

A young man with brown hair is underwater, looking directly at the camera with a slight smile. He is wearing a black t-shirt and a yellow wristband on his left wrist that says "Cystic Fibrosis". His left hand is raised towards the camera, palm facing forward. The background is a deep blue with many small white bubbles.

Cystic Fibrosis Trust

Impact Report
2016/17

Fighting for a
Life Unlimited

What is cystic fibrosis?

Cystic fibrosis (CF) is a devastating condition that affects over 10,400 people in the UK. It's caused by a faulty gene that affects how salt and water move in and out of cells. This means the lungs and digestive system fill with thick mucus, making it hard to breathe or digest food properly.

There is no cure, but there are treatments, which carry a heavy burden – hours of physiotherapy and inhaled treatments each day to loosen the mucus and help keep the lungs clear of infection, and handfuls of tablets to enable the digestion of food and absorption of nutrients. The median predicted survival age of babies born with CF today is 47, and that number is going up with each year and each new medical breakthrough.

Sadly, the average age at death is currently just 31 years old. Lung infections cause frequent hospitalisation and complications can mean that the bones, liver, reproductive system and many other parts of the body are affected, and a double-lung transplant is often required.

What are we doing about it?

The Cystic Fibrosis Trust is fighting for a life unlimited for everyone affected by cystic fibrosis.

That means investing in cutting-edge research to find new treatments, promoting great care, advocating for our community to turn up the volume on issues like access to medicines and transplants, and providing information and support to people who have to overcome so many additional challenges each day as a result of cystic fibrosis.

We are part of a fantastic community that is dedicated to making a difference. You are an essential part of that community and your support and donations are bringing us closer to beating cystic fibrosis for good. Everything you are about to read in this report is down to you.

*Thank you from everyone
at the Trust.*





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(On the cover: Macauley)

“It’s hard to choose just three highlights from this year, but mine would be the announcement of the Clinical Trials Accelerator Platform to increase awareness of and participation in clinical trials, £2.25 million invested into three new Strategic Research Centres to address lung inflammation and digestive issues, and our biggest ever UK CF Conference – attended by hundreds and watched online by over 1,000 people. There’s a lot more to do, but I’m confident that thanks to your help we aren’t far from the next breakthrough.”

– David Ramsden, Chief Executive

Research for a brighter future

Cystic fibrosis creates challenges and obstacles every day. The best way to overcome these challenges is with treatments like medication and physiotherapy, and the good news is that we're making great advances. But it's not enough – so this year we invested £2.25 million into three new Strategic Research Centres, bringing the total number of these internationally collaborative centres of excellence to 12.

We also committed more than £587,000 to fund nine new Venture and Innovation Awards (VIAs), grants that allow short-term projects to take advantage of innovative opportunities. But that's not all they do: because VIAs are designed to leverage additional funding, these awards brought an extra £1.6 million into CF research from external funders.

In 2016 we celebrated our early-career researchers with our first ever 'CF's Got Talent' competition, an interactive event where researchers could share their work with the CF community in an easy to understand way.

Want to find out more about research we are funding? Visit cysticfibrosis.org.uk/trustresearch.



Venture and Innovation Awards we funded last year:

Studying the treatment of rare CF mutations

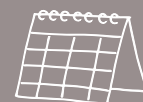


Repurposing drugs to fight Pseudomonas

Funding pre-clinical trials of a new potential treatment



The first ever 'CF's Got Talent' competition reached over 100,000 people on Facebook!





Ciara's story: cystic fibrosis-related diabetes

We sent 24-year-old vlogger Ciara along to our cystic fibrosis-related diabetes (CFRD) Strategic Research Centre to meet Professor Shaw who is working with his team to investigate how CFRD works and what causes it.

"Living with CF is tough enough, but the added complication of CFRD is a disruptive addition to the ongoing complex management of my condition. I was so excited to go along and meet Professor Shaw at Newcastle University to find out about his research. CFRD isn't the same as Type 1 and Type 2 diabetes, so without the Trust's funding I don't know who else I could rely on to try to find a way of lifting the limits it places on me. I can't wait to see what they come up with!"

Visit cysticfibrosis.org.uk/diabetes to find out more.



May 2016: We launched a new international research centre to investigate gene editing for treating lung disease in all forms of cystic fibrosis.

Campaigning hard: Stopping the Clock

In 2016, the phrase on everybody's lips was 'precision medicines', a new type of treatment that helps tackle the cause of CF, not just the symptoms. Two of these treatments are Kalydeco, which could help to treat just over 4% of people with CF in the UK, and Orkambi, which could work on over 40%. We began our Stopping the Clock campaign to ensure that people can gain access to these potentially life-changing treatments as quickly as possible, by supporting every step of the development and licensing process.

April – The National Institute for Health and Care Excellence chose not to recommend Orkambi to NHS England on cost grounds. 6,000 people used our e-action to contact their MPs in support of our proposed solution to making drugs like Orkambi available to everyone who needs them.

May – When Orkambi and Kalydeco were both rejected in Scotland, we helped hundreds of people to contact their MPs to make their voices heard and urge the Scottish Government to support our solution.

October – Orkambi negotiations between the drug's manufacturer Vertex, the Government and the NHS got underway. Kalydeco was made available to two-to-five-year-olds in Scotland.

December – We held a parliamentary debate encouraging the Government to support our solution to making vital treatments readily available and help break the deadlock. Ian Austin MP joined the CF community in a Twitter debate ahead of the debate in parliament.

Kalydeco was made available to two-to-five-year-olds in England, meaning that the drug is now available to everyone over the age of two who is eligible for it.



But it doesn't stop there. Next year we're continuing the fight for Orkambi and preparing ourselves for the next precision medicines in the pipeline. Thanks to our community, we know that we're ready for whatever comes our way.

Since it began, Stopping the Clock has provoked more than 30,000 campaign actions, including signing petitions, writing to MPs or taking part in surveys.

Visit cysticfibrosis.org.uk/stoppingtheclock to find out more.



Starting a family: support for all

Thanks to new treatments and advances in care, people with CF are living longer, healthier lives. These incredible changes mean that there are more chances for people with CF to start a family than ever before.

We are committed to supporting people with CF and their families, especially in times of need, and empowering everyone to make the right decisions for them. This year we produced a booklet about starting a family, which is full of information for men and women on genetics, carrier testing, fertility treatment and alternatives like adoption, surrogacy and choosing not to have children. As well as speaking to medical professionals, we worked with people with CF and their partners in developing the pack, who provided their personal stories and valuable feedback.

Visit cysticfibrosis.org.uk/startingafamily to see the booklet and find out more about starting a family and cystic fibrosis. We have also created a series of videos where we spoke to parents Michael, who has CF, and his wife Amy, and a doctor about the issues surrounding fertility. Visit youtube.com/cftrust to watch the videos.



"Usually when you wake up with CF in the morning it's pretty tough, but most mornings I wake up to him giggling. It makes getting out of bed that little bit easier."

– Michael, who has CF, pictured with his wife Amy and their son Oscar.

Over **1,200** people watched our fertility video on YouTube



July 2016: A 22,000 signature-strong petition calls for access to Orkambi.

Cystic fibrosis doesn't just take its toll on the lungs and the rest of the body, it can place families under financial strain too. Here's a breakdown of some of the grants we awarded last year.

799 grants
totalling just over £240,000



including 334 health and wellbeing grants, that covered...



162

For white goods,
furniture and essential
household items



116

For exercise: gym
fees, equipment
and classes



37

For home repairs
and improvements



19

For 'others' such as
music lessons and
childcare costs





Last year, we helped 418 people access at least...

£1.3 million
in benefits

Last year we contributed more than **£6,600** to support a pilot scheme providing benefits advice through a partnership with Citizens' Advice Bureau Belfast, supporting 228 individuals and families affected by CF in Northern Ireland.



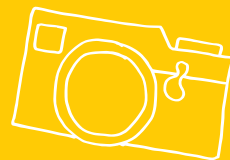
Meet our new Welfare and Rights Advisor!
Sangeeta Enright supports people with CF and their families with bespoke benefits advice.



September 2016: We announced our Clinical Trials Accelerator Platform at our UK Cystic Fibrosis Conference. Find out more about the Trials Accelerator on page 13.

It was all yellow!

On 1 July 2016 we held our third annual Wear Yellow Day. A whopping £10,000 was raised through community events, which even included a whole town turning yellow for the day. Hundreds of our amazing supporters shared #CFYelfie photos on social media, and £4,000 was raised from text donations alone! Visit cysticfibrosis.org.uk/yelfie to find out more.



Community fundraising

We receive no government funding, which means that the incredible people who raise vital funds by taking part in community fundraising and events every year are a hugely important part of our fight for a life unlimited. Last year, their amazing efforts raised more than £4 million! That's enough to fund five of our ground-breaking Strategic Research Centres. Which goes to show there's no such thing as 'just a cake bake'.

Take a look at some of the ways our amazing community raised money for the Trust through events and fundraising last year...

Abseils £19,361

Balls £120,765

Cake bakes £39,281

Christmas events £67,308

Cycling £265,950

Music events £42,353

Community raffles £13,737

Runs £1,013,359

Schools fundraising £68,853

Sky dives £82,720

Treks £133,544

Walks £286,151

And that's just the tip of the iceberg. Since last year, community activities have grown by over 50%, and our biggest event, the one and only London Marathon, raised a whopping £369,000!



November 2016: We started our brand new CF Insight Survey to help build a picture of what CF looks like year on year. Almost 900 people took part and provided us with their valuable feedback.



Macauley's story: Fighting for Breath

People with CF lose around 2% of their lung function every year – if they're lucky. We worked with 19-year-old Macauley on our 'Fighting for Breath' campaign, to raise awareness of CF, which has been featured on billboards across the country.

Visit cysticfibrosis.org.uk/fightingforbreath to find out more.



Clinical trials: ensuring access

We announced our Clinical Trials Accelerator Platform in September 2016. The Trials Accelerator will increase awareness and understanding of clinical trials, making it easier for people with CF to take part in research, and thus helping to unblock the path to new treatments. In March 2017 we announced our first Trials Accelerator centres, where we will fund a dedicated CF Trials Coordinator to oversee the running of clinical trials and work with nearby adult and paediatric care centres to ensure people with CF in the region have the opportunity to take part in clinical trials.

“The Trials Accelerator is the Trust’s newest flagship programme. Not only are we forming a UK network of specialist CF clinical trial centres, but we are also developing an exciting CF Clinical Trials Hub. The Hub will provide a wealth of information about taking part in trials as well as including the UK’s first and only CF clinical trials database, the CF Trials Tracker.”

– Rebecca Brendell (pictured),
Head of the Clinical Trials Accelerator Platform

Drugs pipeline

What new treatments for cystic fibrosis are currently at trial stage?

5 are anti-inflammatory lung treatments



16 are precision treatments that correct the underlying cause of CF



12 are anti-infection medications to fight bacteria like MRSA



Visit cysticfibrosis.org.uk/clinicaltrials to find out more.

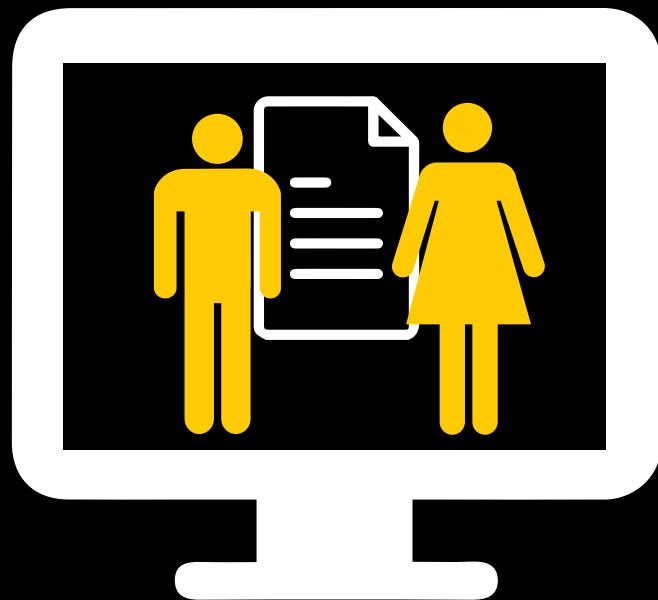


January 2017: The James Lind Alliance Priority Setting Partnership, funded by one of our VIAs, released the top 10 research priorities in cystic fibrosis, as voted for by the CF community.

Spotlight: UK Cystic Fibrosis Registry

The Registry holds consented data for over 99% of those living with CF in the UK and helps to gather vital information that is used to improve the health of people with CF through research, guide quality improvement at care centres and monitor the safety of new drugs.

This year, we launched My CF Registry, which allows people with CF to contribute directly to the Registry by sharing their own experiences of quality of life and wellbeing, and CF START, the first randomised CF registry-based trial in the UK. CF START aims to investigate how antibiotics are prescribed to children with CF, which could have long-term health implications for everyone born with the condition.



"CF START is taking an innovative approach to clinical trials. Results on the Registry will record how infants are progressing, which means families in the trial will not have any additional burden aside from their usual clinic visits."

– Professor Kevin Southern, CF START lead





Looking forward: our plans for the future

Funding ground-breaking research by exploring the effects of the environment on the progression of CF, applying complex mathematics to CF data and exploring new ways to understand the digestive system.

Improving access to clinical trials by launching our online searchable clinical trials database, the CF Trials Tracker.

Promoting great care by developing a CF centre staffing audit tool to help improve staffing levels in CF centres across the UK.

Providing specialist training to CF clinicians to ensure they feel confident in managing difficult conversations about advance care planning.

Campaigning hard for access to new medicines and technologies by contributing high-quality, evidence-based information to health technology appraisals in the UK.



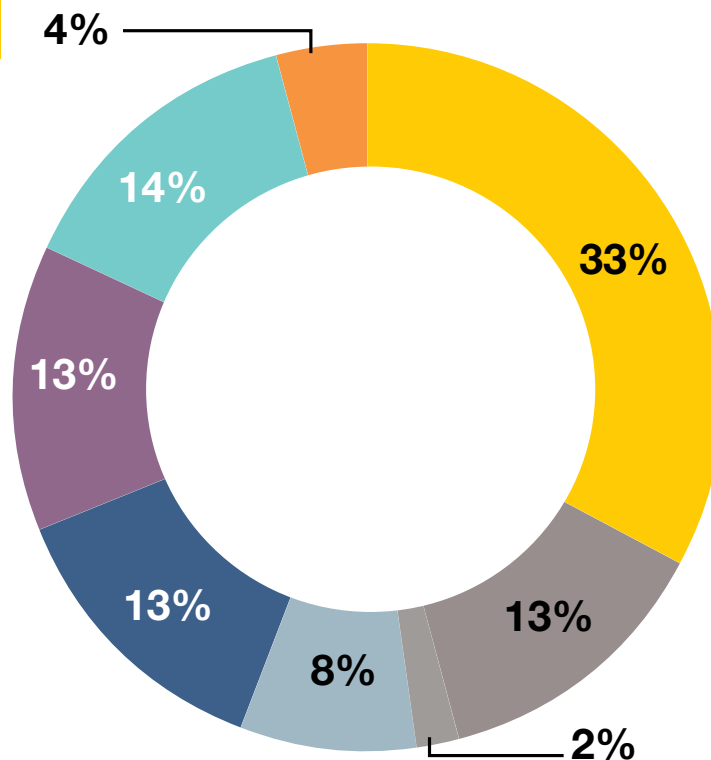
We're continuing to investigate *Pseudomonas aeruginosa*, starting with some clever research into viruses that could work to help destroy the dangerous bug.

Visit cysticfibrosis.org.uk/pseudomonas to find out more.



March 2017: Trust-funded PhD student Sara Cuevas Ocaña presented her research into cellular models of CF and non-CF airway cells to MPs at the Houses of Parliament.

Accounts



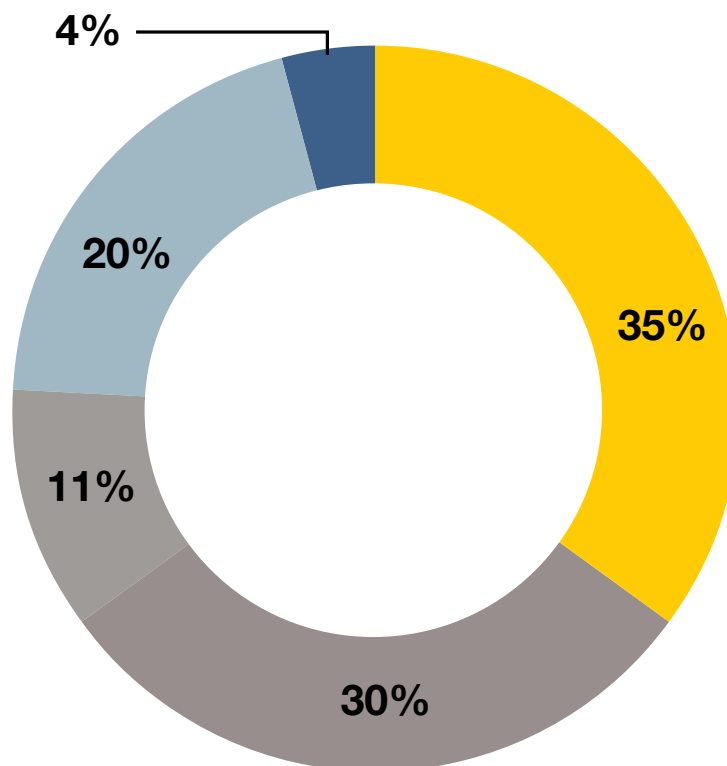
2016/17 income by income stream

Income from normal activities: £'000

Branches, groups & community	4,373
Regular and individual giving and appeals	1,647
Corporate partnerships	291
Trusts	994
Cystic Fibrosis Services Limited	1,729
Legacies	1,766
Donated goods and services	1,901
Other income	481

Total income from normal activities	13,182
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- Branches, Groups & Community
- Regular and individual giving and appeals
- Corporate Partnerships
- Trusts
- Cystic Fibrosis Services Limited
- Legacies
- Donated goods and services
- Other income



2016/17 expenditure by cost type

Expenditure:	£'000
Research	5,505
Information, advice & support	4,656
Clinical Care	1,678
Charitable activities total	11,839
Costs of raising funds	3,119
Cystic Fibrosis Services Limited	592
Total expenditure	15,550

- Research
- Information, advice and support
- Clinical Care
- Costs of raising funds
- Cystic Fibrosis Services Limited

Full details of our accounts can be found in our Annual Report and Financial Statements at cysticfibrosis.org.uk/annualreview.

Sixty Five Roses Club

Be a part of our plans for the future, and join our Sixty Five Roses Club or Sixty Five Roses Club Scotland. Sixty Five Roses is designed for supporters of the Trust who can give a personal gift of £1,000 or more annually to help the Trust fund vital projects.

By becoming a member of one of our Sixty Five Roses Clubs, you will receive newsletters, updates on our work and invitations to bespoke events to thank you for your generous contribution.

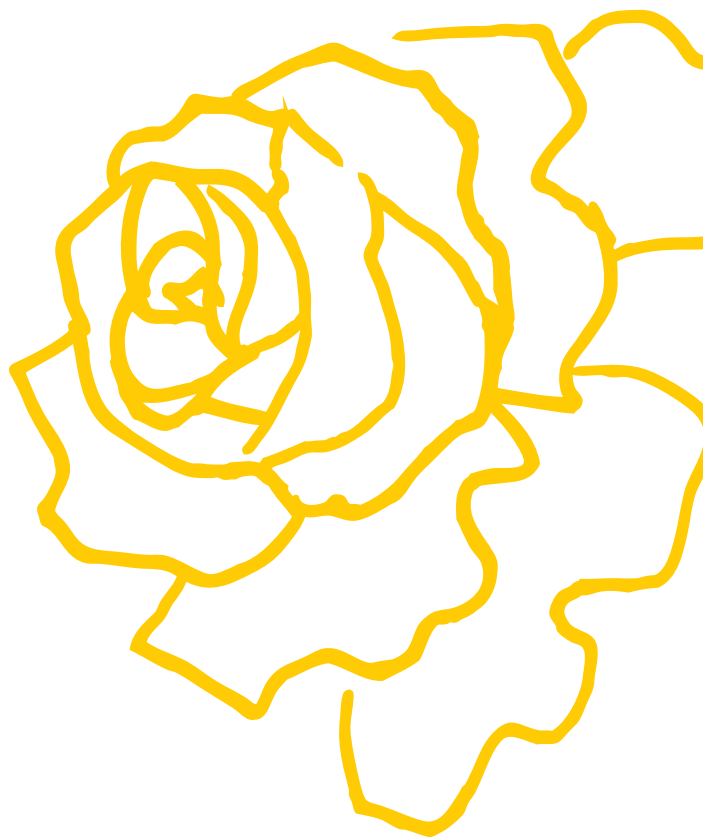
Visit cysticfibrosis.org.uk/sixtyfive to find out more about joining.

"When my adorable granddaughter was diagnosed with cystic fibrosis I was desperate to do something to help. By joining the Sixty Five Roses Club I feel like I'm making a real difference to the lives of people affected by this dreadful, life-limiting condition."

– Mary Stannard, Sixty Five Roses Club member

A kind thank you to the 87 members of the Sixty Five Roses Club, some of whom are listed below, for their generous support.

Colin and Victoria Jones
Faulkner family
Jan and Moira De Kok
Lorna A. King
Malcolm Thorpe
Rev. Iain and Mrs Marjorie Paton
Richard Parkinson
Richard and Alison Dillon
Robert and Jane Aitken
Tim Miller and Emma Hawkey



Thank you, from everyone at the Trust

We'd like to thank all of the Trusts and organisations that we work with, some of whom are mentioned here. An extra special thank you to all of the people in our incredible community who have donated, fundraised, taken part in challenges and events and volunteered for the Trust. We couldn't do anything we do without your help!

Trusts

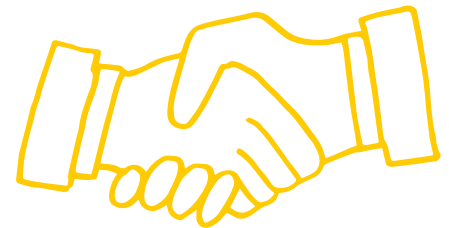
- Anna Trust in memory of Anna and Milly Douglas-Pennant
- The Barbour Foundation
- The Constance Travis Charitable Trust
- Donald Forrester Trust
- The D'Oyly Carte Charitable Trust
- Elizabeth and Prince Zaiger Trust
- The Enid Linder Foundation
- The Eranda Rothschild Foundation
- The Fidelity UK Foundation
- Garfield Weston Foundation
- The Inman Charity
- The Joseph Levy Foundation
- The Joseph Levy Education Fund
- The Kirby Laing Foundation
- The Marjorie and Edgar Knight Charitable Trust
- The Masonic Charitable Foundation
- The Norton-Freeman Charitable Trust
- Pears Foundation
- The Pharsalia Charitable Trust
- The P F Charitable Trust
- Pilkington Charities Fund
- PTC STRIVE Awards
- The QBE Foundation
- Robert Luff Foundation
- Sir Samuel Scott of Yews Trust
- The Swire Charitable Trust
- The Welbeing Trust (Sussex)

Corporates

- AJN Steelstock Ltd
- CDL
- Champneys
- Clear Channel
- Cycle Pharmaceuticals
- David Owen & Co
- Finsbury
- Kim Carey Ltd
- Nationwide Home Counties
- Sainsbury's Central Retail Division
- Star Cargo
- Vertex
- Wider Plan Ltd
- Workman LLP

Individuals and families

- The Boyden Family
- The Dujardin Family
- Mr T Edge & Ms H Begbie
- The Nigel Langdown Fund
- Mr & Mrs M Thompson
- Mr & Mrs P Whight



We extend a warm appreciation of the following generous supporters, who recently died and kindly remembered us in their wills. Gifts in wills are an important source of income and allow us to know that we can continue fighting cystic fibrosis until we beat it for good.

- Ms Bridget Ann Howard
- Mrs Eleanor Maysie Muir
- Mr Emyr Lloyd
- Mrs Pamela Leah Majaro
- Ms Jill Elizabeth Smith
- Mr John Hooper
- Ms Joyce Eileen Green
- Mr Lester John Desmond
- Mrs Peggy Armitage

Cystic Fibrosis Trust

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