

**CROHN'S &  
COLITIS UK**

—  
FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

—  
**WE ARE  
LEADING  
THE BATTLE**

AGAINST CROHN'S  
AND COLITIS

OUR ACHIEVEMENTS  
IN 2014

## ABOUT US WHO WE ARE

Crohn's and Colitis UK is the **leading UK charity** in the battle against Crohn's Disease and Ulcerative Colitis.

We are fighting to achieve a **better quality of life for the 300,000** people in the UK suffering physically and emotionally from these and other forms of Inflammatory Bowel Disease (IBD). Ultimately, we want to find a cure.

For more than 35 years, we've been working with and for patients and their families, the nurses, doctors, and all those that work in healthcare that treat them, and the policymakers who can bring about change.

We provide high quality **information, practical help, and support** to enable people to manage their conditions. We believe people living with Crohn's and Colitis should be able to live their lives to the fullest.

We work with the UK health sector to **improve diagnosis, treatment and management** of IBD. We want everyone with the conditions to have access to the best specialist services.

We support **life-changing research** to increase knowledge of the causes and the best treatments for Crohn's and Colitis. We want to improve lives now, and lead the mission to find a cure.

We campaign vigorously alongside the IBD community and our partners – for more knowledge, better services and more support for our ongoing fight against IBD.

**We won't stop until we've won.**

**JOIN OUR FIGHT AGAINST  
INFLAMMATORY BOWEL DISEASE.**

“

By uniting the strength and passion of everyone affected by Crohn's Disease or Ulcerative Colitis, we are creating a powerful community with positive impacts across the UK. ”

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**David Barker,**  
Chief Executive

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### ABOUT THIS BOOKLET

We are proud of what we achieved in 2014, and with more support we can do so much more. This booklet explains who we are and what we do, and gives a few highlights of our work in 2014.

## WHAT WE WANT TO DO

During 2014 we began to embed our new strategic plan. Our vision couldn't be more ambitious, yet with determination, a clear focus and a strong strategy, we passionately believe that it is possible to achieve it.

Our plan concentrates on three distinct strands: Education and Support, Better Health Services, and Life-changing Research.

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### OUR VISION & MISSION

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#### OUR VISION

We want to see a world in which people's lives are not limited by Crohn's and Colitis.

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#### OUR MISSION

We work with everyone affected by Crohn's and Colitis, and help them achieve a better quality of life by providing support, improving services and ultimately finding a cure.

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## WHAT WE AIM TO ACHIEVE

### EDUCATION & SUPPORT

By 2018, as a result of our focus we expect...

- A better public awareness and understanding of IBD, and of Crohn's & Colitis UK's work
- People with IBD to have the information they need, when and how they need it
- People affected by IBD to have access to support; emotional, psychological and financial

### BETTER HEALTH SERVICES

By 2018, as a result of our focus we expect...

- IBD health services to be adequately resourced, commissioned and working to defined quality standards
- GPs to efficiently identify IBD patients and refer, support and treat them within defined protocols
- People with IBD to face reduced disadvantage and discrimination in welfare, education and employment

### RESEARCH

By 2018, as a result of our focus we expect...

- To be working to a long-term research strategy based on insight, need and understanding of the areas where we can make greatest impact
- People with IBD to be aware of the importance of clinical trials and know how to engage with them
- Our research outcomes to be effectively communicated and used to further build profile and momentum

We will work in partnership with people affected by Inflammatory Bowel Disease (IBD) to inform, develop and deliver our work. We will ensure people affected by IBD have a strong voice and play an integral part in the development of IBD services nationally and locally.

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## EDUCATION & SUPPORT

### EDUCATION: RAISING AWARENESS

We raise awareness of Inflammatory Bowel Disease to patients, their families, healthcare professionals and the general public.

In 2014 we:

- Gave out more than 250,000 **booklets, guides and information leaflets**
- Reached 11,000 newly diagnosed patients with **patient information packs** via healthcare professionals and hospitals
- Received 6,000 calls to our **Information Helpline**, an increase of 7% on 2013
- Produced a series of **patient information films** with support from the Catherine McEwan Foundation
- Expanded our **online community** to 100,000 Facebook and 13,500 Twitter followers
- Attracted more than 750,000 visits to our **website**
- Attended 250 **education/information events** and our 750 volunteers reached 15,000 people via 50 local groups



**100k**  
FACEBOOK  
LIKES



**13,500**  
TWITTER  
FOLLOWERS  
BY END OF 2014

**WE HAVE EXPANDED  
OUR ONLINE COMMUNITY**

## INFORMATIVE AND PERSONAL SUPPORT

In 2014 we:

- Trained more volunteers for our **confidential helpline** 'Crohn's and Colitis Support'
- Increased membership of our private **Facebook group** to more than 10,000. The group is a confidential resource for people with IBD
- Increased appointments to our **Disability Benefits Service** and **Parent to Parent Helpline**
- Held **family network and activity days** in Scotland, England and Northern Ireland which were attended by nearly 500 people

**We believe people living with Crohn's and Colitis should be able to live their lives to the fullest.**



**10k**  
GROUP MEMBERS

### INCREASED MEMBERSHIP OF OUR CONFIDENTIAL FACEBOOK GROUP



### HELPLINE IS A LIFELINE

*Becka, a trained counsellor, was diagnosed with Crohn's Disease in 1998. Becka volunteers for our telephone service 'Crohn's and Colitis Support', a supportive listening service staffed by volunteers with personal IBD experience.*

"We don't know who will phone up. It could be people with the condition, relatives or carers, or even health professionals. We give people a confidential safe space to talk about whatever is on their mind, and we recognise the individuality of the condition to each person. People will often be anxious about going to see their consultant or doctor, but saying out loud what they are experiencing helps to validate their experiences.

What makes us unique is that we offer rigorously trained volunteers who are a mixture of people with IBD, parents of or, carers for people with IBD, offering this safe space for people to talk. The feedback we get is that it's been very helpful, people have felt heard and the service is really valued.

**I enjoy what I do. I find it incredibly enriching as somebody with IBD to be working in this counselling area."**

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## BETTER HEALTH SERVICES



### SECURED TREATMENTS

#### HELPED SECURE ACCESS TO UNDER-THREAT TREATMENTS

We campaign vigorously with the IBD community and work with the UK health sector to **improve diagnosis, treatment and management** of Inflammatory Bowel Disease (IBD).

We are driving genuine change for people with Crohn's Disease and Ulcerative Colitis.

For example, we've successfully pressed for the development of quality standards for treatment of IBD. We also campaign to protect vital health services and to make the benefits system fairer for people with IBD.

In 2014 we:

- Submitted evidence to **consultations by NICE** (the National Institute for Health and Care Excellence), the **Scottish Medicines Consortium** and the **All Wales Medicine Strategy**, which includes those on increasing access to biological therapies and the development of a NICE Quality Standard
- Helped secure **access to under-threat treatments** for people with Ulcerative Colitis
- Held receptions in the **Scottish Parliament** and **Welsh Assembly** to raise awareness of the updated IBD Standards and highlight the need for improvements to IBD services
- Contributed, as a member of the **National Voices Coalition**, to roundtable meetings with health spokesmen for the three major parties: Jeremy Hunt MP, Andy Burnham MP and Norman Lamb MP

**But this is just a part of the leadership role we take in pressing for improvements to healthcare services for people with IBD.**

## LEADING CHANGE FOR PEOPLE WITH IBD

As Chair of the **UK IBD Standards Group** we want to ensure patients with IBD receive consistent, high quality care. We have actively supported the work of the UK IBD Audit and the launch of a UK-wide IBD Registry.

We continue to push for **free prescriptions** for people with long-term health conditions through our leadership of a coalition of more than 40 organisations.

With the **Scottish IBD Steering Group**, we work with the Scottish Government, IBD services and Health Boards to lead improvements in patient care.

**We want everyone with Crohn's and Colitis to have access to the best specialist services.**



**40**  
ORGANISATIONS

### PUSHING FOR FREE PRESCRIPTIONS



### A NICE WAY TO A REVOLUTION IN TREATMENT

*Elizabeth, 29, was diagnosed with Ulcerative Colitis (UC) in 2011. She was nominated by Crohn's & Colitis UK to be one of two 'patient experts' in a NICE appraisal of a new treatment for the condition.*

"Vedolizimab is the first treatment for Ulcerative Colitis (UC) that specifically targets white blood cells in the bowel and has proven more effective than other treatments, with fewer side-effects. The NICE consultation looked at how clinically effective and cost-effective this new biological treatment is. NICE had to decide whether the NHS should recommend it.

NICE's draft guidance recommended the drug only for UC patients who hadn't received biological therapy in the past. Crohn's & Colitis UK responded to NICE's guidance by explaining why we wanted it to incorporate all patients with moderate to severe UC. NICE held a second consultation. They listened, and changed their guidance.

**It was really empowering to be involved in that process. Previously I didn't always feel I had a voice, even in my own care, but this has meant I've influenced a decision which will help thousands of UC patients. There is such a desperate need for these medications."**

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## LIFE-CHANGING RESEARCH



**71%**  
INCREASE

### IN SPENDING ON LIFE-CHANGING RESEARCH

We support **life-changing research** to increase knowledge of the causes and the best treatments for Crohn's Disease and Ulcerative Colitis.

Clinical research we've funded has led to medical discoveries about the conditions and helped to **improve their treatment**. We also backed innovative programmes to understand the challenges faced by those living with IBD.

In 2014 we awarded **£696,873** to research projects – a **71% increase** on the previous year.

**We want to improve lives now and lead the mission to find a cure.**



### ROWING FOR RESEARCH

*James is the father of Fergus, 11, who was diagnosed with Crohn's Disease at the age of 5. In early 2014, James rowed the Atlantic to raise money for IBD research.*

"We recognised that we were on a long journey and wanted to make a difference. Crohn's and Colitis UK were supporting good research projects and we wanted our contribution to lead to something greater. Our money went in as a stake on a project and another £1 million came in on the back of that.

We wanted people to sit up and take note. That's why I rowed the Atlantic. It was brutal. It's hard keeping your body together in that environment and it reflects the daily discomfort you have with Crohn's. But I've never heard Fergus complain, so I wasn't allowed to complain. It took us 32.5 days and we raised over £120,000.

Crohn's and Colitis UK have specific criteria for research projects and you can see what your fundraising will achieve. Their impact on research is incredibly important.

**They understand IBD and its impact on families and patients. They listened to what we were trying to do. They're genuinely trying to beat this disease."**

£ 696,873

SUPPORT FOR  
GROUNDBREAKING  
RESEARCH IN 2014

## MEDICAL RESEARCH

£ 106,298

The genetic factors determining adverse drug reactions in patients with IBD.

Dr. Tariq Ahmad,  
University of Exeter

£ 119,602

Exploring the protein interactions of the colonic microbiota and the epithelium in IBD.

Prof. Brian Henderson,  
University College London

£ 73,134

A novel combination therapy for fibrostenosing disease in Crohn's disease.

Prof. Andrew Silver &  
Dr. James Lindsay,  
Barts and the London  
School of Medicine

£ 107,680

The genetics of prognosis in Crohn's Disease.

Prof. Ken Smith,  
University of Cambridge

£ 120,212

Centralised database of 25,000 IBD patients to understand the causes and treatments of IBD.

Dr. Miles Parkes,  
Addenbrooke's Hospital and  
the University of Cambridge

Information about our research strategy and all our funded programmes can be found on our website: [crohnsandcolitis.org.uk](http://crohnsandcolitis.org.uk)

## LIVING WITH IBD RESEARCH

£ 101,917

A self-administered intervention to target psychological distress in IBD.

Dr. Lyndsay Hughes,  
King's College London

£ 48,742

Stomas and IBD – how do people decide and does reality match anticipation?

Lesley Dibley,  
King's College London

£ 19,288

Sleep disturbance in patients with Inflammatory Bowel Disease.

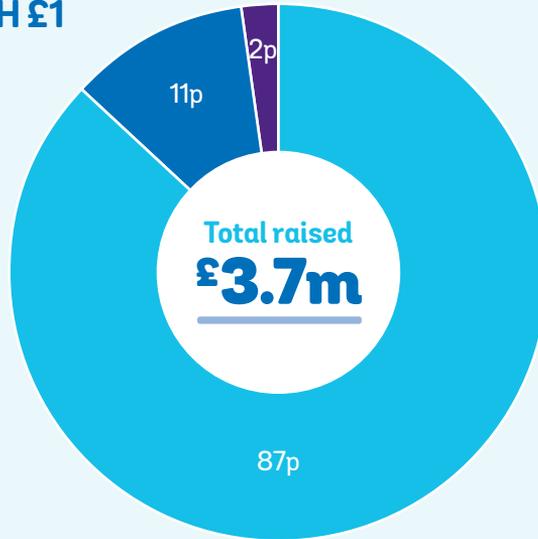
Dr. John Potokar,  
University of Bristol

## 2014 – THE FIGURES

We are transparent about all of the money we raise and spend.

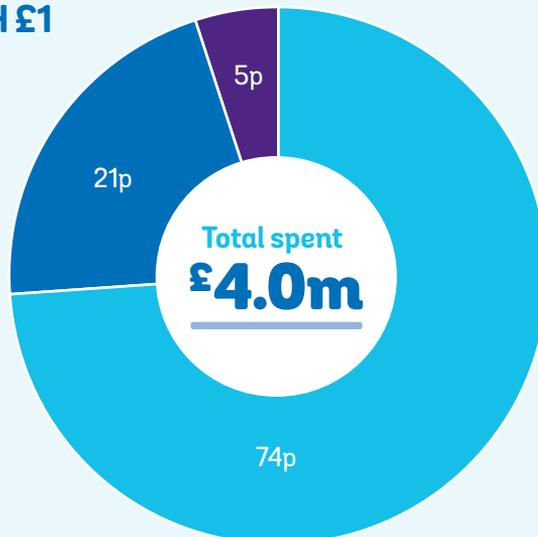
### HOW WE RAISED EACH £1

- Fundraised Income
- Membership
- Investments



### HOW WE SPENT EACH £1

- Charitable Activities
- Raising Funds
- Governance



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# ONE LAST THING THANK YOU

Thousands of you give your time, money, energy, devotion, support and skills to help in the battle against Crohn's and Colitis.

The investment you make in our work is having a direct impact on the lives of people affected by Inflammatory Bowel Disease.

By uniting the strength and passion of everyone affected by Crohn's or Colitis we are creating a powerful community with positive impacts across the UK.

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# CROHN'S & COLITIS UK FIGHTING INFLAMMATORY BOWEL DISEASE WITH YOUR SUPPORT

## JOIN OUR FIGHT

Fundraise with us, volunteer with us,  
campaign with us or become a member  
– **together our voice is stronger.**

To find out more about what you can do to  
support us, visit [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

Call: **01727 830 038**

Email: [enquiries@crohnsandcolitis.org.uk](mailto:enquiries@crohnsandcolitis.org.uk)

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### Follow us

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**CROHN'S &  
COLITIS UK**

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INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

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Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease. Charity registered in England and Wales Number 1117148, Scotland Number SC038632. A company limited by guarantee in England: Company number 5973370. 4 Beaumont House | Sutton Road | St Albans | AL1 5HH | General enquiries 01727 830 038.