

Cystic Fibrosis Trust

Impact Report
2018/19

Fighting for a
Life Unlimited

What is cystic fibrosis?

Cystic fibrosis (CF) is a devastating condition that affects over 10,500 people in the UK. It's caused by a faulty gene that affects the movement of salt and water between cells, causing the lungs to fill with thick mucus, making it hard to breathe and clear harmful bacteria. Cystic fibrosis can also stop the digestive system from breaking down food effectively, and makes people with CF susceptible to catching dangerous bacteria, meaning that they can never meet each other in person.

While there is no cure, there are treatments, but these carry a heavy burden. Most people with the condition will have to undertake hours of physiotherapy and inhaled treatments every day, and consume handfuls of tablets to digest their food. Lung infections cause frequent hospitalisations and other complications affect the bones, liver, reproductive system and other parts of the body. A double-lung transplant is often the last resort for people with cystic fibrosis. While babies born with the condition today are expected to live much longer than they were years ago, the median predicted age of survival is still only 47 years of age. Sadly, the average age at death is currently just 31 years.

What are we doing about it?

The Cystic Fibrosis Trust is fighting for a life unlimited for everyone affected by cystic fibrosis. That means funding ground-breaking research, fighting for access to life-saving drugs for everyone who could benefit from them, providing vital information and support, and promoting the highest quality of clinical care.

In this report you'll hear about what we've been doing this year, and find out how your support has had an impact on people with CF, whether you've been raising much-needed funds or raising your voice on the issues that matter. Thank you for your continued support – without it we wouldn't be able to do the work we do, and thanks to you we are moving closer every day to a world where people with cystic fibrosis can live their lives unlimited by this cruel condition.

*Thank you from everyone
at the Trust.*





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(On the cover: Michelle and her daughter Chloe, who has CF, who both featured in CF Week 2018)

“As this report shows, the last 12 months have been a period of intense activity across the Trust. Thanks to the unprecedented level of support from our community we have seen our highest fundraising total yet. This has allowed us to continue to develop our portfolio of research, including investing in infection and airway-clearance research. We have also been able to continue to offer direct help and expanded our information resources.

“The last year has also been one of bitter frustration as we have fought together to achieve universal access to the new generation of disease-modifying drugs, and we know that for so many the wait has been too long and real harm has been done.

“We will continue to fight on all fronts for a life unlimited by CF and are deeply grateful to every one of you who has helped us this year.”

– David Ramsden, Chief Executive

Research

In 2018 we launched our new five-year research strategy, focusing on the following challenges:

- Developing unique treatments
- Improving licensed treatments to create the 'next generation' of precision medicines
- Understanding CF in older age
- Using gene editing to correct the CFTR gene
- Treating lung infections
- Repairing damaged lungs

This year we funded three new £750,000 Strategic Research Centres (SRCs) in important areas of CF research.

1. Understanding *Pseudomonas*

Pseudomonas aeruginosa is the most common bacterial infection affecting people with CF today. This research will aim to inform the development of new drugs to target the bacteria in ways it hasn't been targeted before, helping to combat the issue of antibiotic resistance.

2. Targeting fungal infections

This research will help to develop a personalised approach to treating the fungal infection *Aspergillus fumigatus*, a bug that approximately 15% of people with CF will catch at some point.

3. Personalised treatments for airway clearance

A number of biochemical and physiological processes affect lung clearance, but which of these go wrong in CF and why? This research will investigate ways to improve lung clearance, which could lead to new treatments that would work for anyone with cystic fibrosis.

Find out more at cysticfibrosis.org.uk/SRC



£2.25 million

was pledged to fund three new SRCs, and we continue to fund the ongoing work of 11 existing SRCs.

Venture and Innovation Awards

This year we funded 14 new Venture and Innovation Awards (VIAs), which help to bring funding into the field of CF research from external sources.

Research Innovation Workshop on cancer

With people with CF living longer, they may develop diseases of older age such as cancer and cardiovascular disease. In November 2018 our latest Research Innovation Workshop (previously called 'research sandpits') investigated the risk of cancer in people with cystic fibrosis. Representatives from Cancer Research UK and Bowel Cancer UK attended alongside a multi-disciplinary group of CF and cancer clinicians and scientists. Following the workshop, priority research ideas were given small amounts of preliminary funding to explore and develop applications for further funding.



For every **pound** raised by our incredible community to fund our Venture and Innovation Awards, **six pounds** were invested by external funders, amounting to **£3.7 million**.



Life-saving drugs now

Thanks to the incredible support of our community, our continued fight for access to life-saving drugs is currently one of the biggest political issues in health.

In **Scotland** in September 2019, we celebrated a landmark moment as the Scottish Government announced that Orkambi and Symkevi would join Kalydeco in becoming routinely available through NHS Scotland, as part of a five-year deal. The agreement includes a commitment to use the world-class UK CF Registry to track the impact of the drugs, a move we have campaigned for since 2015.

In **Westminster**, March saw the Health and Social Care Committee's investigation hold an evidence session with top officials from NHS England, NICE and drug manufacturer Vertex Pharmaceuticals attending. Over 300 campaigners submitted their testimonies and 200 demonstrated outside the Houses of Parliament.

The session brought fresh urgency to negotiations in England and after collectively meeting with the Secretary of State for Health and Social Care, Vertex, NHS England and NICE resumed their talks that stalled last year.

In **Wales**, CF campaigners delivered a 5,000-signature petition to the Welsh Assembly. Cross-party support from Janet Finch-Saunders AM, David Rees AM and others has kept the attention focussed on getting access to life-saving drugs for people in Wales, and Health Minister Vaughan Gething AM has told the Trust that Vertex have made a commitment to submit their drugs for review in Wales.



In **Northern Ireland**, despite the ongoing suspension of the Assembly, campaigners have worked hard to make sure decision-makers are engaged and looking for solutions. In Spring 2019, Richard Pengelly, Permanent Secretary for Health and Social Care in Northern Ireland, confirmed that his department are in close contact with colleagues in the Scottish Government to learn from their progress.

The status of access to life-saving drugs for people with CF across the UK is constantly changing, and we hope that the recent progress in Scotland will soon be replicated across the rest of the UK.

Find out more about our campaigning work at cysticfibrosis.org.uk/lifesavingdrugs



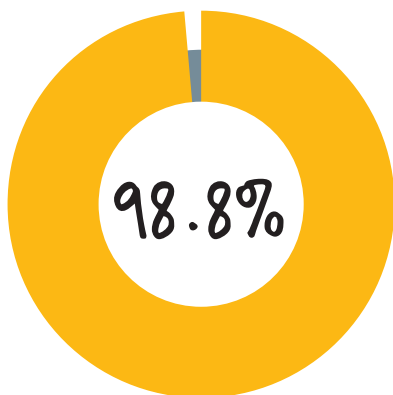
We engaged over **250 parliamentarians** from across the political spectrum this year, more than double the number in 2017/18.

UK CF Registry

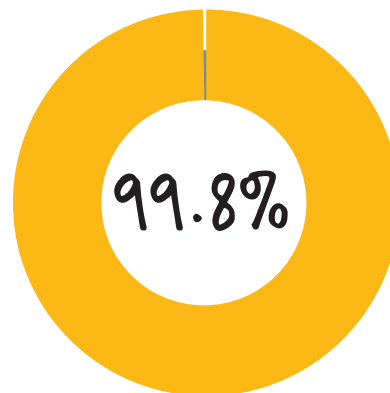
The UK CF Registry is a world-class database that records data on over 99% of people with CF in the UK, who have consented to their data being submitted by their care team.

This year, Data Validation visits took place in CF centres across the UK to check the accuracy of data entered onto the Registry. The results show that information on the Registry is 99.8% complete, and 98.8% accurate for the key data used for analysis.

Accuracy



Completeness



The 2017 Annual Data Report was published in August 2018 (the first CF registry report to be published in the world that year), and gives information on the health and treatment of people with CF, and shows how things are changing over time. The report showed a rise in the number of annual reviews recorded and a new median predicted survival age of 47 years for people born with CF today.

In January 2019, a paper was published by researchers who used Registry data to make dynamic survival predictions for people with cystic fibrosis. Unlike population-based estimates, the paper shows personalised predictions of survival based on a person's current health status.



Clinical Trials Accelerator Platform

The Clinical Trials Accelerator Platform is a UK-wide initiative to bring together CF centres to increase access to, and participation in, CF clinical trials. By creating a robust infrastructure for clinical trial delivery, and funding dedicated CF Trial Coordinators around the UK, we are ensuring the UK is speeding up the development of breakthrough CF therapies. Here are just a few of the recent achievements of the Trials Accelerator.

70%

of patients have spoken to their CF team about clinical trials in general



43%

said they have had the opportunity to consider a clinical trial



- Since the Trials Accelerator was launched in September 2017, 286 people with CF have taken part in a clinical trial at a Trials Accelerator centre.
- Our annual clinical trials survey has shown an increase in awareness and opportunity for the CF community to discuss trials with their CF team or to consider participation in a trial.
- The Trials Tracker, which lists all CF studies taking place in the UK, was visited over 5,600 times this year.
- The Patient and Public Involvement workstream of the Trials Accelerator has allowed representatives from the CF community to give feedback to pharmaceutical companies on how to make trials more desirable, accessible and participant-friendly.

"The Trials Accelerator has changed the entire landscape for CF clinical trials at our site. Since becoming a Trials Accelerator site our portfolio has gone from strength to strength and there are many more trials for our patients to participate in. They also now have a familiar face, their own CF researcher who they know is their point of contact for trial information."

– Jessica Longmate, Trial Coordinator,
Nottingham University Hospital

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

Information and support

Cystic fibrosis is a complex condition that affects many parts of the body and creates obstacles that can make it hard to live a healthy, happy and productive life. We provide vital information resources about the condition and support people with CF and their families every day to make life that little bit easier.

This year we awarded over 950 grants totalling £265,000, including:

£47,000

in emergency grants to fund daily living costs and essential items for people with CF in immediate financial crisis, ensuring they can focus on their health at difficult times.

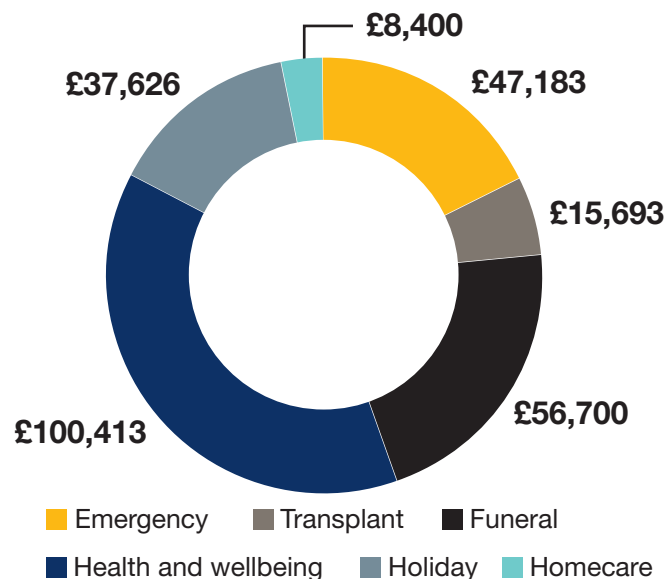


£10,000

through the Helen Barrett Bright Ideas Awards, helping people with CF to build their business or career and achieve financial freedom.

£56,000+

in education grants awarded by the Joseph Levy Education Fund, to help people with CF pursue university or vocational training.



Our Welfare and Rights Advisor helped people with CF and their families in England, Scotland and Wales to access over **£1.1 million** in benefits they were entitled to, and we offered a benefits advice service in Northern Ireland through a specialist partnership.

Our helpline responded to over **3,300** enquiries from people affected by CF, over 40% of which related to financial concerns or support, underlining the critical importance of our welfare grants programme and benefits advice service.

Over **600** young people engaged with our Building Brighter Futures workshops, funded through BBC Children in Need.

Find out more about the support we offer at cysticfibrosis.org.uk/financialsupport

Burgeoning bright ideas

The Helen Barrett Bright Ideas Awards offer applicants up to £5,000 to help develop a hobby, business idea or career, or to fund training and resources to help their business venture grow.

35-year-old Colin Milne, who has CF, received an award this year to fund his business, String-a-Ling-a-Ding-Dong, where he designs chalkboards, string art and carved pieces.

“I had a tough time over the Christmas period and suffered pneumonia, pleurisy and a collapsed lung, which resulted in getting IVs for the first time in 17 years. This brought things into perspective a bit and made me start taking my health a lot more seriously.”

Colin received £2,500 to insulate his garage, where he does the majority of his work.

“In the winter time especially, the garage is freezing cold, and I really can’t spend more than an hour or so out there. If I were to insulate and heat the garage, then I’d be able to use the space year-round.”

While Colin still has a full-time job and hopes to continue working on String-a-Ling-a-Ding-Dong alongside it as long as he can, he is aware that this might not always be possible.

“If the time comes and I have to give up my work then I hope to be able to work away at my own business.”

Find out more about the awards at cysticfibrosis.org.uk/brightidea

The Helen Barrett Bright Ideas Awards were established in memory of Helen Barrett, an entrepreneur with CF who set up her own gym. Helen sadly died a week before her 32nd birthday, but her gym is still thriving.



Colin Milne

CF Week and Wear Yellow Day

This year, for the biggest awareness-raising event in our calendar, we looked at time and the impact CF has on the time of people with the condition and their families. We heard from Dom, Michelle, Chloe and Amy about their unique perspectives on how their time is affected by cystic fibrosis.

“Things have come a long way over the years, but as you get older you have to do more and more to keep yourself well, so it takes up more time. I want to keep working, I want to support myself, and being able to stay well is key to that.” – Amy

The number of Wear Yellow Day events increased from 127 to 157, raising over **£41,000**. People, pets, schools and towns were turned yellow, attracting attention from local media to the realities of CF, and over **£9,000** was raised through #CFYelfies alone!

On Wear Yellow Day we also held our first ‘Style It Yellow’ campaign, where we asked popular social media influencers to post selfies in their yellow outfits.



Amy

Fundraising

Thanks to the extraordinary generosity and commitment of our supporters, in 2018/19 we had our most successful fundraising year ever, raising over **£12.1 million**, an increase of £3.4 million from the previous year. The amount raised by those who included gifts in their wills and gave in memory also increased from 10% to 21% of our income total this year, raising £3.7 million, for which we are incredibly grateful.

Here are just some of the ways our amazing supporters pulled out all the stops to make this a record-breaking year.



£28,248
cake bakes



£559,862

regional branches
and balls

£39,703
abseils



£53,831
skydives



£76,455
Christmas events



£1.1 million
runs and muddy challenges



£278,361

community Charity of
the Year partnerships

£137,474
cycling



£69,373
schools fundraising

Tim's marathon journey

Tim Hughes has cystic fibrosis and signed up to take part in the 2019 Virgin Money London Marathon for the Trust, his first full marathon!

"I wanted to do something incredible for my 40th birthday and to show others that CF can still allow you to do crazy challenges.

"As the treatments for CF and knowledge about CF get better and better, our outlook is better now than it ever has been. By pushing ourselves we can strive to achieve much more than was ever imagined.

"I know that running is hugely beneficial. I love the way that it's given me masses of energy and a new outlook on life. I am absolutely petrified about the London Marathon, yet extremely excited at the same time!"

Our amazing marathon runners raised over **£390,000** in the 2018 Virgin Money London Marathon



Tim Hughes

Plans for the future

In 2018 we launched our new three-year Strategic Framework. Below are our five goals, and what we'll be doing in the next year to achieve them.

Invest in a dynamic portfolio of research and innovation

Our Research Strategy 2018–2023 will continue to ensure we have a balanced portfolio of research programmes that take advantage of external funding and use novel approaches to tackle important issues.

Collaborate with and support the clinical community to promote the highest quality of care

A new UK CF Registry dashboard will allow clinical teams to monitor the care they provide and the quality of their data, and will offer a way to share Registry data with people with cystic fibrosis.

Support access to medicines at every step from laboratory to medicine cabinet

As well as continuing to push for access to life-saving drugs, we will call for a reform to reimbursement mechanisms to allow for managed access to these drugs while uncertainties and negotiations play out. At the same time, the Clinical Trials Accelerator Platform will expand its network of trial centres to increase the inclusivity of the platform.



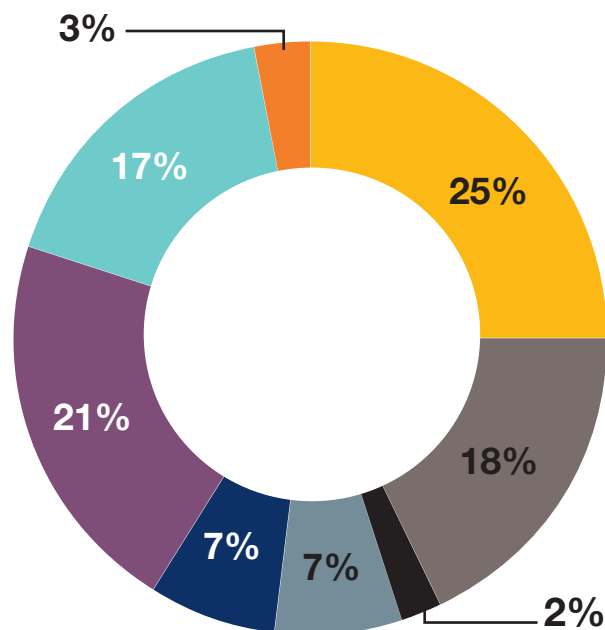
Provide day-to-day support

We'll be updating our clinical guidelines to support best practice in CF clinical care, and producing new guidelines in palliative care and mental health. We will also launch a programme of information evenings across the UK.

Seek to reach all people with CF when they need us most

The Quality Improvement team will launch a new patient recorded experience survey allowing people with CF to share their experiences of the care they receive from their team.

Accounts in



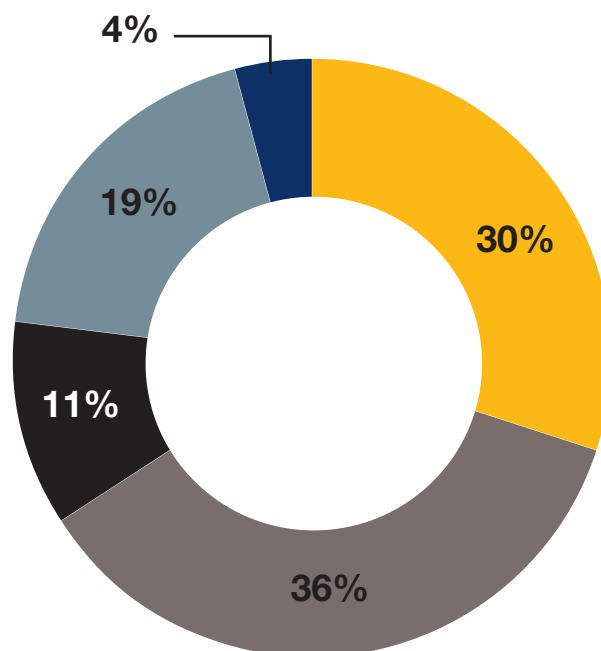
2018/19 income by income stream

Income from normal activities: £'000

Branches, groups and community	4,366
Regular and individual giving and appeals	3,137
Corporate partnerships	373
Trusts	1,339
Cystic Fibrosis Services Limited	1,321
Legacies	3,745
Donated goods and services	2,962
Other income	526

Total income from normal activities	17,769
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- Branches, groups and community
- Regular and individual giving and appeals
- Corporate partnerships
- Trusts
- Cystic Fibrosis Services Limited
- Legacies
- Donated goods and services
- Other income



2018/19 expenditure by cost type

Expenditure:	£'000
Research	4,695
Information, advice and support	5,722
Clinical care	1,804
Charitable activities total	12,221
Costs of raising funds	2,927
Cystic Fibrosis Services Limited	590

Total expenditure	15,738
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- 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, designed for supporters who can give a personal gift of £1,000 or more annually to help us fund vital projects.

By becoming a member, 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.

"I would like to thank every member of the Club for your support over the past year. I am extremely honoured to be a Patron of the Sixty Five Roses Club. Your support has helped us to continue to work towards our goal to create a world where being born with CF no longer means a life-long burden of care, and people with the condition can live a life unlimited."

– Rob Law MBE, creator of the Trunki children's suitcase and Sixty Five Roses Club Patron



Rob Law MBE

Thank you

We would 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 our incredible donors, fundraisers, challenge and event participants and generous volunteers. We couldn't do anything we do without your help!

The UK Cystic Fibrosis Conference continues to be a popular event, with ongoing support via sponsorship from the pharmaceutical industry raising nearly £65,000. Existing relationships continued to blossom this year, including with the Garfield Weston Foundation, the Robert Luff Foundation, the Joseph Levy Foundation and the Eranda Rothschild Foundation.

Individuals and families

■ Boyden Family ■ Mrs N Carr ■ In memory of Robert Ashby

Corporates

■ AJN Steelstock ■ Bird & Bird ■ Goldman Sachs ■ Innovate UK ■ Nex Group ■ Vertex ■ Whisky Auctioneers

Trusts

■ 65 Roses Trust ■ BBC Children in Need ■ The Gay and Keith Talbot Trust ■ The Joseph Levy Foundation
■ The Joseph Levy Education Fund ■ The Marjorie and Edgar Knight Charitable Trust ■ The Medicash Foundation
■ QBE Foundation ■ The Queen's Trust ■ The Robert Luff Foundation ■ Sir Samuel Scott of Yews Trust
■ Sport England ■ Swire Charitable Trust

Gifts in wills

We extend a warm appreciation of all generous supporters, who recently died and many years ago had kindly remembered those with CF in their wills. Gifts in wills help ensure our future work and allow us to know that we can continue fighting CF until we beat it for good. The families, loved ones or Executors of the following estates agreed to acknowledgement of the gifts kindly received.

Our Online Book of Remembrance remembers all those who kindly thought of us in such an extraordinary way to shape the future, as well as acknowledgement of the following:

■ Geraldine Armstrong ■ Sylvia Heffernan
■ Margaret White

You can view the Online Book of Remembrance on our website: cysticfibrosis.org.uk/bookofremembrance

Cystic Fibrosis Trust

Find us online

cysticfibrosis.org.uk

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 [cftrust](https://www.youtube.com/c/cftrust)

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 [linkedin.com/company/cystic-fibrosis-trust](https://www.linkedin.com/company/cystic-fibrosis-trust)