You have the power to change tomorrow for children living with inflammatory bowel disease.

cicra

better lives for children with crohns and colitis

We are the specialist charity for children and young people affected by crohns 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.

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@CICRAcharity

CICRA is the operating name of
Crohns in Childhood Research Association,
a registered charity in England and Wales
(number 278212) and Scotland (SC040700)

Photographs by Vicki Sharp Photography

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In 1978, as a small group of parents with young children being treated for Crohn's by Professor John Walker-Smith at St. Bartholomew's Hospital, London, we desperately wanted to find out why our children had been affected by a condition which, until then, had only been seen in adults. Steroids and surgery were the only options available but we couldn't fault the care our children were receiving, so the only practical way we could help was by raising funds.

How could we have imagined that just a handful of children with a rare condition could increase so much that we now have 27 very busy IBD specialist centres in the UK? Unfortunately, the incidence in children is still increasing, some being diagnosed as babies or toddlers. The need to continue and expand our research programme is vital.

As a comparatively small national charity we are able to give personal support and understanding to all members of the family - my original thought in 1978 being that if I could prevent just one family going through what we had gone through I would be happy. Our family information days around the UK, supported so well by members of the medical profession, are definitely days when we go home knowing that we have helped.

Hearing that your child has Crohn's disease or Ulcerative colitis is exactly the same for families today as it was in the seventies - the initial shock, perhaps relief at somebody putting a name to it, but then fear for the future. Fortunately, we have come a long way. Specialists are able to diagnose IBD earlier and improved treatments allow better management.

However, we still need to do more. If the elusive 'cure' still evades the researchers then we hope for a time where long lasting remission is the norm and children can experience all the usual childhood activities, education and social life unimpeded by IBD.

By leaving a gift in your will to CICRA, you'll be leaving a lasting legacy of compassion, reassurance and hope - helping children and families in their time of need. What happens to our money and the things that are most precious to us when we're gone should not be left to chance - that's why writing a will is so important. Of course, making sure our loved ones are provided for will be at the top of the list, but if Crohn's, colitis or inflammatory bowel disease has affected you or someone you care for – if you're able, please remember us in your will too.

Margaret Lee MBE, Chair and Founder, CICRA

about IBD

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**.

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 new and more effective treatments but there is still much we need to know.

It is estimated there are **more than 300,000 people of all ages with IBD** across the UK. Of those newly diagnosed, an increasing number are under 18 including those under 5 years of age, with very early onset IBD (VEOIBD).

With considerable public ignorance about the impact of IBD on childhood, even with prompt diagnosis and appropriate treatment and support, **many children still struggle to lead a normal and happy life.**

how Crohn's and colitis affect childhood

Inflammatory bowel disease (IBD) is a life-long condition, which is very **unpredictable** and can have **frequent flares** and relapses. When IBD is active, children and young people need regular and prolonged access to toilets, as a common, **embarrassing and distressing** symptom is frequent diarrhoea. However, the impact of the disease is much wider and many children suffer with **fatigue and pain, fever, nausea, loss of appetite, loss of concentration and lack of energy**. Some children also live with **pain and inflammation of the skin, joints and eyes**.

Many children with IBD are small for their age, making them appear younger than their classmates which can make them a **target for bullies**. Combined with the strain of living with their condition, this can make them become **withdrawn, anxious and depressed**. Relapses can be particularly difficult to deal with emotionally. Children with IBD require treatment with medicines. Steroids are a common treatment and have **distressing side effects**, which affect a child's appearance (e.g. weight gain, puffy face and acne), mood and behaviour. Others suppress the immune system, leaving children more **vulnerable to normal infectious diseases like chicken pox**. Some children will also have a nutritional feed via a nasogastric tube. Children with IBD will need to visit hospital for regular routine appointments and for **invasive investigations**, including endoscopy. Some children will require surgery to remove diseased sections of the bowel and some may need a stoma.

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how your gift can help

We'll ensure that any gift you bequeath to us will be put to the best possible use and bring the best outcomes for future generations and families. However, if you would like to specify how you want your gift to be used, we will adhere to your wishes.

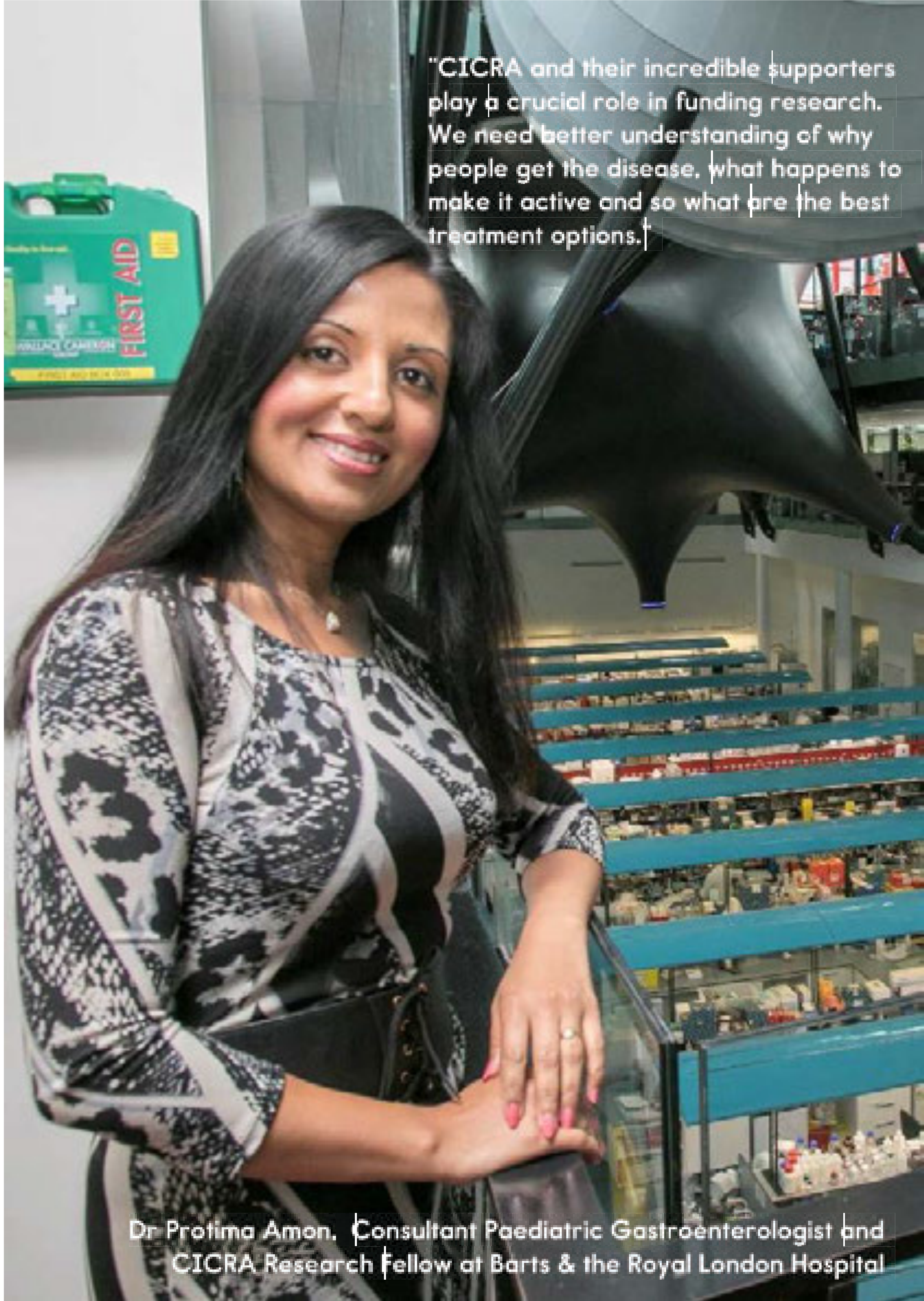
Much of our world leading research programme has been made possible thanks to the generosity of gifts in wills. Leading specialists treating children in the UK today received their training through our Research Fellowship scheme. Supporters who left a gift in their will funded young scientists to carry out three year scientific research, with many choosing to continue this line of research as their future career. A gift in your will can support a new generation of doctors and scientists, to help future generations of children.

our research

For 40 years, we have been getting closer to our goal through our ground-breaking research programme. We have invested over £5 million on 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. Today, more children with Crohn's or colitis can see a childhood IBD specialist, because of the research we have funded. CICRA is a member of the Association of Medical Research Charities.

what makes our research unique?

- our focus is children and paediatrics, a less commonly funded area for IBD research, where the condition is lifelong and impacts education, childhood happiness and future careers
- we help train paediatric gastroenterologists, so more children can see a specialist
- it brings new knowledge and specific understanding of how IBD affects children
- the impact lasts as our researchers gain huge expertise and continue to work in paediatric gastroenterology helping children with IBD
- pharmaceutical companies and other research funders tend to focus on adults because of regulatory requirements, but this means a lack of attention on those whose disease can have a much bigger impact on the entirety of their lives, striking when they are still growing and in education



"CICRA and their incredible supporters play a crucial role in funding research. We need better understanding of why people get the disease, what happens to make it active and so what are the best treatment options."

Dr Protima Amon, Consultant Paediatric Gastroenterologist and CICRA Research Fellow at Barts & the Royal London Hospital

> "When I first came to CICRA I felt that there were other people in the same boat as me which helped me open up a bit more. Last year I was in Year 7 and I struggled to talk about Crohn's, this year I've been able to open up more about it with my friends at school."

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. Over time, as more children were diagnosed, we increased our support and information for families with a child affected by IBD. We have supported around 10,000 families to cope with their diagnosis and feel more positive about managing their condition.

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 to achieve their full potential.

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 and current research is looking at how treatments could 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 information and support

CICRA provides children and their families with:

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

Your gift can make the difference for children with Crohn's and colitis.

Gifts in wills are an extremely valuable source of income for all charities and CICRA is extremely grateful for any that we receive. We will always respect your wishes if you specify a particular part of our work to support and we will ensure that your gift is properly administered and fully acknowledged.

Some donations come as a direct bequest and others as part of the residue of a will distributed by the Executors/Trustees of the Will using their own discretion as to the wishes and desires of the deceased.

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 Citizens' Advice. 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. 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 of The Treasurer for the time being shall be a good discharge to my Executors"

Alternatively, you may wish to leave CICRA the remainder of your estate, after other specific bequests have been settled, in which case your will should include:

"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 of the Treasurer for the time being 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.

Thank you for considering making a lasting gift that will help children affected by Crohn's and colitis for generations to come.

"When your child is diagnosed with an incurable disease, life stops. You realise you were naive to think you could protect them in the world. You suffer tremendous grief, and no one really understands what you are going through."

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