CROHN'S & COLITIS UK

500,000 stories to tell. 500,000 reasons to be better.

Across the UK, there are 500,000 people living with Crohn's and Colitis (also known as Inflammatory Bowel Disease – IBD). More people get diagnosed every day.

They could be any age, live anywhere in the UK, rich or poor, of any faith or none, of any ethnicity, sexuality, or gender. They could be anyone walking down a UK street.

Whoever you are, a diagnosis of Crohn's and Colitis will be life changing, **but in the last five years there have been improvements.**

You are more likely to have access to a specialist team including an IBD nurse specialist. Biological drugs are providing more chances to keep the conditions under control and new formulations mean you may be able to administer at home instead of hospital.

But some things never seem to change.

Your journey to diagnosis is not guaranteed to be quick – for 1 in 4 of you it will take over a year and for nearly 1 in 2 of you, it will involve at least one A&E visit. When you are diagnosed, your care will not necessarily be personalised, and tailored to what matters to you. You may feel that the only thing people see are your gut symptoms and your medications. Your education is still likely to be interrupted and you may feel the need to limit your career ambitions. Even your social life and intimate relationships could be affected. Living your best life may simply not be an option.

That is why Crohn's & Colitis UK are setting out a new strategy to stand up for your needs whoever you are. This strategy sets out a plan for the next three years until 2024.

With you every step of the way

We are making it our mission to understand all of your stories so we can fight for everyone affected by Crohn's and Colitis. Thousands of people engage with us every day and as a result we can tell society powerful stories about your lives and what needs to change, backed by facts and statistics. But we know that we are not reaching every community and so we cannot reflect the full range of experiences.

We will build the evidence and collect the stories of experiences throughout the UK that help us fight for better lives for people living with Crohn's and Colitis everywhere.

And where the support isn't there for you now, we will improve how we can support you directly.

It will be research that creates the long-term solutions to these lifelong conditions. We will drive pioneering research in a way that only we can.

What will be different in three years' time?

Experts in your experience

The charity will understand the diversity of Crohn's and Colitis experience, see where there are gaps in knowledge and work to address them.

You will be able to see yourself, in our work with service providers, researchers, policymakers and politicians, as well as the media.

Over the next three years we will:

- Bring together all the facts, statistics, and evidence we have about people affected by Crohn's and Colitis and work out what is missing.
- Fill the gaps in our knowledge by commissioning research to find out more about the experiences of everyone affected by Crohn's and Colitis.
- Use what we learn to underpin our services and campaigns to change healthcare, working lives and experience of education.

A treasure trove of information and support

Over the years the charity has built up a treasure trove of information and support which is trusted and valued. But it isn't always easy to find the right support at the right time and we know that many people affected by Crohn's and Colitis aren't aware of all the information and support we provide.

Over the next three years we will:

- Target information and support tailored to your needs at any stage of living with the conditions.
- Create structured patient education material that can be adopted by service providers elsewhere.
- Ensure you can speak to others affected by the conditions regardless of where you live.

Standing alongside you in demanding better

And we will speak up on your behalf on issues that have profound impact on your quality of life such as healthcare, education and employment. We've carried out unique work with leading healthcare professional organisations and other charities to articulate and measure standards of care, which lays the groundwork for systemic change. We must use that as a launchpad to persuade NHS leaders and commissioners that IBD care deserves a better deal.

We can use what we have learnt about working with our supporters to engage with the wider community to make practical changes in public spaces, educational institutions, and the workplace.

Over the next three years we will:

- Campaign for better symptom recognition and faster diagnosis.
- Drive the use of the IBD Standards as the measure of quality in NHS IBD services.
- Support the invaluable work of IBD nurse specialists.
- Champion support for invisible conditions with employers and educators.

Driving the long–term solutions that will bring long term relief

Crohn’s & Colitis UK has always been committed to drive pioneering research and we will continue to do that. But the research landscape is changing. Medical and clinical research requires huge investment and is increasingly undertaken by fewer but bigger research teams attracting multi-million-pound funding from well-resourced institutions such as the Wellcome Trust, the Medical Research Council and private investment. We need to ensure our funds are not duplicating or peripheral to those of the main funders.

However, we’re the only organisation that has an understanding of the needs of people with Crohn’s and Colitis at it's core. We are able to identify where important concerns are not being addressed in research and use our influence and limited funds to direct attention to these areas.

And we can use our influence to ensure that Crohn’s and Colitis is included in major research programmes. The recent award of a £4.5m grant for a programme of work on pain will now address IBD as one of the conditions where the treatment of pain is overlooked and under researched. Without the charity identifying the need and uniting experts in the area, IBD would have lost out on much needed research funding.

We will extend this approach of convening expertise and influencing research programmes to drive more resource to meet the needs of our community.

There will still be an ongoing role in direct support of research, but we will ensure that where this is done it is clearly targeted in work that meets identified needs and can lead to more investment by others.

Over the next three years we will:

- Drive increased funding for research that delivers maximum impact against the research priorities identified by people with Crohn’s and Colitis.
- Work with others to ensure IBD is included in any research into shared experiences with other disease areas such as pain and fatigue.
- Ensure people with Crohn’s and Colitis can influence and get involved in research that affects them.

Supporting delivery

Our supporters are an essential part of Crohn's & Colitis UK, whether you are a fundraiser, cheerleader, or volunteer, and without you we would not be able to do the work we do. Despite the challenges of the COVID-19 pandemic, you continued to fundraise, to campaign and to offer support to your peers throughout. We know that we cannot take your support for granted and we will work to ensure that the way we serve you is positive and professional. We will continue to involve you in the development of our work and products.

We will look to work with others, where doing so will deliver high quality and impact, release funds to spend elsewhere, and bring in expertise where needed.

Our staff are vital to delivering our strategy as well and we will ensure that we have a skilled and motivated team to take forward this work.