidance,  
information and support

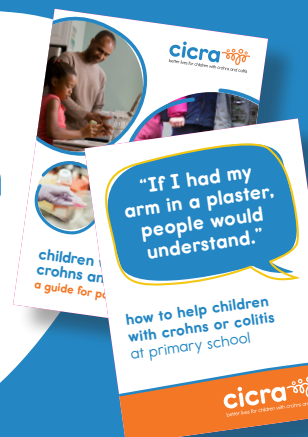


**77 children**  
took part in the e-pal  
scheme and chatted to  
other children with IBD



**3,084 school booklets**  
were provided for parents,  
teachers and support staff to  
explain IBD, school responsibilities  
and how the school can help

**35,419 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 that 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 chance of a healthier future.



Crohn's In Childhood Research Association (CICRA) is a registered charity in England & Wales (278212) and Scotland (SC040700)



## Thank you

We would like to thank everybody who donated to our cause in 2023. We rely on the generosity of Trusts, supporters, and the families of the children affected. The donations from families varied from a child sending in their birthday money to a weekend fundraising event. We are grateful to you all.