



Cystic Fibrosis Trust

Impact Report
2017/18

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 fill with thick mucus, making it hard to breathe and clear harmful bacteria. These bacteria mean two people with CF can never meet each other in person. The mucus also stops the digestive system from breaking down food effectively. There is no cure.

There are treatments, but these carry a heavy burden – hours of physiotherapy and inhaled treatments for the lungs each day, and handfuls of tablets to enable the digestion of food. The median predicted survival age of babies keeps rising, in part due to these treatments and improvements in our understanding of the condition, but it currently stands at only 47 years of age. Sadly, the average age at death is currently just 31 years.

Lung infections cause frequent hospitalisation and other complications can mean that the bones, liver, reproductive system and other parts of the body are affected. A double-lung transplant is often the last resort for people with cystic fibrosis.

What are we doing about it?

The Cystic Fibrosis Trust is fighting for a life unlimited for everyone affected by cystic fibrosis. This year that has meant stepping up our campaign for access to precision medicines, broadening our research portfolio, adapting to the changes in the benefits process and much, much more.

In this report you'll find out exactly what impact your support has had on people with cystic fibrosis and their families, whether that's by helping to fund our new Innovation Hub at the University of Cambridge or helping us to engage hundreds of parliamentarians across the UK 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: Vicky who featured in our transplant pack)

“This year the passion of the cystic fibrosis community has been vividly demonstrated by UK-wide campaigning for access to medicines. Alongside that continuing fight, we have been working hard to continue to drive change; from awarding two new fellowships to attract the best talent into CF care to launching new resources reflecting the diverse ways CF impacts people’s lives. All of this, and the research you will read about here, is only possible because of your support. Thank you to everyone who contributed to the fight for a Life Unlimited by cystic fibrosis this year.”

– **David Ramsden, Chief Executive**

£887,797

was raised through **running events and muddy challenges** last year, enough to fund an SRC!



Finding the next breakthrough

High-quality research is the best way to find the next breakthrough in care and treatment. Here are some of the ways we used the money you donated to help make our vision of a life unlimited a reality.

We pledged **£1.5 million** to support two new Strategic Research Centres (SRCs), bringing together the brightest scientific minds to find a way of restoring lung function in people with CF – regardless of their genotype – and develop cutting-edge methods for detecting and treating Pseudomonal infections.

Innovation Hub

Bacteria that are resistant to antibiotics, a sudden worsening of symptoms and the long-term degeneration of lung health – just three of the risks people with CF face. Our new research partnership with the University of Cambridge will focus on delivering transformational new treatments for bacterial infections, chronic inflammation, and lung repair. It will also support CF research across the UK by creating collaborative networks in key research areas, and providing resources, funding and training for researchers in other centres.

We have committed to raising **£5 million** for the Hub over the next five years, which will be matched pound for pound by the University of Cambridge. Generous pledges totalling £1.2 million to date have been received from AJN Steelstock, the Robert Luff Foundation and other generous individuals.

Venture and Innovation Awards

We pledged £569,000 to fund 11 new projects, looking at:

For every **£1** we've spent on our VIAs, we've brought in almost £4 of external funding



Breaking antibiotic resistance

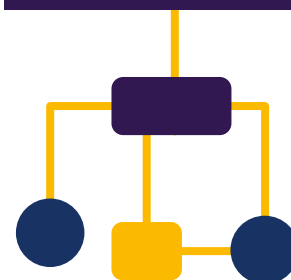


Gene editing for all genotypes



Home health monitoring

Machine learning to answer complex questions



Detecting and fighting CF lung pathogens



Using existing medications to fight CF

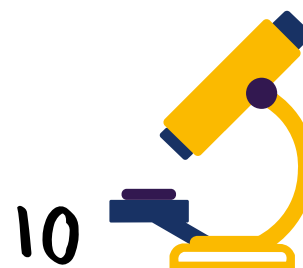
This brought an additional **£1.75 million** into CF research from external organisations like the **National Institute for Health Research (NIHR)**, **Great Ormond Street Hospital**, the **Cystic Fibrosis Foundation**, **Action Medical Research** and many more.



CF's Got Talent! had a 'live' online audience of 850 people

4,500

a further 4,500 watched some of the content later.



10 Summer Studentships in partnership with the British Lung Foundation

Campaigning hard

Our campaigns help us show that the CF community is a force to be reckoned with, catching the attention of decision makers and inspiring action across the country. Together with the Trust through our Stopping the Clock campaign, our supporters call for fair access to potentially transformational precision medicines to treat cystic fibrosis. Here's our campaigning year in numbers:

Protests

- 400 protestors in all four UK nations with 15 moving personal stories shared and 155 pieces of news coverage

Parliamentary questions

- 6 asked in the Welsh Assembly
- 15 asked in Holyrood
- 49 asked in the House of Commons

Parliamentarians

- 218 engaged Parliamentarians across the UK Governments
- 66 MLA signatures on a cross-party letter to the then-Health Secretary, Jeremy Hunt, and the Permanent Secretary, Richard Pengelly
- 42 MPs at our Parliamentary event in November 2017
- 40 MPs at our roundtable meeting to discuss access to medicines
- 59 MPs at our Westminster Hall debate in March 2018

Petitions and letters

- 100,000 signatures on a community-led petition in just 10 days, leading to a debate in London
- 5,000 signatures on a petition to the Welsh Assembly

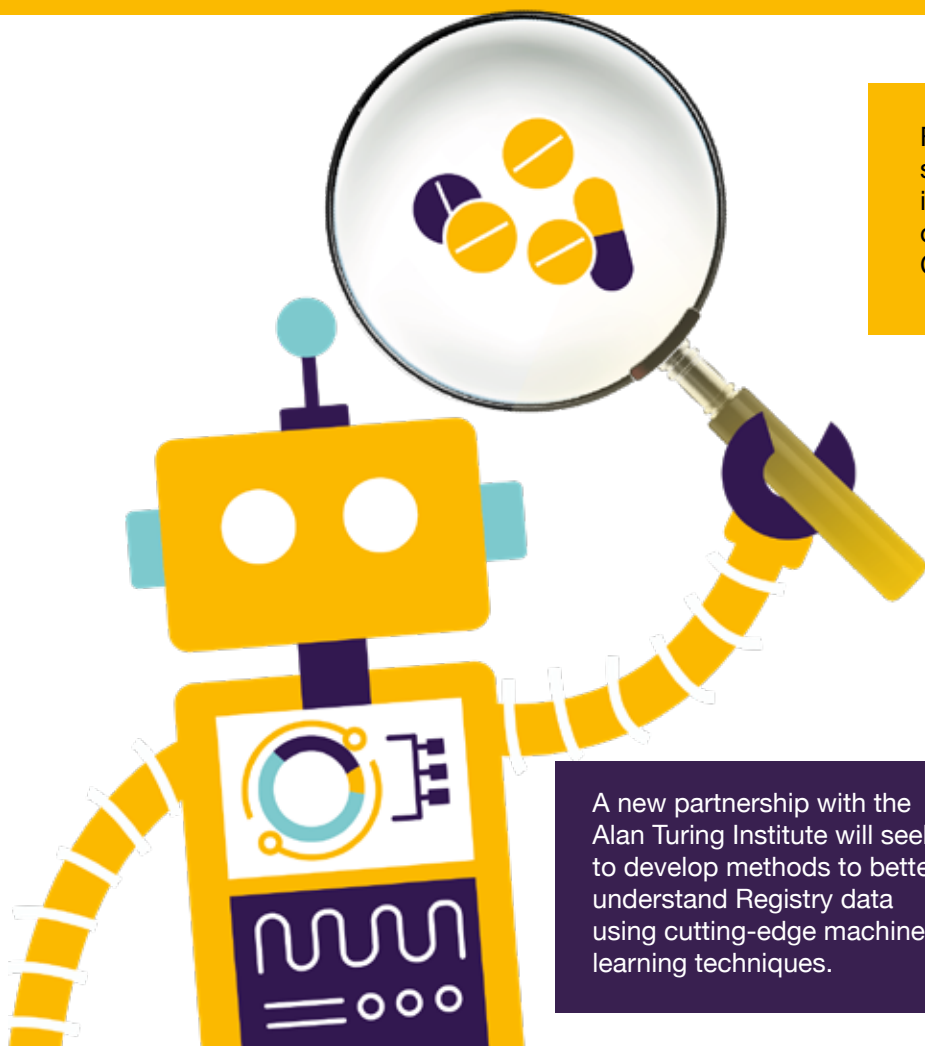


Catch up on our campaign for access to medicines by visiting cysticfibrosis.org.uk/stoppingtheclock

Spotlight: UK CF Registry

The UK CF Registry is a world-class database that includes data on over 99% of people with CF in the UK, who have consented to their data being submitted by their care team. It's been a busy year for the Registry team!

A Vertex CF Circle of Care award allowed us to begin work with the London School of Hygiene and Tropical Medicine to create survival and milestone prediction tools for the CF community.



A new partnership with the Alan Turing Institute will seek to develop methods to better understand Registry data using cutting-edge machine learning techniques.

Four drug safety studies, one observational study and two NHS contracts generated income of £1.8 million, a significant proportion of which has been used for grants to support CF centres in their data entry to the Registry.



Support when it's needed most

Cystic fibrosis is a complex condition that makes it harder to live a healthy, happy and productive life. By providing trusted, accessible and reliable information and support in all areas, we help the CF community to get the help they need each and every day.

Benefits advice

Sangeeta Enright, our Welfare and Rights Advisor, supported almost 400 people with the provision of welfare advice, securing over **£1.6 million** in benefits income for people with CF this year alone, **£300,000** more than last year. We also continue to offer a benefits advice service in Northern Ireland through our partnership with Citizens' Advice Bureau Belfast.

In the last two years, Sangeeta has helped to secure over **£3 million** in benefits for people with CF and their families.

"In June 2017 Nicholas, supported by me, was shocked when he was deemed to have scored nil in all aspects of PIP.

"We received initial help from the Social Worker at St James's Hospital, and then invaluable advice from Sangeeta Enright. With her help we formulated an appeal which was held locally and Nicholas had his allowance re-instated in July 2018. Many thanks to all in the CF family."

– Jim, Nicholas' dad

Grants This year we awarded:

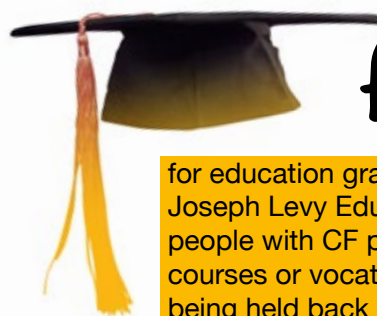


£10,000

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

£7,720

in homecare grants, enabling people in very poor health to remain comfortably at home



£59,570

for education grants awarded by the Joseph Levy Education Fund, to help people with CF pursue university courses or vocational training without being held back by financial worries

£282,000

to help with emergencies, transplants, health and wellbeing, holidays and funerals



Information

We're dedicated to helping people understand CF and the many aspects of its care and treatment by providing award-winning resources. This year, we created:

- Three transplant packs for people with CF and their friends and families
- A series of practical leaflets on physiotherapy techniques
- Two printed picture books and accompanying animations for children whose parents have CF
- A series of printed resources and an animation for young people leaving school
- Updated clinical guidance on good practice for the management of CF physiotherapy and the prevention and control of *Mycobacterium abscessus*

Award-winning resources

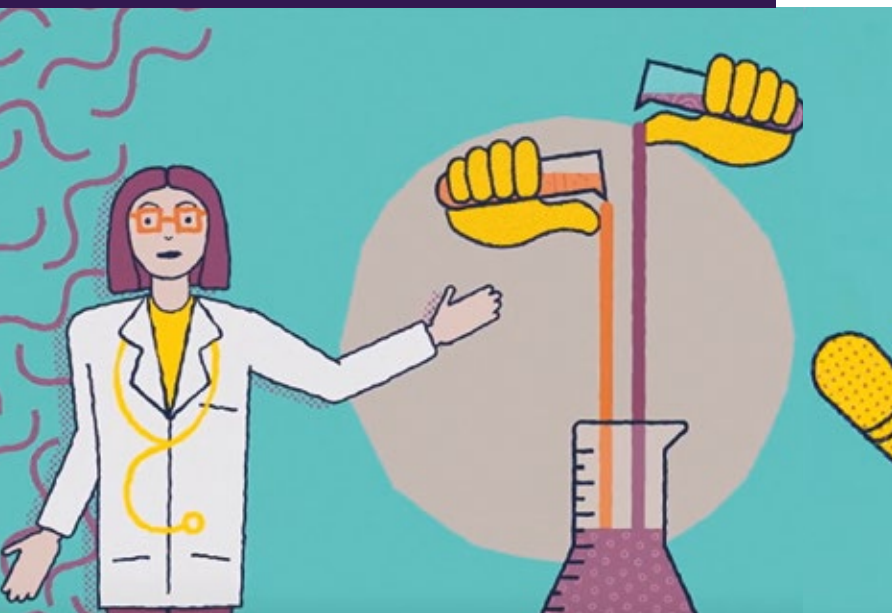
Our 'starting a family' pack won first place in the 'aid to decision making' category of the British Medical Association Patient Information Awards.



Patient information awards
Winner

Building Brighter Futures

This pilot project, funded by BBC Children in Need, helps to improve the overall health, wellbeing and confidence of young people with CF through a series of online talks and six-week workshop programmes.



Talking trials

This year, our Youth Advisory Group (YAG), made up of under-25s with CF or with a close connection to the condition, helped produce an animation about clinical trials for young people. The animation was designed, written and voiced by YAG-member Jade, and was generously funded by the Queen's Trust.

Hello yellow!

Our annual awareness week focussed on demonstrating the impact your donations have on the lives of people with cystic fibrosis and their families.

The community loved our 'What is CF?' video and infographics about the research we fund, and the icing on the cake was our best Wear Yellow Day ever! From Portsmouth's Spinnaker Tower to the whole town of Knutsford, our wonderful community turned all kinds of things yellow.

Over £5,000 was raised through #cfyelfie donations alone, and a further £35,000 through community events. All of this helps us keep doing the work we need to!



Your fundraising

A big thank you to all our fundraisers, event participants, individual donors, charitable trusts, foundations, organisations and corporate partners (and many more)! We receive no government funding, so every penny shown here is the result of your ongoing commitment. Here are some of the ways we raised more than £8.7 million (nearly £300,000 more than last year)!

- 5,187 supporters took part in a challenge event.
- 1,227 community events took place.
- New multiyear grants and partnerships secured, including support from The Queen's Trust, BBC Children in Need, Sport England and Bird & Bird LLP.
- The Virgin Money London Marathon, our biggest fundraising event of the year, raised **£339,000**.
- Our Great Strides™ events raised over **£250,000**, and our new Ultra Marathon raised an impressive **£11,000** on its own, bringing the total for all treks and walks to **£450,785**!



£37,196

Cake bakes



£887,797

Runs and muddy challenges



£69,678

Sky dives



£14,751

Balls



£30,038

Abseils



£85,000

Schools fundraising

£150,000

Christmas events



£292,662

Cycling



£296,673

Raised by our fantastic regional branches

Martin's story

Our Christmas campaign highlighted the research funded by supporters, through the eyes of Martin, who has CF and wants to live a long life to be there for his five-year-old daughter, Emily.

"I've ticked a lot of things off my bucket list over the last few years, like taking my family to Disneyland Paris and seeing Emily's first nativity play, but there are a lot of special moments I still want to see. Christmas mornings, birthday parties, school sports days, her first day of secondary school.

"Cystic fibrosis kills, but the Trust's dedication to funding new research and treatments provides a glimmer of hope for brighter days ahead. We need that support; we need people to understand the battle of CF, and we need every chance to live longer lives."

– Martin

£196,000

could fund a year of one of our ground-breaking SRCs that offer hope to thousands of families like Martin and Emily.



Clinical Trials Accelerator Platform

Clinical trials are a vital part of the development of new drugs, but they demand time and resources not previously available at CF centres and recruiting participants can be difficult. Last year, we launched the Clinical Trials Accelerator Platform, a network of CF centres across the UK, to lead in the delivery of cutting-edge clinical trials. Features of the Trials Accelerator include:

- 32 lead CF centres, representing England, Scotland, Wales and Northern Ireland and over 80% of the CF population.
- The UK's only CF-specific clinical trials database, the CF Trials Tracker, which lists all trials that are open to recruitment.
- Development of resources to engage with the community, increasing understanding and awareness of clinical trials opportunities or activity.
- 20 Trial Coordinators and Research Nurses funded, increasing research capacity.
- Increased engagement with the pharmaceutical industry responsible for creating and testing new CF drugs.
- Facilitation and delivery of feasibility studies for a variety of trials, which will open to recruitment during the 2018/19 financial year.



"Funding a clinical trials coordinator as part of the Trials Accelerator to inform and streamline patients' access to new therapies for CF has been one of the most innovative and practical initiatives I have been involved with. The research process for adult and paediatric CF studies at Southampton General has greatly improved. We are enormously grateful to the Cystic Fibrosis Trust for evolving this creative concept, which patients need at this exciting time of new drugs and therapies."

– Dr Mary Carroll, Lead Investigator at University Hospital Southampton

Why is clinical trial participation so important?

Martin: "I took part in a trial for DNase when I was a teenager. The DNase trial showed the treatment was effective, and I'm still benefitting from it today. Now I want to do all I can to help the younger generation living with cystic fibrosis."



Jane: "Over the years I have been involved with many studies, surveys and trials. I have undoubtedly benefitted from advances in CF care brought about by clinical trials, and I feel it is the least I can do to give something back."

Find out more at
cysticfibrosis.org.uk/trialstories

Plans for the future

We set out to beat CF through innovation, empowerment and accelerating the pace of change. We are ambitious for the Trust and believe that we can substantially grow our impact in the coming years.

Our new Strategic Framework and refreshed Research Strategy set out the following priorities, which are at the heart of everything we do:

- Continuing to campaign for access to life-changing treatments by mobilising the CF community to raise their voices with us and contributing high-quality, evidence-based information to Health Technology Appraisals in the UK.
- Developing a patient/carer experience survey, new national guidelines for all Allied Healthcare Professionals and a CF centre staffing audit tool to help to drive up safe and effective staffing levels in all CF centres.
- Continuing to develop award-winning resources and support for people with CF and their families to help them through the issues they face every day.
- Involving more of the CF community in the work we do and the support we offer, and developing new ways of ensuring our work is relevant to the entire CF population.

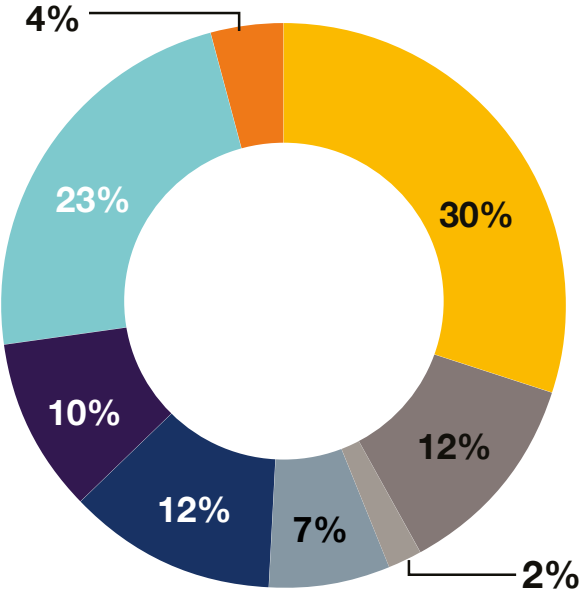


64% of people with CF said access to new medicines was their greatest concern (CF Insight Survey 2018 results)

We will also expand the reach of our Clinical Trials Accelerator Platform, continue to bring new expertise to the ever-growing field of CF research, further develop the My CF Registry portal and offer an exciting portfolio of events and activities to inspire people to continue to support us.

We have achieved a great deal in recent years and there are some big opportunities coming up to help us get closer to our vision of a life unlimited. All our supporters, now and in the future, are a vital part of this vision. Thank you for making it possible.

Accounts in

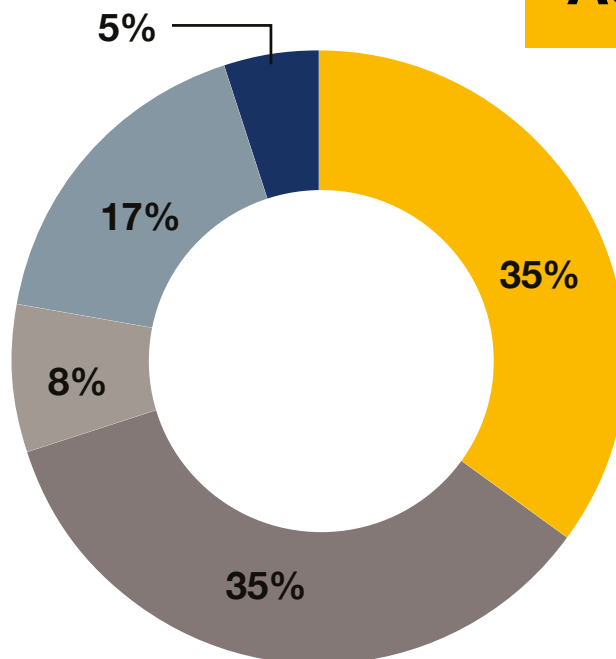


2017/18 income by income stream

Income from normal activities:	£'000
Community, branches, groups and events	4,475
Regular and individual giving and appeals	1,881
Corporate partnerships	270
Trusts	989
Cystic Fibrosis Services Limited	1,830
Gifts in wills	1,513
Donated goods and services	3,491
Other income	720
Total income from normal activities	15,169

- Community, branches, groups and events
- Regular and individual giving and appeals
- Corporate Partnerships
- Trusts
- Cystic Fibrosis Services Limited
- Gifts in wills
- Donated goods and services
- Other income

Accounts out



2017/18 expenditure by cost type

Expenditure:	£'000
Research	6,096
Information, advice & support	6,191
Clinical care	1,443
Charitable activities total	13,730
Costs of raising funds	3,057
Cystic Fibrosis Services Limited	858
Total expenditure	17,645

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

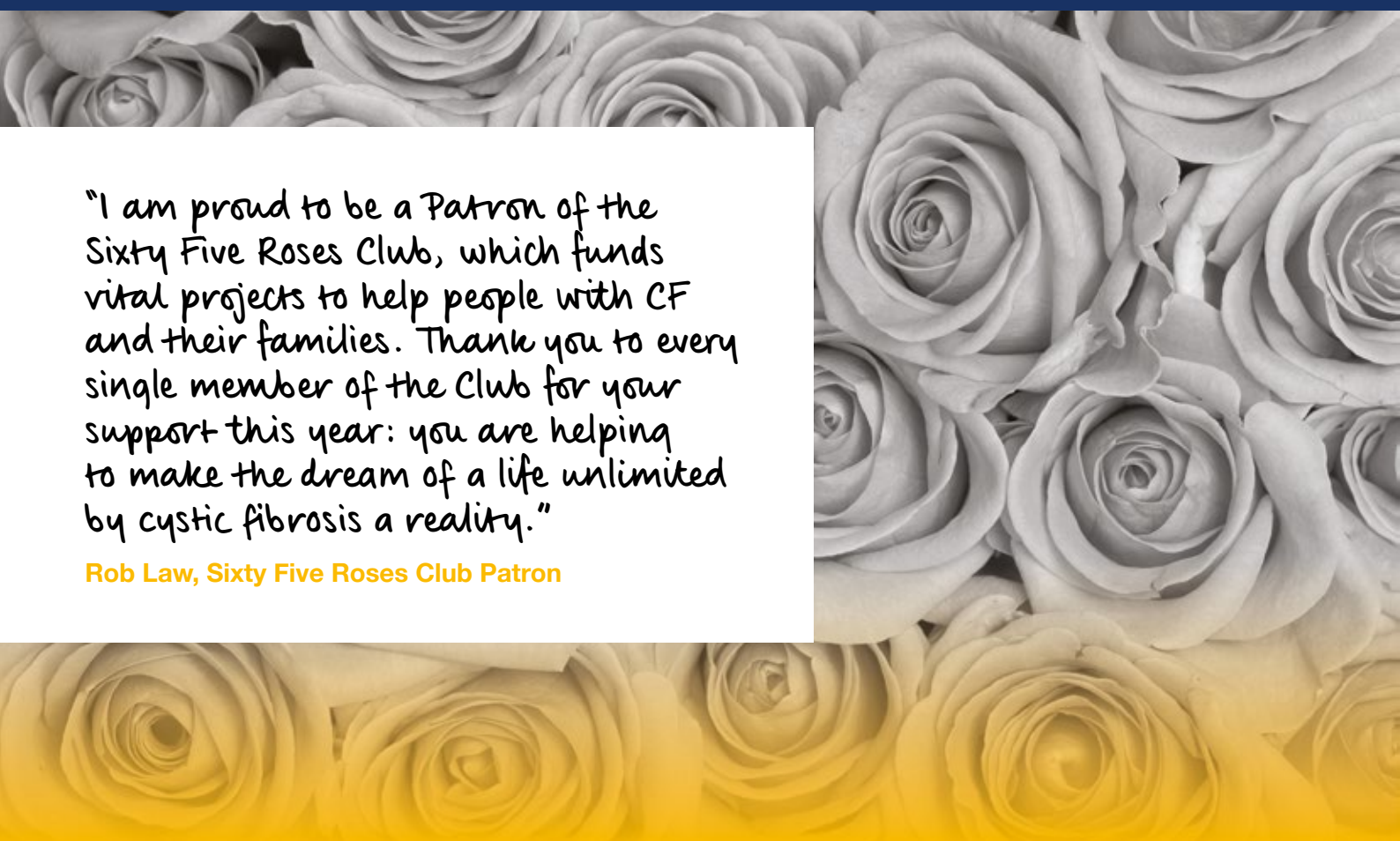
Full details of our accounts can be found in our Annual Report and Financial Statements at cysticfibrosis.org.uk/annualreview

Sixty Five Roses

Be a part of our plans for the future, and join our Sixty Five Roses Club, 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, 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 am proud to be a Patron of the Sixty Five Roses Club, which funds vital projects to help people with CF and their families. Thank you to every single member of the Club for your support this year: you are helping to make the dream of a life unlimited by cystic fibrosis a reality."

Rob Law, Sixty Five Roses Club Patron

Thank you

We would like to thank all of the Trusts and organisations that we work with, some of whom are mentioned here.

Special thanks

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

The Anna Trust
The Boyden Family
The Dujardin Family
The Gay and Keith Talbot Trust
Mr John Tweddle
Mr Terence Kyle

Corporates

AJN Steelstock Ltd
Champneys
Gaiger Brothers
Vertex

Trusts

BBC Children in Need
The Childwick Trust
The Eranda Rothschild Foundation
Garfield Weston Foundation
James Tudor Foundation
The Joseph Levy Foundation
The Joseph Levy Education Fund
Robert Luff Foundation
Sir Samuel Scott of Yews Trust
The Kirby Laing Foundation
The QBE Foundation
The Queen's Trust

Gifts in wills

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

Mrs Jill Smith
Ms Kathleen Mary Millican
Ms Nellie Thirza Jey
Mrs Susan Jane Waterman

Cystic Fibrosis Trust

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