

support for children with Crohn's and colitis

about us

We are the specialist charity for children and young people affected by Crohn's and colitis.

We lead research into better treatments, support children and families with relevant information, work with health professionals to improve care and give children a voice to increase public understanding of Crohn's and colitis.

We believe that all children deserve a childhood unlimited by inflammatory bowel disease.

get in touch

Pat Shaw House, 13–19 Ventnor Road, Sutton, SM2 6AQ 020 8949 6209 support@cicra.org www.cicra.org

Find us on social media

Find us on social media

GUICRAcharity

CICRA is the operating name of Crohn's In Childhood Research Association, a registered charity in England and Wales (number 278212) and Scotland (SC040700).



about IBD in children

Crohn's disease and Ulcerative colitis are two of the most common diseases in a group of conditions known collectively as inflammatory bowel disease (IBD). Although only seen in children since the mid-1970s, over the last four decades there has been a dramatic increase in the number of children affected doubling in the past 20 years alone.

We do not yet fully understand what causes IBD, but CICRA-funded research has helped highlight genetics, the immune system, and the bacteria that live in the gut as important factors. There are also now more and more new and effective treatments. Any treatment should be tailored to the individual and, as children and adults often require different treatments, children should be seen by a specialist in paediatric gastroenterology.

It is estimated there are more than 300,000 people of all ages with IBD across the UK. An increasing number of new diagnoses are young people under 18 including more babies, toddlers and children under 6 years old, with very early onset IBD (VEOIBD).

Despite public ignorance about the impact of IBD on childhood, with a prompt diagnosis and appropriate treatment and support, most children should feel well most of the time and be able to lead a fairly normal and hopefully happy life. 300,000 people with IBD in UK

dramatic increase in under 18s

+ in very young

increasing numbers are under 5 years old

how we help

FIRE T

Children and their families tell us that CICRA is so important because we provide trusted information and a reliable source of support that many describe as a lifeline. To stop IBD impacting childhood, we are working hard on many fronts:

information to give knowledge and more control of IBD

Our website and information booklets inform about different aspects of IBD from psychological issues to treatments to diet and nutrition. We reassure children with straightforward, easy to understand insights into all aspects of Crohn's and colitis. We provide information for schools and teachers to help them support their pupils.

a voice to say what matters most

We give children a voice in all the areas that affect their health and wellbeing. We help explain to friends and the public what it is really like to live with IBD. We give children and young people influence with key health organisations and at conferences on paediatric IBD.

research to find better treatments and a cure

We advance knowledge of childhood IBD by supporting high quality, peer-reviewed medical research which has led to new treatments. Our research programme over 40 years has helped train many specialists who are now treating children and current research is looking at how medicine can be personalised to individual patients, avoiding the need to try different treatments in the search for the one that works.

support for children with IBD

We give children and families the opportunity to spend time with others in a similar situation and share their experiences of living with IBD. Growing up is hard enough, without having each and every rite of passage ruined by a chronic disease you can't talk to anyone about. Being able to hang out with other people who know what you are going through is one way in which we help children and young people feel ok.

our impact

CICRA was the first IBD charity in the UK and our research had national impact from the start by giving young qualified doctors the opportunity to specialise in paediatric gastroenterology, so that there would be expert help for children with Crohn's and colitis.

Over time, as more children were diagnosed, we increased our support and information for families with a child affected b



We have invested over £5 million into research in the UK, leading to new treatments and specialised training in gastroenterology for 25 paediatricians, including many at the leading centres caring for children with IBD. As a result, more children with Crohn's or colitis can see a childhood IBD specialist.

CICRA is a founding member of IBD UK and a member of the Association of Medical Research Charities. We work closely with the British Society of Paediatric Gastroenterology, Hepatology and Nutrition, and help ensure the IBD Standards are relevant to children's care.

membership

CICRA is the only national charity in the UK focused specifically on supporting children and young people with Crohn's disease and Ulcerative colitis.

Membership of CICRA is free for children with IBD. parents, family members, supporters or anybody interested in our work, and gives you:

- expert information on Crohn's, colitis, IBD unclassified, oral Crohn's and very early onset IBD
- understanding & **support** for the whole family
- *the insider* **newsletter** produced twice a year and sent free of charge to families
- easy to understand booklets & leaflets for parents, teachers & young people

Make Some on 5th Oct

• help with the transition from child to adult services

- 'can't wait' cards issued FREE of charge to help children explain their condition when in urgent need of toilet facilities, and RADAR keys
- epals scheme for children & young people to chat and support each other by email
- parents in contact, for parents to provide practical support to each other
- regular IBD family information and support days across the UK
- information on travel insurance



If you are interested in becoming a member, or receiving information booklets, please email Jayne on support@cicra.org

"Being a member of CICRA has helped me develop new friendships with other young people going through similar worries as me. I attended a family information day which was really



fun as it gave me the opportunity to meet other families.

CICRA has really helped me in feeling not so alone with my illness and always knowing there's someone to talk to who understands." **Anna**

better lives for children with crohns and colitis

get in touch 020 8949 6209 | support@cicra.org | www.cicra.org

find us on social media find u

Crohn's in Childhood Research Association Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ Registered charity in England and Wales no. 278212 and in Scotland no. SC040700





Thanks to Vicki Sharp Photography Updated 05/2019