Cystic
Fibrosis why
we're here

Cystic Fibrosis Trust
Annual Report and Financial Statements

For the year ended 31 March 2020

Company Registration No. 3880213
Charity No. 1079049 (England and Wales)
OSCR No. SC040196 (Scotland)

Fighting for a
Life Unlimited

Contents

Introduction 4

Chairman's statement 4

Objectives and activities 5

About cystic fibrosis 5

About us 5

Our mission 5

Our vision 5
  Measuring success 6

Achievements and performance 6
  Research and innovation 6
  Our research invetments 6

Strategic Research Centres (SRCs) 6
  New SRCs 7
  Existing SRCs 7

Venture and Innovation Awards 8

Developing and supporting talent 8
  Summer Studentships 8

Research and funding activities outside of the core funding streams 9
UK Cystic Fibrosis Innovation Hub 9
Gene Therapy Consortium (GTC) 10

CF Syndicate in Antimicrobial Resistance 10

SmartCareCF and Project Breathe 11

Promoting our research: UK Cystic Fibrosis Conference (UKCFC) 11

CF's Got Talent 12

Quality of care 12

Clinical Fellowships 12

UK CF Medical Association (UKCFMA) 13

Data and quality improvement 13
  Registry Annual Meeting 13
  Annual data report 14
  My CF Report 14
  National Collaborations 14
  Quality improvement 14

Clinical Trials Accelerator Platform 14
  Network of CTAP centres 15
  Engagement with sponsors 15
  Patient & Public Involvement (PPI) 15
  Clinical Trials Digital Hub 15

Campaigning hard 16

Day to day support 17
  Welfare Grants 17
  Benefits advice 17
  Information 18
  Helpline 18
  CF Connect 18
  Youth programme 18

Reaching all people 18
  Effectively engaging with our community and the public 18
  Information evenings 19
  Christmas campaign 19
  Social media 19
  Community involvement 20

Communicating with supporters 20
  Volunteering 20

Being an effective organisation 20
  Supporter experience 21

Fundraising 22
  Fundraising events and activities 22
  Gifts in wills 23
  Regular gifts 23
  Corporate partnerships 23

Philanthropy 23

Plans for the future 24
Research and UKCFC 24
Improving the quality of care 24
UK CF Registry 24
Improving access to clinical trials 24
Campaigning hard and raising awareness 25
Day-to-day support 25
Being great fundraisers 26
Being an effective organisation 26

Impact of COVID-19 26

Financial review 27
Income 27
Expenditure 28
Investment policy 29
Review of investments in the year 28
Reserves 29

Principal risks and uncertainties 30

Our work with the pharmaceutical industry 31
Clinical Trials Accelerator Platform 31
The UK Cystic Fibrosis Registry 31
Venture & Innovation Awards (VIAs) 32

Sponsorship and donations 32
Our guiding principles for working with the pharmaceutical industry 32

Statement of Trustees' responsibilities 33

Independent auditor's report 34

Consolidated statement of financial activities 36

Consolidated income and expenditure account 37

Consolidated and charity balance sheets 38

Consolidated Statement of cash flows 39

Notes to the Financial Statements 40

Structure, governance and management 61
Recruitment, induction and training of Trustees 62
Senior Leadership Team 62
Public benefit 62
Legal structure 62

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2020.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Charities Act 2011 and the Statement of Recommended Practice: Accounting and Reporting by Charities published in 2015.

The requirements of 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013' are included within this Trustees' report. Pages 40 to 62 also form part of the Trustees' report.

Chairman's Statement

I am pleased to present the Cystic Fibrosis Trust's annual report for 2019/20.

This second year of our current three-year strategy saw the biggest and hardest-won victory so far in our fight for access to life-saving drugs for people with cystic fibrosis (CF). After more than four years of campaigning shoulder-to-shoulder with the CF community, the precision medicines Orkambi and Symkevi were finally made available to all eligible people in each of the four UK nations. This major breakthrough is a testament to the commitment, resilience and dedication of our community, and means that around 50% of the UK CF population can benefit from these new drugs.

While we may have won this battle, our campaign for access to further new drugs and treatments will continue. The next and most immediate priority is for the Vertex triple combination therapy, known as Kaftrio, which is in the final stages of gaining approval from the European Medicines Agency and ensuring that is available to all who would benefit as soon as possible.. This game-changing drug could extend potentially life-changing benefits to around 90% of people with CF and, therefore, remains central to our agenda.

I would like to acknowledge the support of everyone who joined the community in this campaign and for the help and support we know you will offer us in the future.

However, access to medicines is only part of the story. We continue to support fundamental research to benefit everyone with CF, regardless of their genotype. Our dynamic research portfolio tackles CF on every front, from the deadly bacteria that attack the lungs to the diverse symptoms that characterise this complex condition, as well as exploring the exciting potential of digital healthcare.

Our Clinical Trials Accelerator Platform (CTAP) has continued to grow from strength to strength, promoting access to vital clinical trials for people with CF across the country. In December, the Accelerator Platform received further support from the Cystic Fibrosis Foundation (CFF) in the US to expand access to trials and thereby accelerate the development of new treatments. A new collaborative scheme will see a network of affiliate centres develop to increase trial capacity further.

We are pleased that by working with clinicians we have seen the further development of the UK CF Medical Association and we will continue to work closely with them to ensure we offer our community up-to-date expert advice and general support and, through our welfare advice, our Helpline team and our emergency grants, we will do everything we can to be there when we are needed. We recognise the need for balancing supporting progress in the future with making help available to those that can benefit from it now.

Our work is only possible with the help and support of the CF community, our donors, funders and supporters. We are incredibly grateful for everything that they do, whether raising funds or adding their voice to speak up on vital issues, and we will continue to fight with them.

I, along with everyone at the Trust, am looking forward to a positive but no doubt challenging year ahead. We are optimistic that we will make further progress with our current strategic plan and move closer to our vision of a 'life unlimited' by cystic fibrosis. However, the year ahead will also bring unexpected challenges. At the time of writing, the country is facing the unprecedented upheaval caused by the coronavirus (COVID-19) pandemic, which impacts every individual and organisation in the country. It has also meant significant changes to how we work as a charity, and this may continue to be the case for some time. In the face of these challenges we will adapt and improve, remaining focussed on making a difference for everyone living with CF, whatever the year brings.

Finally, my thanks to everyone at the Trust – all our staff and our amazing volunteers – for their work and commitment over this past year. We have been joined on the Board by some new Trustees and we are committed to bringing a diverse range of experience to our discussions and decision making. My thanks in particular to those Trustees who completed their periods of office during this year, for all their past work and support, and I am delighted that both David Turner QC and Caroline Cartellieri Karlsen will continue to remain close to the Trust. I have this feeling that those 'once Cystic Fibrosis Trust' remain in some way 'always Cystic Fibrosis Trust'.

Thank you.

Richard Hunt CBE
Chairman of Trustees

Objectives and activities

Our vision is to deliver a Life Unlimited for people with cystic fibrosis and our objectives, as stated in the Articles of Association, are to promote:

- research into the causes of, and a cure for, cystic fibrosis and the dissemination of the useful results thereof for the public benefit,
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from cystic fibrosis in any form, and
- the education of the general public about the causes and effects of cystic fibrosis.

About cystic fibrosis

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. More than 10,500 people in the UK live with the condition and have to undergo a brutal daily regime of physiotherapy and take up to 60 tablets a day, just to stay healthy. Despite these treatments, many people with CF will go on to require a double-lung transplant.

According to the 2018 UK Cystic Fibrosis Registry Report, the median age of death of those who died in 2018 is just 32. The median predicted survival age of people born with CF in the UK today is 47.

About us

Our mission

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited for everyone affected by cystic fibrosis. Our mission is to create a world where being born with CF no longer means carrying a life-long burden; where everyone living with the condition will be able to look forward to a long, healthy life. In 2018 we launched our new three-year Strategic Framework.

To reach our goal we will:

- invest in a dynamic portfolio of research and innovation,
- collaborate with and support the clinical community to promote the highest quality of care,
- support access to medicines at every step from laboratory to medicine cabinet,
- provide day-to-day support; and
- seek to reach all people with cystic fibrosis when they need us most.

Our vision

We believe that through innovation, empowerment and accelerating the pace of change, we can beat CF for good. A Life Unlimited by cystic fibrosis continues to be our ambition.

>Measuring success

We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact for the CF community.

We have established Delivery Review Groups to assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track the progress of projects using our Project Portfolio and internal monthly and quarterly monitoring mechanisms, including both data-driven and narrative analysis, backed up by 'SMART' Key Performance Indicators. Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.

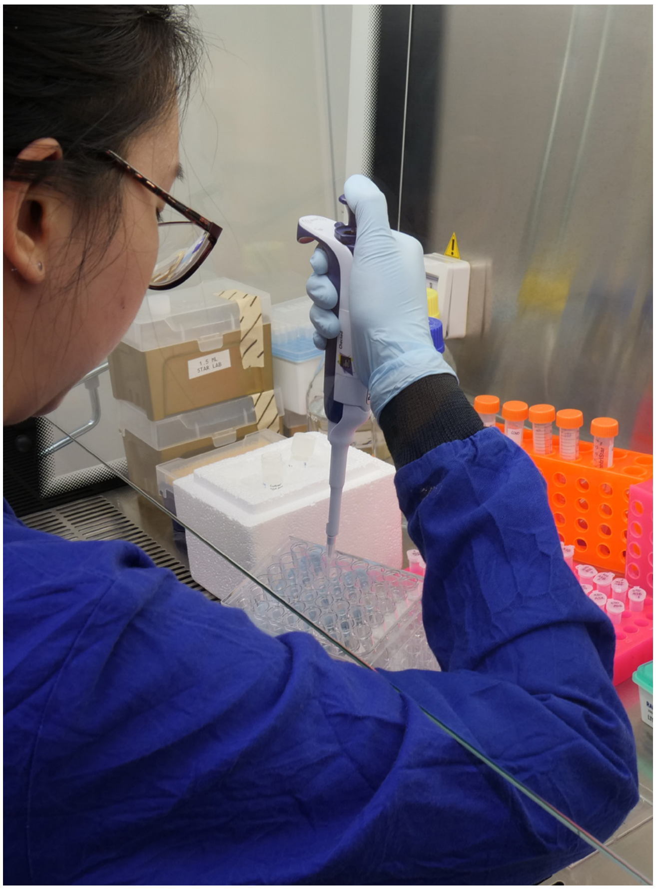
Achievements and performance

>Research and innovation

The Cystic Fibrosis Trust is the biggest charity funder of research specifically for the benefit of people with CF in the UK. New research is vital for discovering the next transformational breakthrough that will help deliver our vision of a life unlimited.

>Our research investments

We evaluate all proposals to ensure they are of benefit to people with CF, are strategically relevant and demonstrate scientific excellence.



Strategic Research Centres (SRCs)

These virtual centres of excellence bring together researchers from within and outside the field of CF, supporting scientists and other specialists around the world to work together to address specific issues arising from cystic fibrosis.

Our SRCs aim to:

- create clusters of world-class researchers;
- bring experts from different disciplines together to tackle the complex problems caused by cystic fibrosis;
- widen awareness of CF research by attracting high-quality investigators from different research fields; and
- recruit the brightest and best young researchers into CF research.

Each SRC typically includes funding for five or six early-career researchers who work alongside experts, building a life-long interest in the field. The centres investigate the big issues affecting people with CF, such as CF-related diabetes, that are too big for smaller projects to tackle. The long-term nature of these centres allows an in-depth exploration of the issue and possible solutions.

Governance for funding for the SRCs at the Trust is overseen by the Strategy Implementation Board (SIB). Applications undergo a rigorous external peer-review process before being considered by SIB, which recommends the highest-quality applications for funding. We maintain a balanced portfolio of high-quality research activity to address the varied issues associated with living with CF, from diagnosis to all stages of life.

> **This year we pledged a further £1.5 million to fund two new SRCs, as well as continuing to fund the ongoing work of 14 existing SRCs.**

New SRCs

This year, eight highly competitive preliminary (Expression of Interest) applications were submitted in April 2019. Of these, two arose from the CF and Cancer Research Sandpit, organised and hosted by the Trust in November 2018. Following an initial triage process, SIB decided to progress four of these to full application, alongside one invited re-application from the previous year's SRC competition.

The five full applications underwent rigorous external specialist peer review in the autumn period. The resulting scores and comments from the external peer reviewers and SIB members – as well as the rebuttal from the applicants – were deliberated in detail by SIB at their meeting early in 2020.

Following scrutiny of the applications and based on the excellence of the science and strategic relevance, SIB recommended applications for funding by the Trust:

1. Preventing gastrointestinal cancer in cystic fibrosis.

Lead Investigator: Professor Stephen Renshaw, University of Sheffield.

Co-Investigators: Co-investigators: Andres Floto (Cambridge), Carl Smythe (Sheffield), Matthias Zilbauer (Cambridge), Robert Cormier (USA), Ludovic Vallier (Cambridge), Patricia Scott (USA), Inke Näthke (Dundee).

2. Mechanisms and measures of the pathways through which CF exocrine pancreatic disease leads to beta-cell dysfunction and diabetes.

Lead Investigator: Professor James Shaw, Newcastle University.

Co-Investigators: Mike Gray (Newcastle), Shafagh Waters (Australia), Daniel Faurholt-Jepsen (Denmark), Kieren Hollingsworth (Newcastle), Roy Taylor (Newcastle), Peter Hegyi (Hungary), Andrea Párniczky (Hungary), Günter Klöppel (Germany), Lena Eliasson (Sweden), Imogen Felton (Brompton), Catriona Kelly (Ulster).

The award letters for these two SRCs were sent in March, with work due to begin in October 2020.

>Existing SRCs

The Trust continues to support and monitor 14 existing SRCs, spanning a range of topics of benefit to the whole CF community.

1. CF-EpiNet: Harnessing data to improve lives (Dr Siobhan Carr, Imperial College London)
2. Investigating the F508del-CFTR protein (Dr David Sheppard, University of Bristol)
3. Personalised engineered cell therapies for cystic fibrosis (Prof Stephen Hart, UCL Great Ormond Street Institute of Child Health)
4. Cystic fibrosis-related diabetes research (Prof James Shaw, Newcastle University)
5. Physical activity, exercise, sport and recreation promotion for adolescents with cystic fibrosis (Prof Craig Williams, University of Exeter)
6. Targeting joint disease in CF: identifying therapeutic targets in CF arthropathy (Prof Michael McDermott, University of Leeds)
7. The impact of gut dysbiosis on lung inflammation in cystic fibrosis (Prof Daniel Peckham, University of Leeds)
8. Restoring fluidity in the gut (Prof Soraya Shirazi-Beechey, University of Liverpool)
9. Novel therapies for Mycobacterium abscessus (Prof Andres Floto, University of Cambridge)
10. Restoring airway function in CF using alternative chloride channels (Dr Mike Gray, University of Newcastle)
11. Personalised approach to *Pseudomonas aeruginosa* (PAPA) (Prof Jane Davies, Imperial College, London)
12. Gas, food and lodging; understanding the physiological and metabolic requirements of Pseudomonas aeruginosa in the CF airways (Dr Martin Welch, University of Cambridge)
13. Mucociliary clearance – from fundamentals to personalised treatment (Prof Pitero Cicuta, University of Cambridge)
14. Targeting immunotherapy for fungal infections in cystic fibrosis (TrIFIC) (Dr Darius Armstrong-James, Imperial College London)

Visit cysticfibrosis.org.uk/SRC to find out more about these programmes of research.

Venture and Innovation Awards (VIAs)

These awards form part of our five-year research strategy. By awarding grants to innovative new research projects that leverage funding from external sources, we can allow CF researchers to respond rapidly to new developments, gain additional funds for potentially transformational opportunities and add value to our investment in research.

VIA grants are awarded on a rolling basis by an internal committee that assesses the validity and value of individual projects against an agreed set of criteria.

The award is contingent on the project undergoing the rigour of the peer review process of the partner organisation.

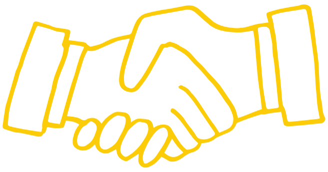
In 2019/20, we committed £469,201 to fund 11 new VIA projects, two of which are still subject to successful peer review. The estimated external funding leveraged will total around £3.8 million.

Visit cysticfibrosis.org.uk/VIA to find out more about this programme of research.

Developing and supporting talent

>Summer Studentships

Nine summer studentships of £1,500 each were awarded in 2019, five funded by the Trust and four by the British Lung Foundation. These studentships provide living expenses for promising undergraduate students to carry out a research project over their summer academic break. The support also provides an additional £500 allocation per award to allow the students to attend the Trust’s flagship event, the UK Cystic Fibrosis Conference (UKCFC), or another related conference. This year, one of the Trust-funded summer students was a person with cystic fibrosis. They could not attend UKCFC due to the risk of cross-infection as someone else with CF was giving a talk, so we set up a virtual conference from our headquarters.



The awarded studentships are detailed below:

- **Mr Chai Zheng Hua (Supervisor – Dr Timofey Skvortsov, Queen's University Belfast)** – Isolation of bacteriophages active against Stenotrophomonas maltophilia.
- **Mr Daniil Zorkin (Supervisor – Dr Bettina Schock, Queen's University Belfast)** – Anti-inflammatory itaconate in CF airways inflammation.
- **Miss Hafssa Anfishi (Supervisor – Prof Deborah Baines, St George's)** – Investigating effectiveness of optimised codon CFTR against enhanced CFTR in Class I CF Mutations.
- **Mr Jacob Bradbury (Supervisor – Prof David Sheppard, University of Bristol)** – Rescuing faulty chloride channels in CF with combinations of CFTR correctors.
- **Mr Karol Steckiewicz (Supervisor – Prof Stefan Marciniak, University of Cambridge)** – Investigating the role of MPZL1 in type 2 pneumocyte mobility.
- **Miss Rebecca Eckles (Supervisor – Prof Eshwar Mahenthiralingam, Cardiff University)** – Understanding the community of microbes that cause lung infections in people with CF to combat antimicrobial resistance and develop new therapies.
- **Mr Shyam Sawhney (Supervisor – Dr Claire Smith, University College London)** – Investigating the behaviour of neutrophils from people who do not have CF and people who do, during trans-epithelial migration into the airway.
- **Mr Thomas Nancarrow (Supervisor – Dr Chris Scotton, University of Exeter)** – A multicentre retrospective cohort comparison of aetiology and survival in patients with hypersensitivity pneumonitis (HP) versus idiopathic pulmonary fibrosis (IPF).
- **Mr William Harrison (Supervisor – Dr Daniel Murphy, University of Glasgow)** – Sensitivity of Mesothelioma PDCLs to inhibition of the Hippo Pathway regulators NUAK1 and NUAK2.

Following a judging session overseen by CF researchers and clinicians at the UKCFC, the winning posters were:

1. Joint first place: Mr Shyam Sawhney and Miss Hafssa Anfishi

2. Third place: Mr Jacob Bradbury

Research and funding activities outside of the core funding streams

>UK Cystic Fibrosis Innovation Hub

The UK Cystic Fibrosis Innovation Hub, based at Cambridge University, is a ground-breaking partnership between the Cystic Fibrosis Trust and the University of Cambridge. Launched in 2018, its aim is to harness multidisciplinary world-class research to accelerate progress towards preventing lung damage in CF and the subsequent loss of lung function. The Trust aims to raise £5 million over five years for the Innovation Hub, which the University of Cambridge has already committed to match pound for pound.

- to develop better ways to diagnose and treat exacerbations;
- to develop new antibiotics to treat exacerbations when they occur; and
- to work towards a long-term aim of developing alternatives to lung transplant, which are required as a consequence of infections and exacerbations.

The solutions to improving CF lung health require input for a range of varied expertise, including CF clinicians, microbiologists, medicinal chemists, bioinformaticians, computer scientists and stem cell biologists. Working collaboratively and meeting on regular basis brings a focus to their work and enhances the pace of progress. The Innovation Hub funding from the Cystic Fibrosis Trust is facilitating this multi-disciplinary collaboration.

The International Scientific Advisory Board met in November 2019 and praised both the Trust for the vision to set up the hub and the investigators for the excellent progress towards the hub's goals.

Progress so far:

Workstream 1: New approaches to treat infection and chronic lung inflammation. This work looks to develop new antibiotics to fight the bacteria carried by people with CF and to develop new, more effective ways to treat long-term inflammation in cystic fibrosis.

- A combination of sophisticated and high-tech genetic analyses has led to the identification of new anti-bacterial drug 'targets' against *Pseudomonas aeruginosa* and *Mycobacterium abscessus*. At the time of writing, medicinal chemists have begun work on designing new drugs for five of these targets (three against *M. abscessus* and two against *P aeruginosa*). Early research on one of the *M. abscessus* targets has been published.
- Computer models of all of the 3,400 proteins of *M. abscessus* have been generated and made available in a new publicly accessible database. Previously, data on only 53 of these proteins were available. A similar database for the proteins of P. aeruginosa is in preparation. Information on these protein structures will be of great assistance in designing new drugs, as it gives researchers information about the shape requirements and desired chemical properties that the drugs need to have to block the activity of the proteins.

Workstream 2: Accurate diagnosis and earlier intervention for lung exacerbations. This work is centred around computer analysis of clinical data to develop tools (e.g. algorithms) that can predict a lung exacerbation and reduce the risk of lung damage.

- Using over 160,000 data points from 'SmartCareCF', a previous home-monitoring study in adults with CF, artificial intelligence and machine learning experts have identified three patterns of lung exacerbation. The researchers have also developed a predictive computer algorithm, which may be able to detect when someone's health is declining and an exacerbation is expected more than a week before it happens.

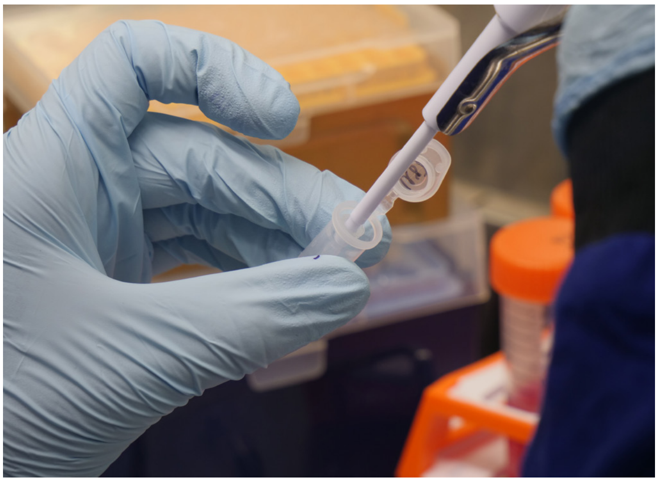
Workstream 3: Developing personalised and regenerative medicine approaches to treating individuals with CF, and exploring opportunities for repairing permanent lung damage caused by the condition.

- A 'proof of principle' protocol converting blood samples from people with CF into lung cells in a dish using stem cell technology has been refined to give a higher 'conversion rate' of stem cells into lung cells. The cells can be frozen and successfully revived, making future studies significantly quicker with savings of up to two months of lab time (this is the length of time a typical stem cell protocol takes). Studies on 3D lung 'organoids', representing mini-lungs in a dish, made from these cells form all of the cell types found in human lung tissue, a significant advance on existing organoid models that have only a selection of the cell types found in the lung. Advances have also been made in testing how these cells can be used to repair permanent lung damage.

The final component is the development of a national CF research infrastructure resource. This is still being development and progress has been delayed by the COVID-19 crisis.

>Gene Therapy Consortium (GTC)

An end-of-grant report was received by the GTC in December 2019 following completion of the latest VIA funding awards, which were awarded in April 2017 for a total of £500,000. The report described progress of a number of the GTC work packages (Waves 1 to 4) and importantly recognised the role the most recent Trust awards played in helping the GTC secure a tripartite agreement with two commercial partners, Boehringer Ingelheim and Oxford BioMedica. This commercial partnership has enabled the GTC to make further progress in moving their technology towards the clinic, and we hope that the GTC may be in a position to move into a small, early-phase clinical trial within the next few years.



CF Syndicate in Antimicrobial Resistance

Antimicrobial resistance (AMR) is a growing concern, particularly for people with CF who frequently suffer from antibiotic failure. The NHS and the UK Government have highlighted AMR as an urgent priority. The Trust has partnered with the Medicines Discovery Catapult (MDC) to create the CF Syndicate in AMR, which was launched in September at the UK Cystic Fibrosis Conference.

The aim of the Syndicate is to accelerate the translation of novel antimicrobials to the clinic. To do this, the current aims of the Syndicate are to:

- 1. Streamline and enable access to clinically relevant samples for the preclinical screening and testing of CF antimicrobials.
- 2. Map and validate the preclinical screening and testing pathways to provide faster routes of bringing CF antimicrobials to the clinic.
- 3. Develop guidance for industry on the key characteristics and requirements that CF antimicrobials should meet in order to address the needs and priorities of people with CF, through the development of Target Product Profiles.

The Syndicate steering committee consists of a panel of CF clinicians and academics, members from industry and other bodies (such as Public Health England), representatives from the Trust and the MDC, as well as people who have cystic fibrosis. Detailed work plans, with short-term, medium-term and long-term milestones and objectives for each of the emerging workstreams, are being developed by the Steering Committee and the joint CF Trust/MDC management team to drive the successful implementation of these goals.

SmartCareCF and Project Breathe

We have received a £2.5 million grant from the Cystic Fibrosis Foundation to enable us to investigate how artificial intelligence could revolutionise CF care. SmartCareCF's earlier work in the field of home health monitoring laid the foundations of 'Project Breathe', a collaborative study to develop new technologies that allow people with CF to spend less time in clinical facilities and more time doing what they love.

Data from the Project Breathe research study so far has shown that answering self-monitoring questions such as 'how much have you coughed today' or 'how well you are feeling' are useful ways to assess your health. If you have your own scales, thermometer, or even a spirometer, but they don't have Bluetooth or Wi-Fi connectivity, then measurements can be entered manually into the app. The research team are also working on plans to be able to include activity monitors such as FitBits into the app too.

In response to the coronavirus (COVID-19) pandemic, the Project Breathe research team have made the project app available for people living with CF to remotely monitor their health, and successfully applied to the CFF to allow them to accelerate plans to widen the research study from one centre (Cambridge) to three (Cambridge, Glasgow, Cardiff).

Promoting our research: UK Cystic Fibrosis Conference (UKCFC)

In September 2019, UKCFC was held in London at the Oval and was attended by approximately 350 delegates in person across two days, as well as approximately 260 individuals online. We used split-screen technology to allow outside speakers to Skype in and participate, enabling Oli Lewington (the Trust's Director of Marketing and Communications) and two virtual attendees with CF to take part in the panel discussion. It also allowed a live presentation from Dr Al Faro from the CFF, USA.

The first day (Thursday 26 September) focused on research activity. This year, we were able to showcase some of the research investments made by the Trust. In particular, the Trust used the meeting as a way of indicating the various activities we are undertaking in the research area of Digital Health.

The feedback from the conference was overwhelmingly positive, with 82% of our attendees rating the conference as excellent, and, in particular, the value of having people with CF involved in the scientific sessions was noted in the post-conference feedback from 'professionals working in CF'.

Day two of the conference was dedicated to anyone from the wider CF community with a personal or professional interest in cystic fibrosis. Sessions covered the challenges of growing older with CF and the psychological impact of transformational treatments for the condition, as well as practical workshops on managing the burden of treatment and on parenting children with cystic fibrosis.

Social media engagement at the conference was high (Facebook engagement up 113% and Twitter up 114%), and 82% of attendee feedback rated it as an excellent event. Using digital-only brochures and other smart savings, we reduced our production costs by £15,000.

CF’s Got Talent!

Thirty-two early career researchers from our ongoing SRC programme submitted abstracts for the 2019 CF’s Got Talent competition, held at the 2019 UKCFC. Five researchers were selected by a CF community panel to present their work in the final, based on the summaries of their research submitted.

This year, we asked each presenter to work with a member of the CF community to ensure that their presentations were accessible to a non-scientific audience prior to the conference.

The presentations were engaging and well received, including explanations using the Spice Girls and Harry Potter to get their messages across. The CF community panel appreciated the opportunity to interact with researchers; one has become involved on a longer-term basis with the research group and another has accepted an invitation to visit the lab.

The following researchers presented their work:

- **Dr Heledd Jarosz-Griffiths**, a post-doctoral researcher based at Leeds University, working within our arthritis and inflammation SRC. Her presentation was titled ‘Inflammation ‘who do you think you are?’

- **Helen Douglas**, a physiotherapy PhD student from UCL, London, working within our physical exercise SRC programme. Her presentation was titled ‘Exercise maintenance – who needs help?’

- **Bartholomew Harvey**, a biomedical PhD student from Bristol University, working within our ‘F508Del’ SRC. His presentation was titled ‘Cystic fibrosis and the myth of the hero.’

- **Attila Ébert**, a biomedical PhD student from Szeged University in Hungary, working within our CF-related diabetes SRC. His presentation was titled ‘In search of causative factors of CF-related diabetes (CFRD).’

- **Anh Thu Dang**, a post-doctoral researcher based at Monash University, Melbourne Australia, working within our ‘Restoring balance in the gut for less inflammation in the lungs’ SRC. Her presentation was titled ‘Short-chain fatty acids as CF therapeutics against pulmonary infections.’

The competition was won by Bartholomew Harvey, who won an expenses-paid trip to the 2020 North American Cystic Fibrosis Conference (NACFC) to present his research.

The overall success of the CF’s Got Talent competition was celebrated in the presentation of a poster explaining the programme at NACFC in 2019.

Quality of care

Receiving the best possible clinical care is vital to the lives of people with cystic fibrosis. Supporting continuous improvement in the provision of care across the UK is a fundamental role of the Cystic Fibrosis Trust. In December, King’s College Hospital opened its refurbished adult CF unit, which we co-funded alongside the King’s College CF Fund. The unit now features improved inpatient facilities and has four en suite rooms designed to minimise the risk of cross-infection.

Clinical Fellowships

Over the course of the year, we continued to support the education and recruitment of clinical staff in the field of CF care with our Clinical Fellowship programme. We committed to sponsor one clinical fellow and one physiotherapy fellow. We continue to encourage our fellows to gain additional training that is of benefit to the CF community, such as gastroenterology and transplantation.

UK CF Medical Association (UKCFMA)

We have supported the formation and work of the UKCFMA throughout the year, supporting the establishment of a lung transplant working group, hosting their AGM at UKCFC, and organising meetings at European Cystic Fibrosis Society (ECFS), NACFC, and their own annual event. We have also co-produced and collaborated with the UKCFMA on policy work and information about COVID-19. We have encouraged the collaboration of the UKCFMA with leads of the other allied health professional groups. Our Clinical Advisory Group (CAG) now consists of the chairs of all the clinician groups and four new representatives of people with CF and parents, including the chair of the UK CF Medical Association.

Data and quality improvement

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 CF team. This year saw the completion of one drug safety study using Registry data, with a further two continuing to run, which generated over £980,000 in income. A significant proportion of these funds were used as grants to support centres in their data entry to the Registry.

More information about how we use Registry data to keep medicines safe can be found at **cysticfibrosis.org.uk/registry**.

The Registry received a further £90,000 from NHS contracts for generating public reports and supporting the commissioning of CF services in England.

Anonymised Registry data supports research, service improvement and information materials. In 2019/20, the Registry approved 26 requests for data, bringing the total up to 376.

The UK CF Registry is playing a pivotal role in evaluating the effect of Orkambi and Symkevi following interim access agreements in Scotland and England.

The Registry is supporting an observational study of Orkambi and Symkevi to satisfy the Vertex Data Collection Agreements with NHS England and NHS Improvement. Data analysis will cover the whole of the UK and will be made available to regulators in Scotland, Wales and Northern Ireland. This includes sufficient funding to boost the Trust's Registry Support Grant programme and enable CF centres that choose to opt in to enter three 'encounters' (records of height, weight and lung function) throughout the year, so that a more robust analysis can be conducted of the impact on rate of change in lung function of these new medicines. You can read more about the study here: cysticfibrosis.org.uk/news/the-latest-on-interim-access

The programme of data validation visits was completed in 2019. Over the course of the programme, 49 out of 60 CF centres were visited. The summary report concluded that UK CF Registry data has a high level of accuracy (98%) and completeness (99%).

The visits also proved to be a rich source of ideas for enhancements to the Registry, which feed into our development programme, and enriched the relationship between the sites and the Cystic Fibrosis Trust. The UK CF Registry Data Validation Visit Programme has been adopted as a model of best practice by other CF Registries in Europe.

The UK CF Registry team were the first Registry in the world to adapt data collection processes to collect important data on COVID-19. The team have set up a COVID-19 reporting hotline, enabling clinicians to report cases directly to us, supporting clinical care teams with Registry data entry. This model has been adopted by other CF Registries worldwide, and the UK CF Registry is at the forefront of international collaborative efforts to monitor COVID-19 within the CF community and ensure rapid publications to support future care.

>Registry Annual Meeting

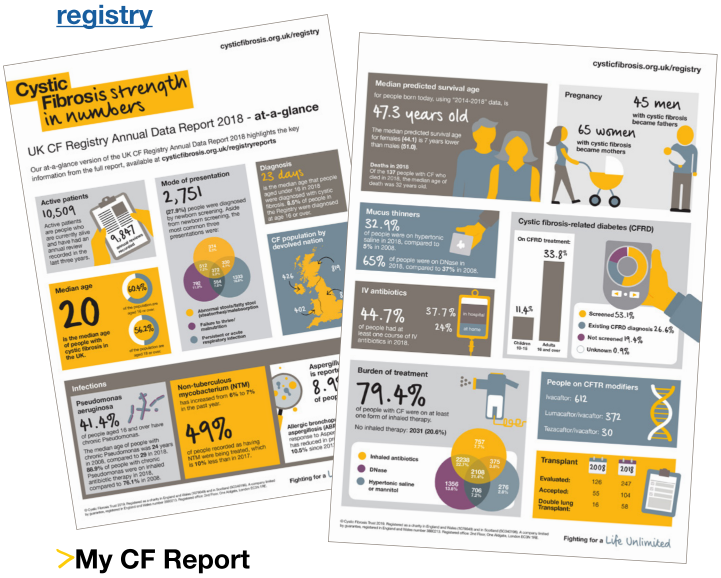
Our Registry Annual Meeting in July saw over 100 doctors, nurses and data managers who use the Registry on a daily basis come together to share knowledge about data entry best practice and find out how the data is used for research. Attendees also heard international inspiration from the French CF Registry.

>Annual data report

The UK CF Registry was the first in the world to publish its Annual Data Report for 2018. An accessible 'at-a-glance' summary of infographics highlighting the main trends for that period was also published, helping people with CF and their families to understand the data contained in the report.

A special edition of the annual report was published for the 2019 European Cystic Fibrosis Conference (ECFC) in June, where the Registry also presented three posters. One demonstrated the ability of the Registry to measure the burden of treatment for people with cystic fibrosis. The second showed that updates to Registry software have led to an improvement in the timeliness of Annual Reviews. The third reported on the latest programme of data validation visits, which have shown that key information on the Registry is accurate in 98% of cases.

We submitted anonymised 2018 data to the European CF Society Patient Registry, which published its reports here: www.ecfs.eu/projects/ecfs-patient-registry



>My CF Report

We released a new feature on the Registry called 'My CF Report', which provides a summary of individual patient health data captured on the Registry for CF centres. This easy-to-read health summary is intended to empower patients to have meaningful discussions with their clinical team about their condition.

>National Collaborations

This year we joined the Wellcome Trust's 'Understanding Patient Data' initiative to make patient data more accessible and trusted for patients, the general public and health professionals. Partners include a wide range of charities and health, research and data-related organisations.

>Quality improvement

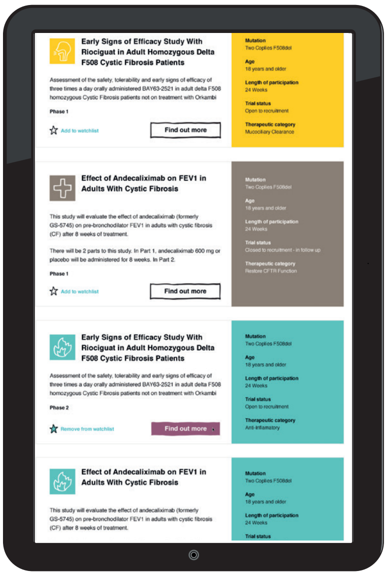
In 2019, the Quality Improvement (QI) Team launched two UK-wide projects. The first project was the Patient Reported Experience Measures (PREMs) survey and captures how paediatric patients and their families feel about the care they receive in their CF centre, benchmarked against UK averages. This information will support clinical teams to continuously improve the way care is delivered. We have already met our data collection target, with close to 700 responses from paediatric sites and data collection in adult CF centres scheduled to begin in late 2020.

The second project is to collect yearly staffing data from CF centres around the UK to benchmarks levels of resourcing and encourage conversations about appropriate clinical support for people with cystic fibrosis. Cystic fibrosis centres have received their first reports on staffing levels, with a second round of the snapshot survey scheduled for this autumn.

Clinical Trials Accelerator Platform

In summer 2019, CTAP successfully secured an additional £2.1 million in funding from the CFF to extend and expand the programme beyond 2020. A significant part of the new funding will support the extension of the 20 Trial Coordinator grants, increasing the length of the grants from three to six years. The funding will also support the recruitment of six more Trial Coordinators to support the delivery of early-phase CF clinical trials, in addition to a Lung Clearance Index (LCI) Training Package for CTAP centres.

We have seen significant impact and progress in each of the four CTAP workstreams: the network of centres, sponsor engagement, Public and Patient Involvement (PPI) and the Clinical Trials Digital Hub.



Early Signs of Efficacy Study With Riociguat in Adult Homozygous Delta F508 Cystic Fibrosis Patients

Assessment of the safety, tolerability and early signs of efficacy of three times a day orally administered BAY63-2521 in adult delta F508 homozygous Cystic Fibrosis patients not on treatment with Orkambi

Phase 1

Mutation Two Copies F508del
Age 18 years and older
Length of participation 24 Weeks
Trial status Open to recruitment
Therapeutic category Mucociliary Clearance

Effect of Andecaliximab on FEV1 in Adults With Cystic Fibrosis

This study will evaluate the effect of andecaliximab (formerly GS-5745) on pre-bronchodilator FEV1 in adults with cystic fibrosis (CF) after 8 weeks of treatment.

There will be 2 parts to this study. In Part 1, andecaliximab 600 mg or placebo will be administered for 8 weeks. In Part 2.

Phase 1

Mutation Two Copies F508del
Age 18 years and older
Length of participation 24 Weeks
Trial status Closed to recruitment - in follow up
Therapeutic category Restore CFTR Function

Early Signs of Efficacy Study With Riociguat in Adult Homozygous Delta F508 Cystic Fibrosis Patients

Assessment of the safety, tolerability and early signs of efficacy of three times a day orally administered BAY63-2521 in adult delta F508 homozygous Cystic Fibrosis patients not on treatment with Orkambi

Phase 2

Mutation Two Copies F508del
Age 18 years and older
Length of participation 24 Weeks
Trial status Open to recruitment
Therapeutic category Anti-Inflamatory

Effect of Andecaliximab on FEV1 in Adults With Cystic Fibrosis

This study will evaluate the effect of andecaliximab (formerly GS-5745) on pre-bronchodilator FEV1 in adults with cystic fibrosis (CF) after 8 weeks of treatment.

Mutation Two Copies F508del
Age 18 years and older
Length of participation 24 Weeks
Trial status

>Network of CTAP centres

As CTAP's national reputation has grown over the past two years, an increasing number of non-CTAP centres enquired about joining the programme. To help more members of the CF community access trials and achieve CTAP's aim of equity of access, CTAP invited additional CF centres to join the network. Nine CF centres were selected to join CTAP in autumn 2019, bringing the total number of centres in the network to 29 and collectively covering over 80% of the UK CF community.

Since CTAP's official launch in September 2017, a total of:

- 625 people with CF have been screened for a clinical trial within the CTAP network; 331 of these screenings took place in the last 12 months.

- 502 people with CF (242 adults, 260 children) have enrolled onto a clinical trial within the CTAP network; 299 of these enrolments took place in the last 12 months.

>Engagement with sponsors

The Clinical Trials Accelerator Platform aims to support sponsors (pharmaceutical companies and academic institutes) with the design, feasibility, set-up and delivery of CF clinical trials.

Engagement with sponsors has significantly increased over the last year, reflecting not only the growing CF drug pipeline but the increasing recognition of the clinical trial infrastructure and resource CTAP has embedded in the UK.

The CTAP Feasibility Service helps sponsors ensure the best-placed centres are selected for trial delivery and has been utilised for a total of 18 clinical trials, six of which were during this financial year. A total of 27 CF trials have been open for recruitment in the CTAP network over the course of the year.

>Patient & Public Involvement (PPI)

Over 50 CF Trial Ambassadors (people with CF and parents of those with the condition) form our CTAP PPI group. It is through these groups that CTAP has created a platform for the CF community to directly engage with sponsors and give meaningful and robust feedback about trial design, from the conceptual stage onwards. The PPI workstream gives the CF community a voice to communicate with sponsors, making future clinical trials less burdensome on participants, resulting in better recruitment and retention rates.

Awareness and recognition of CTAP's PPI groups has grown over the last year, leading to increased activity. Over the past 12 months, PPI group members were involved in 26 different collaborations with sponsors, returning a total of 94 separate responses. We will continue to demonstrate the benefits this collaborative approach brings to researchers, sponsors and our community.

>Clinical Trials Digital Hub

We have created a Clinical Trials Digital Hub to engage and educate the CF community about clinical trials. **cysticfibrosis.org.uk/get-involved/clinical-trials**

Since launching in September 2017, the Hub has been visited over 10,000 times with 3,000 visits in the past year. The Trials Tracker database has been visited 16,000 times, with over 6,000 visits in the last year.

These statistics demonstrate the Trust has been successful in its ambition to establish the Hub as an important place of information for those wishing to find out more about taking part in CF trials.

The programme makes an important contribution to the Trust's campaign for access to life-saving drugs, providing the infrastructure and information to enable the UK CF community to gain the earliest possible access to the newest 'breakthrough' CF medicines being developed by pharmaceutical companies around the world.

Campaigning hard

As an organisation, we campaign hard to ensure the voice of the CF community is heard loud and clear. This year, this work has been a key component of the fight for fair access to life-saving medicines for everyone with cystic fibrosis. We worked hard to build a coalition of support amongst our community, the media, policy makers and politicians. Over the course of the year, CF was mentioned:

- 51 times in written and oral questions and at Prime Minister's Questions (PMQs) in Westminster;
- 2 times at the Northern Irish Assembly since it resumed sitting in Stormont;
- 5 times in Scottish Parliament; and
- 13 times in the Welsh Assembly.

In April, the Trust prepared a patient group response to the Scottish Medicines Consortium (SMC) for the appraisal of two such life-saving drugs, Orkambi and Symkevi. We also wrote to Permanent Secretary Richard Pengelly around access to CF drugs in Northern Ireland. In UK Parliament at Prime Ministers Questions (PMQs, a question drafted by the Trust was tabled on the issue.

In May, a bouquet of 65 yellow roses (symbolic of CF) was handed in at 10 Downing Street with a cross-party letter from 77 MPs calling for action: a poignant reminder of the anniversary of Prime Minister Theresa May's response during PMQs for a speedy resolution for access to Orkambi.

This activity was bolstered by achieving extensive media coverage and the strategic use of our social media channels to remind audiences of the PM's original statement, with our campaign video reaching more than 130,000 people.

In June, we hosted two community meetings to discuss the next steps of the campaign. We also hosted an online focus group, allowing people with CF to brief Paul Scully MP on their experiences ahead of a Westminster Hall debate on access to medicines. The debate saw 41 MPs speaking on behalf of families and constituents affected by cystic fibrosis.

We wrote an open letter to both Jeremy Hunt and Boris Jonson during the start of the election race, calling for them to pledge their support to the Trust's campaign. David Ramsden, the Trust's Chief Executive, also met with the Welsh Health secretary and the Welsh Government's Chief Pharmaceutical Officer to explore access to medicine for people with CF in Wales, including interim access.

The Trust organised a roundtable with supportive MPs to discuss increasing the pressure for a resolution and drafted a cross-party letter via Ian Austin MP (supported by the Trust) to the newly appointed Prime Minister, calling for his support. This gathered 117 MP signatories from across all parties and nations.

In August, the SMC announced it was not able to recommend Orkambi and Symkevi for routine use by NHS Scotland. Vertex and the Scottish Government confirmed that discussions would continue, and the Trust met with Scottish Pharmacy Division to discuss managed access via the UK CF registry.

The Trust held a campaign day on 27 August to demand both parties reach an agreement for all UK nations, sending letters to health bosses in each of the four nations and urging them to finalise talks and reach a deal with Vertex. We organised a 100-strong rally outside Vertex HQ, calling on them to engage with the NHS.

In September there was the first huge breakthrough in the campaign: the Scottish Government reached an agreement with Vertex with support from the UK CF Registry, and announced a five-year deal for access to Orkambi and Symkevi in Scotland for eligible patients.

Following this, we also secured and managed a meeting between PM Boris Johnson, Secretary of State for Health, Matt Hancock, the Trust's Chairman, Richard Hunt, and 12-year-old Isobel Finn (who has CF) at Number 10. This allowed mark a significant milestone and ask the PM and Secretary of State directly for their continued support to secure the speedy availability of the triple therapy.

During this month, the Trust hosted another online focus group with adults with CF from across the UK, discussing their views of the campaign so far and how they could lend their support.

In October, the Trust's Chief Executive met with the Permanent Secretary in Northern Ireland to discuss their progress in making medicines available to people with cystic fibrosis.

This was followed by a second breakthrough: a two-year managed access agreement reached in England, which gave access to Orkambi, Symkevi and Kalydeco for eligible people with cystic fibrosis.

Finally, in November, agreements were formalised for access to Orkambi and Symkevi in Northern Ireland and Wales. During the deal announcements, we collectively contributed to the generation of 900 pieces of coverage, with Trust spokespeople appearing across all major broadcasting outlets.

As the European Medicines Agency progresses its assessment of Vertex's next medicine, the triple combination therapy, we are conscious of the need to ensure rapid access for people with CF and will continue to fight and advocate for the CF community to ensure this.

Day to day 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. Through providing accurate information about the condition and support in all aspects of living with it, we help the CF community live better each and every day.

>Welfare Grants

Last year, we provided over 1,050 welfare grants, totalling £272,000, providing immediate financial support to those in urgent need, as well as access to goods and services to promote long-term health and quality of life. These grants are key in supporting people with CF to stay as well as possible. We have also re-focused our holiday grants this year, ensuring they provide maximum impact by focusing on those who otherwise couldn't afford a break at all.

In addition, we were able to provide £26,000 in homecare grants to support people who are experiencing particularly poor health or a personal crisis, so that they can be safe and comfortable at home.

We spent over £65,000 on education grants awarded by the Joseph Levy Education Fund to support young people with CF into higher education or vocational training, ultimately supporting them to pursue their career goals.

>Benefits advice

Our Welfare and Rights Advice service provides invaluable dedicated benefits advice, and this year our specialist adviser has supported 375 people. We have also launched a new Income Maximisation service, offering individual telephone appointments to guide our community through a range of financial support options, ensuring our service is holistic and sustainable.

In 2019/20, the Cystic Fibrosis Trust helped people to access at least £1.43 million in benefits.

We also continue to offer a benefits advice service in Northern Ireland through a specialist partnership, providing expert advice to navigate their benefits system.

>Information
We have built on our extensive information library, expanding our informative factsheets on physiotherapy and nutrition, developed in collaboration with specialist CF clinicians. We launched a new body image resource, supporting people with CF to develop a positive relationship with their bodies and starting conversations about a range of body image issues experienced by people with the condition. This year saw the publication of our new information resources catalogue, detailing our extensive range of publications in an accessible format. We also continued updating our suite of clinical guidelines and began developing a new guideline on psychosocial care and treatment of people with cystic fibrosis.

>Helpline
This financial year, our Helpline responded to over 3,600 enquiries from people affected by CF, providing information, support and a listening ear on a wide range of topics. Around 55% of enquiries were received by email, and 45% by phone. Over 40% of enquiries were related to financial concerns or support, underlining the critical importance of our welfare grants programme and benefits advice service in providing tangible support to ease the financial burden of life with cystic fibrosis.

>CF Connect
As part of our commitment to offering support for everyone affected by CF, the CF Connect programme continues to put parents of children with CF in touch via phone or email with others who are experiencing similar issues.

>Youth programme
Adolescence can be a period of vulnerability for those with CF, both in terms of physical health and emotional wellbeing. This year, we have continued our successful youth engagement work, which provides dedicated support and information to young people with CF, co-designed by adolescents with the condition.

Our Youth Advisory Group (YAG), comprising over 20 young people affected by CF, has continued to shape the direction of the Trust's youth work. It also provides peer support for the young people involved, who have the opportunity to share their experiences of life with CF in a supportive, online space.

Our Building Brighter Futures programme, funded by BBC Children in Need for three years, has continued to expand. We ran successful workshops on coding and storytelling and held several well-attended gaming nights. We also released a series of videos in which young people shared how their hobbies and interests help their wellbeing, which have been widely viewed.

Reaching all people

>Effectively engaging with our community and the public
Our work relies on the support we receive, not just from those directly affected by CF but from the general public too.

This year, we obtained almost 2,467 pieces of news coverage, worth an estimated £67million in advertising value.

Highlights include:

- 2,007 pieces of print and online editorial coverage across all outlets (Guardian, Times, Daily Telegraph, Express, Daily Mail, Mirror, Sun, Metro); a 5% increase on last year's total.
- 457 pieces of broadcast coverage (national and regional), with a top reach of 33 million people; an increase of 94% on last year's total.
- We contributed to 900 pieces of coverage on the successful conclusion of the battle for people with CF to gain access to Orkambi and Symkevi, including on ITV News, BBC Radio 4 and BBC Breakfast. We are proud that 300 of those mentioned the Trust specifically.

These figures include extensive coverage of all aspects of our work and campaigns and include coverage on all major broadcasters. They also include where we've been quoted or referenced in response to the coronavirus outbreak.

We provided advice to BBC One's Casualty on the development of a new CF clinical trials storyline, which ran for several weeks and concluded in mid-November. While the CF community were disappointed with the show's portrayal of life with CF, we used the show as an opportunity to show what being on a clinical trial is really like and actively promoted our clinical trial resources.

- We used all our social media channels to live blog when our storyline featured and reached almost **500k** people per episode.
- The Clinical Trials Hub saw an increase in traffic of **122%**.
- Our clinical trials newsletter increased to **120** subscribers.
- Visits to our 'What is CF?' webpage increased by **27%**.
- The Google search of 'Cystic Fibrosis' on the first episode went up by **62%**.
- **19%** of people reported that they were aware of the storyline (NFP Synergy).

Our promotion of this included outdoor advertising and paid social, with a view to increasing awareness of CF, and the secondary goal of raising funds. We also provided two stories from people with CF to show the realities of taking part in a clinical trial.

>Information evenings

We held five dedicated Community Information Evenings across the UK, visiting Nottingham, Newcastle, Birmingham, Cardiff and Belfast. Trust staff and local clinicians presented updates on access to medicines, research and the local CF centres. Each event was attended by circa 40-50 people, with the Belfast meeting achieving over 100 attendees as this coincided with the agreement to fund Orkambi and Symkevi. The events were streamed online via Facebook, with approximate 15-20 people tuning in at any one time and joining the conversation online, as well as posing questions which were asked in the room.

> Christmas campaign

Our Christmas campaign focused on nine-year-old Norwich City superfan Jacob. One element of this included the opportunity to be featured as The Daily Express official charity Christmas partner. Donations from the appeal were approximately £8,000.

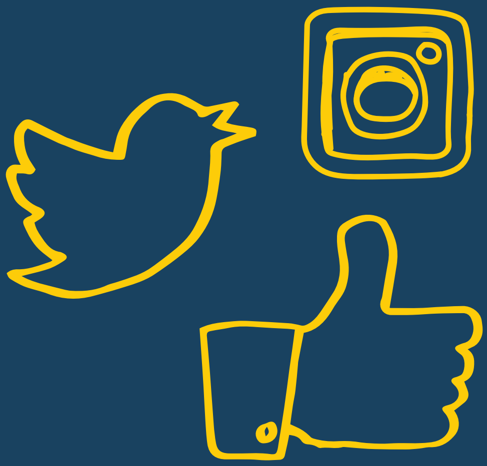
>Social media

Our social media channels are a vital means for the Cystic Fibrosis Trust to engage with new and existing audiences: a shop window showcasing the things we do, a driver for fundraising, and – crucially – a place to convene conversations with the very people we represent.

Increasingly, it has also become an avenue for people turning to us for help with many choosing to direct message us on social media, seeking urgent advice on a range of health and welfare issues, as well as scores of people eager to fundraise for us. Our Facebook page in particular is a key interaction point with our most engaged members of our community, and was a critical means to update and mobilise our community during the access to medicines campaign; in the month of the deals announcements alone, we reached over 40 million people this way. It also offers an important space for celebrating CF Week and bringing Wear Yellow Day to life.

We also began working with a social media company to provide insight into the types of things people with CF are talking about online away from our channels, which allowed us to keep in sync with their needs and remain relevant.

During this year, we saw growth across all of our social media channels (Facebook 3%; Twitter 4%; LinkedIn 13%), particularly Instagram (50%), which is enabling us to engage with younger audiences.



Community involvement

People with CF and their families have been involved in a number of projects, both within the Trust and with external organisations who have approached the Trust to gain feedback from the CF community.

Maintaining relationships with members of our community to seek their insight, input and feedback is key to this process, and this has been recognised in our new pilot involvement plan, ensuring that people with CF and their families are at the forefront of work that we are doing to support them.

Communicating with supporters

We continue to improve our website, with a focus on the user experience for those looking for information and support. We have improved the navigation and content through ongoing testing. We have also been working on an invitation to tender for an updated website platform focusing on future sustainability, improving our search and supporter journeys and easier ways to fundraise. These plans will be rolled out in 2020.

We have been using an ongoing test-and-learn approach with our email communications, with the aim of improving engagement, particularly click-through-rates. Improving and personalising these communications allows us to offer a unique supporter experience and to better support and engage with our community.

We continue to maximise our reach with existing and new supporters through our Google advertising grant and search-engine optimisation, paid options such as social media advertising and by working closely with our outdoor advertising partners.

Volunteering

Once again, we have benefited from the fantastic contribution made by our volunteers within the community, working tirelessly in our many branches, organising or helping out at events, and in our core operations.

We benefit from the fantastic support of nearly 200 registered volunteers and hundreds of fundraising volunteers.

This year, we launched our new volunteering policy and have been working with different teams across the Trust to improve our ability to identify volunteering opportunities that make a real difference. Trust staff have also attended a number of volunteering fairs, particularly at universities, to share these opportunities and ensure the Trust is known as an exciting place to volunteer.

Volunteers have been drawn from a wide range of backgrounds and at different life stages, ranging from university students through to people winding down in their careers and wanting to use the skills they have developed to help us do more for people with cystic fibrosis. We were particularly pleased to host a secondee for three months through the John Lewis Golden Jubilee Trust, who helped us review our online shopping offering.

Being an effective organisation

Our three-year strategic framework, introduced in 2018, sets out four key strategic priority areas in which we focus our work to make the most difference we can for people with CF: ensuring they get access to the medicines they need, improving the quality of their clinical care, empowering them with quality information and support, and ensuring our work reaches all people with cystic fibrosis. Underpinning all this is our Research Strategy, ensuring our work is informed by cutting-edge research and knowledge. Our work is also built upon the twin pillars of 'We are all great fundraisers' and 'We are a great organisation'.

We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact for the CF community.

Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.

Along with our supporters and volunteers, the Trust's employees are its greatest asset and their recruitment, development and retention are vital to our ongoing success. New employees and volunteers are quickly brought up to speed with the Trust's culture, the unique challenges of working with people with CF and mandatory knowledge of Health, Safety and Wellbeing, Safeguarding, Diversity and Inclusion and Data Protection. It is especially pleasing that all new starters are now completing the necessary training in these areas within three months of joining.

Underpinning our wider approach to leading and managing our people are our values: champions for the cause, respectful, collaborative, professional and focused and driven. It has been heartening to see the numbers of nominations for our quarterly values champion rising during the year, and the workshops we have provided for employees on living the values have been well attended and found to be very useful. There has been a focus on improving employee communications and at the staff away-day in December, we challenged employees to come together in teams and present innovative ideas with a focus on collaboration and our connection with the CF community, which was very well received.

As planned, we have further rolled out our leadership and management training programme with sessions for middle and senior managers. Eight members of staff are now qualified as Mental Health First Aiders and provide this service to all employees. The training has helped provide a focus on staff wellbeing and together with improved support for home and lone working, following a review of our policies in these areas. This is proving very helpful in looking after our people during the current COVID-19 crisis. A wider review and update of all our employment policies has ensured these are updated in line with recent changes to legislation, as well as including a new secondment policy.

Our second staff attitude survey was completed by 80% of employees and showed improvements in the areas we have been working hard on, such as having up-to-date job descriptions and increasing awareness of our values. Most results saw an improvement, including 97% of respondents answering positively when asked about the statement "I am proud to work at the Trust". For the next survey we are focusing on reducing the number of people reporting stress at work, improving our ability to manage change, and increasing the uptake of personal development plans.

>Supporter experience

The Trust is grateful to our committed and passionate supporters, who regularly go the extra mile to raise vital funds for our fight for a Life Unlimited for everyone affected by cystic fibrosis. Improving the supporter experience is a key focus for the Trust at every interaction. We continuously use feedback collected from supporters either face-to-face, online or offline, and we are constantly reviewing how we thank them, ensure they have the right materials for their fundraising, and communicate how their hard work is making a real difference to the lives of people living with cystic fibrosis.

In September 2018, the Trust took part in an external supporter survey conducted through an independent research company called About Loyalty, along with eight other charities, to understand what our supporters think about the Trust. The Trust scored highest of the charities taking part. Our loyalty score was driven by very high levels of commitment to the cause by our supporters and strong satisfaction and trust scores. The analysis will be used to underpin our continuing development of an exceptional supporter experience and to test specific stewardship initiatives and strengthen fundraising communications in key areas highlighted by the survey.

The Trust received 53 complaints in 2019–20, up slightly from 46 in 2018–19. Complaints are closely monitored and reviewed by senior management on an ongoing basis. We have recently reviewed our complaints policy and processes to make it easier for people to give us feedback, and to ensure we listen and learn from what our supporters and the community are telling us.

Fundraising

We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice.

We would like to thank all of the fantastic individual donors, organisations, charitable trusts, foundations and corporate partners who support our work. The Cystic Fibrosis Trust receives no government funding.

Our Trustees agree and regularly review our fundraising strategy. We adhere to Data Protection Law and the Fundraising Preference Service. We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice and, as such, commit to their Fundraising Promise. We aim to exceed these standards included in our promise to our supporters:

- **We will be transparent about our work**
- **We will be respectful**
- **We will listen and respond**
- **We are committed to high standards**
- **We are fair and responsible**

With many grateful thanks to the extraordinary generosity of our supporters, we raised over £10.6m in 2019/20.

This fantastic achievement enables the Trust to have an even greater impact on the lives of people with cystic fibrosis.

We are very proud of this achievement, especially considering the challenging external environment, with more regulatory requirements and negative press concerning charity fundraising. We have a strong ambition to continue to grow income over the next few years in order to have even greater impact.

>Fundraising events and activities

Support from people taking part in our events, community and branch activities is a significant part of our income. This year, more than 5,000 people took part in a challenge event for the Trust, and over 1,500 community events took place across the country.

The Virgin Money London Marathon, our biggest fundraising event of the year, raised £373,000. Another one of our most popular events, the Great North Run, which saw 307 runners raise £139,000.

Our 'Wear Yellow Day' campaign during CF Week continues to grow in popularity and saw the number of community events increase from 157 to 322 events, generating an income of over £65,000 driven by an integrated marketing campaign. People, pets, schools and towns were turned yellow, attracting attention from local media to the Trust's work and the realities of life with cystic fibrosis. The #CFYelfie component of the day raised over £5,000.

The Trust's Great Strides™ campaign continues to be extremely popular. The addition of two new weekend treks, Snowdon and Scafell Pike, brings the total number of Great Strides™ events to four walks, three treks and one ultra-marathon. The total raised by all these events was £276,000.

Other popular events included Carols by Candlelight, a one-month pop-up shop in Northern Ireland, London Landmarks and the Royal Parks Half Marathon.

>Gifts in wills

We received news of 61 supporters who had generously included a gift in their will for the Trust, as well as almost 100 pledges to do so. We are immensely grateful to those people who have thought of us in this very special way or are considering doing so, and we continue to promote our Gifts in Wills campaign.

>Regular gifts

We would like to express our thanks to our loyal regular monthly donors, who provide invaluable ongoing support that enables us to plan effectively for the future. Including Gift Aid, these supporters contributed nearly £820,000 in 2019/20.

During this year, we carried out two telemarketing activities through Ethicall, who have a ‘respect and dignity’ policy that turns marketing calls into thank-you calls if they suspect the person that they are speaking to is vulnerable. The activities (a regular giving upgrade and a Direct Debit conversion campaign) resulted in a combined income of nearly £7,000.

>Corporate partnerships

The Trust continues to work in partnership with companies to raise funds and awareness of CF, including Madison Brook and David Wilson Homes, as well as to maximise pro bono and gift-in-kind opportunities. We’re particularly grateful for the ongoing support from Clear Channel and Good Stuff, who provide gift-in-kind outdoor advertising and campaign advice, which is incredibly valuable in helping us promote our work.

This year, we were delighted to secure a donation from Next retail for sponsorship of the student programme. The Trust also welcomed partnerships with Hodge, Jones & Allen, Solutions Recruitment, Clarity Global and Stark, who will be supporting us during 2020.

Corporate partnerships continue to be a key area of growth for the Trust as we continue working to secure multi-year strategic relationships with companies.

The Trust’s commercial portfolio grew as partnerships were agreed with Prestige Flowers and Haven. Any commercial activities where the Trust benefits from the sale of products in exchange for use of our logo operate against a formal agreement and are monitored closely.

This year also saw continued support from the pharmaceutical industry for UKCFC, securing sponsorship for the event and we look forward to working with our sponsors again next year.

Philanthropy

We continue to work with charitable trusts, foundations and individual supporters to fund the work of the Trust. This year we have been pleased to build on existing relationships with: the Joseph Levy Foundation, which supports our Information and Support work; BBC Children in Need and The Queen’s Trust, who support our work with young people; The Alan Miller Charitable Trust; and Sport England. In addition, we have worked with generous individuals who are long-standing supporters of our work.

We have received generous pledges for the Innovation Hub from AJN Steelstock, the Robert Luff Foundation and kind individuals, totalling £1.78 million to date.

Membership of our Sixty-Five Roses Club continues to grow year on year, and many members attended and enjoyed our annual event in October 2019.

Our branches and groups across the country continue to support us by holding events and activities, which have raised a combined income of over £221,000. Our flagship challenge campaign, Great Strides™ – which includes four walks, three weekend treks and an ultra-marathon – raised £276,000.

Plans for the future

>Research and UKCFC

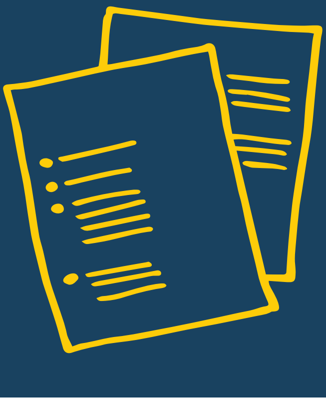
Our Research Strategy 2018–2023 will see the Trust continue to focus on securing access to medicines, ensuring the quality of clinical care, providing effective day-to-day support and reaching all people with cystic fibrosis. Our balanced portfolio of research programmes will continue to take advantage of funding from external sources and use novel approaches to tackle these issues.

Scoping and planning for the 2020/21 conference is ongoing, with the recommendation that the conference itself is held as a one-day research event with a focus on promoting scientific discussion and collaboration. It is also proposed that the next event be held in early 2021 to better align with the other key international respiratory conferences. It is likely that this will be a virtual event, in light of current rules regarding mass gatherings.

>Improving the quality of care

We will work closely and collaboratively with the UK Cystic Fibrosis Medical Association, to ensure people with CF get access to the best possible care and that we react appropriately to new challenges. The introduction of a Quality Improvement (QI) Working Group will ensure patients, parents and CF clinicians work in equal partnership with Trust staff to co-design the Trust's Quality Improvement Programme. The Patient Reported Experience Measures (PREMs) and UK staffing surveys will help provide data to centres to support their quality-improvement programmes.

We will continue to produce and update consensus documents to support CF clinicians in their work.



>UK CF Registry

The UK CF Registry team will continue to adapt as necessary to support the CF community through the COVID-19 pandemic. Data collection will be ongoing and future international publications are expected.

The Annual Registry Meeting will go ahead as a Virtual Video Series, allowing colleagues across the country to still benefit from this important meeting. Virtual content will be developed over the course of the year, providing sharing of best practice and important updates.

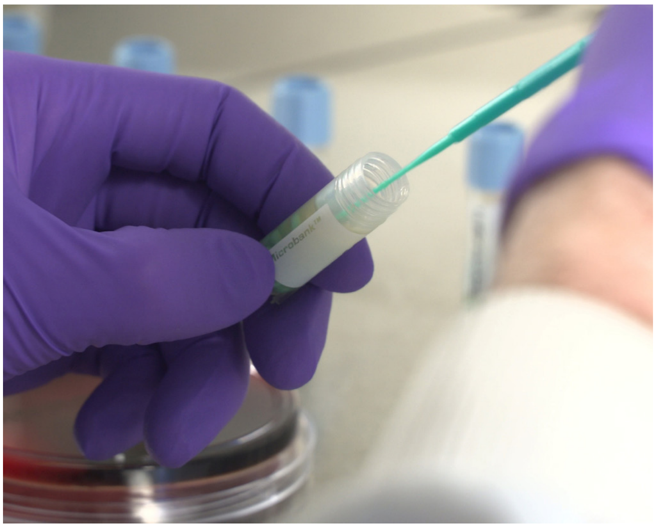
A new Registry for collection of data on people with CFSPID (Cystic Fibrosis Screen Positive, Inconclusive Diagnosis) will be developed during 2020.

>Improving access to clinical trials

Our Clinical Trials Accelerator Platform (CTAP) has innovative plans to continue to make the UK the pre-eminent place to deliver trials for CF therapies in Europe.

CTAP will continue to focus on ensuring equity of access to trials for the UK CF community. One method we will use to achieve this is through empowering the 20 CTAP trial coordinators to become Regional CF Trials Champions. CTAP trial coordinators will visit CF centres in their region with little or no clinical trial activity to engage the local clinical and research teams in CF clinical trials – highlighting the clinical trial resources available to their patients and outlining how to refer patients to CTAP centres for clinical trial participation.

We will continue to build our reputation with pharmaceutical companies to establish the UK's position as a desirable place for such businesses to invest in commercial CF trials, including early-phase trials: an increasingly important challenge given the UK's current political and healthcare climate.



Campaigning hard and raising awareness

Across the UK, we continue to push for agreement to allow universal access to CF medicines. We will continue to apply pressure to Ministers and top executives from the NHS, NICE, the Department for Health and Social Care, and their equivalents in Scotland, Wales, and Northern Ireland.

We will keep working to identify key dates and opportunities for parliamentary and community action to help ensure we keep significant momentum and pressure on all sides. In the long term, we are calling for reform to reimbursement mechanisms to allow for managed access to medicines while uncertainties and negotiations play out.

Day-to-day support

We will continue our work to understand the current and likely future information and support needs of the CF community, particularly in the context of a changing landscape of treatment. This will include a review of our grants programme to ensure best value for money and maximum impact for supporters and beneficiaries, and will explore new digital channels for our Helpline service. Our youth programme will continue innovating to provide specialist support to young people with cystic fibrosis.

We will expand our suite of information resources, moving into new areas including emotional wellbeing. Across all our work we will increase our focus on ensuring all our services and resources are accessible and relevant for the whole CF community in the UK, and that we are reaching those most in need of support.

Being great fundraisers

We will continue to work closely with our network of branches and groups, who are vital to our success at a local level, and develop new and innovative fundraising ideas. We will continue to offer an exceptional event portfolio, which will include virtual events that enable all supporters to take part, irrespective of age and ability. We will also continue to maximise the potential of our Great Strides™ and Wear Yellow Day campaigns. In addition, we will introduce additional processes and procedures to give fundraisers the very best experience when supporting the Trust.

We are also focusing on increasing engagement in our flagship activities such as CF Week, Great Strides™, Christmas and Resolutions (now known as Team CF Superheroes) while offering a diverse and exciting event portfolio.

We will continue to focus on developing multi-year partnerships with individuals, companies and Trusts, ensuring we can invest in cutting-edge research such as our exciting Innovation Hub partnership with the University of Cambridge, alongside providing vital support, information and advice services.

>Being an effective organisation

We will develop a series of impact indicators to help us track the long-term difference we are making in each area of our work for people with cystic fibrosis.

Following on from training in Mental Health First Aid, we will launch a new policy in this area. We also plan to review and relaunch our management toolkit, used to review individual employee performance and development, to review our recruitment approaches and ensure they follow best practice in diversity and effectiveness and to address issues raised in the staff survey as identified above. In terms of volunteering, we will improve our collection of data about our volunteers, particularly those associated with branches and in the community.

As we enter into the third and final year of our current three-year strategic framework, we will review our effectiveness so far in achieving our strategic objectives, and begin the process of developing our new forward three-year strategy, informed by the views, priorities and needs of people with cystic fibrosis.

Impact of COVID 19

At the time of reporting, the COVID 19 crisis is still unfolding. The impact on the Trust's activities has been significant. Our fundraising income has fallen as a result of cancelled events and activities, while the need for our services from the cystic fibrosis community has never been greater. We have maintained core activities throughout, without any drop off in services delivery, due to staff transitioning smoothly to working from home. We are very grateful to those supporters who have responded to our emergency appeal.

In response to the crisis the Board of Trustees have been meeting with the Senior Management Team on a regular basis to ensure appropriate oversight. The Trust's strong financial position going into the pandemic means that there are no immediate concerns about our ability to continue to operate. We have taken some short-term mitigating actions and the Board and Executive are considering the appropriate longer term response.

Financial review

Income

The Trust's income from normal activities for the year to March 2020 was £16.5million, a decrease of 7% over the previous year.

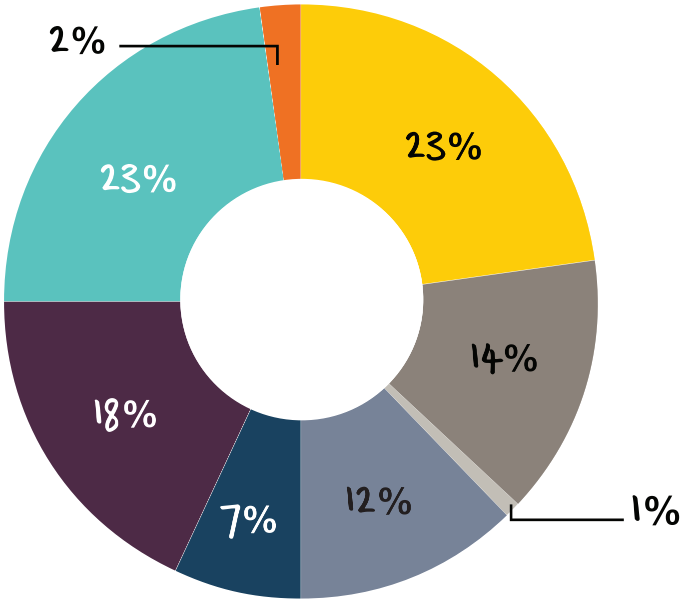
92% of the Trust's total income is made up of donations and legacies, totalling £15.2million, (2018/19 – £16.1m). This percentage is 6% lower than in the previous year, with the decrease driven by reductions in community and events income, regular and individual giving appeals income, and corporate partnerships income, offset by an increase in income from Trusts and Foundations. Donation income was again boosted by a non-monetary donation of digital advertising space, which was worth £3.8 million (2018/19 – £3.0m).

Total donations and legacies excluding this donation in kind were £11.4m (2018/19 – £13.1m). Fundraising by members of the community and through our fundraising branches continues to be a key source of funds, with a total including gift aid of £3.9m, which represents 34% of the total (2018/19 – 33%). The impact of COVID 19 on this funding stream started to be felt towards the very end of the financial year, as mass participation events were cancelled from mid-March 2020.

Income from Trusts and Foundations grew by 47% during the year.A key contributor to this was new partnership funding from the Cystic Fibrosis Foundation, who are now supporting two flagship projects (the Clinical Trials Accelerator Platform and the Digital Health Programme). Legacy income decreased by 22%, and accounted for 19% of the total (2019/20 – 25%).

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £1.1m (2018/19 – £1.3m). There were 2 (2018/19 – 3) long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, with a third contract ending during the year. We continue to actively seek new contracts in this area.

> 2019/20 income by income stream



Income from normal activities:	£'000
Branches, groups & community	3,877
Regular and individual giving and appeals	2,240
Corporate partnerships	223
Trusts	1,964
Cystic Fibrosis Services Limited	1,078
Legacies	2,931
Donated goods and services	3,833
Other income	381
Total income from normal activities	**16,527**

- 🟨 **Branches, Groups & Community**
- ■ **Regular and individual giving and appeals**
- ■ **Corporate Partnerships**
- ■ **Trusts**
- ■ **Cystic Fibrosis Services Limited**
- ■ **Legacies**
- ■ **Donated goods and services**
- 🟧 **Other income**

Expenditure

The Trust's total expenditure for the year was £16.5m, a 5% increase compared to the previous year. The largest area of spend was on charitable activities at £12.9m (2018/19 – 12.2m), accounting for 78% of total spend. This comprises programmes of research, information, advice and support and clinical care.

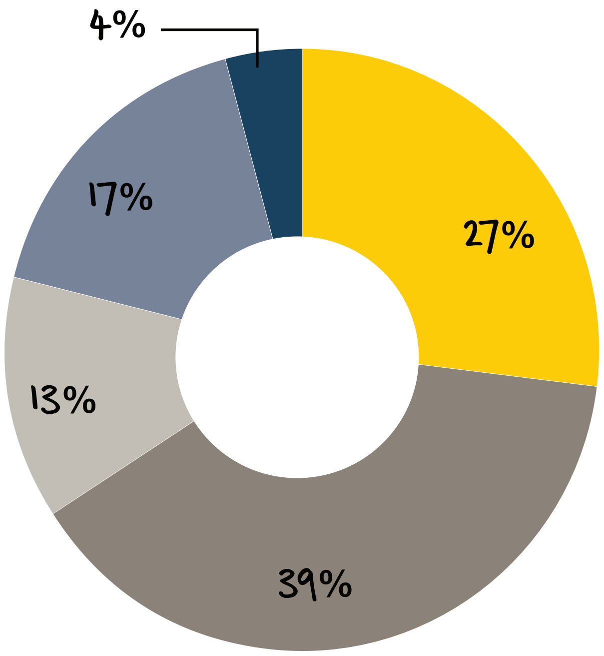
The remainder was spent on activities for generating funds, including £0.6m paid to NHS cystic fibrosis clinical centres across the UK to support the resources necessary to add patient data to the CF Registry.

Total grant commitments in the year were £4.8m (2018/19 – £4.6m), of which £4.4m (2018/19 – £4.3m) were committed to a range of institutions, including £1.5m committed for two Strategic Research Centres (2018/19 – £2.3m for three centres). The remaining £0.4m (2018/19 – £0.4m) was awarded to individuals through our ongoing Welfare Grant progamme.

The Clinical Trial Accelerator Platform flagship programme continued to develop throughout the year, with total spend of £0.8m (2018/19 – £0.7m). Through the new Digital Health Programme £0.6m of grant funding was awarded to Cambridge University/Papworth Hospital. A new commitment of £0.3m was made to support the next phase of activity at the Innovation Hub at Cambridge.

The final result for the year, including movements on investments, was a net deficit of £0.3m (2018/19 net surplus of £2.1m). This will be funded through brought foward Retained Reserves, leaving £4.8m to be carried forward to future years.

> 2019/20 expenditure by cost type



Expenditure:	**£'000**
Research	4,432
Information, advice & support	6,373
Clinical Care	2,132
Charitable activities total	**12,937**
Costs of raising funds	2,900
Cystic Fibrosis Services Limited	663
Total expenditure	**16,500**

🟨 **Research**
🟫 **Information, advice and support**
⬜ **Clinical Care**
🟪 **Costs of raising funds**
🟦 **Cystic Fibrosis Services Limited**

>Investment policy

The Finance Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to maintain real long-term capital value, looking to balance short-term volatility and protection against inflation with a moderate risk tolerance. The Trust does not permit direct investment in tobacco. General funds are invested in a balanced portfolio that includes some exposure to less liquid assets such as property, and utilises funds that do not invest in tobacco. A number of small endowments funds are invested for income. We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance Committee.

>Review of investments in the year

The value of the investment portfolio (including endowment funds) has decreased by £0.4 million in the year (2018/19: increase of £0.1 million); a 6% fall in value due to a market downturn around the year end. Income generated on investments totalled £0.1million, while realised and unrealised losses on the investment portfolio totalled £0.4 million.

>Reserves

The Trust's reserves as at 31 March 2020 totalled £8,225,000 (2019 – £8,552,000). Reserves are held in order to ensure the continuity of service provision, as well as enabling the Trust to move forward with strategically important programmes of work as and when opportunities arise. The Trustees maintain the following reserves:

- Designated reserves – the Trustees have opted to set aside free reserves for the following purposes:
  - A fixed asset reserve, equal to the net book value of the fixed assets (£24,000) is held to ensure these funds are not considered to be realisable

An Appeal Deficit has been recognised, being the difference between the £2.0 million grant awarded to the Innovation Hub at Cambridge and the £0.9 million income fundraised so far for the corresponding appeal. This deficit has been under-written by the Cystic Fibrosis Trust while we continue to appeal to donors for funds.

- Operating reserve – held at a value (£3,366,000) sufficient, as a minimum, to cover six months' operating costs, major fluctuations in income from budget, contingencies for long-term commitments and any deficit on restricted reserves due to over commitment or payment on those projects

- Retained reserves – (£4,778,000) to be deployed in financing the ambitions described in the Trust's Five-Year Business Delivery Plan in a way that maximises the impact for people with cystic fibrosis. Retained reserves had been expected to be utilised through a managed spend programme over the next 36 months. The impact on income generation due to the COVID 19 pandemic means that these reserves are likely to be utilised over a shorter period. It is the intention to use retained reserves while maintaining the Operating reserve as described above.

- Restricted income funds – (£239,000) relating to donations restricted to various specified activities.

More information about the reserves can be found in note **17a** to the accounts.

The Trustees keep reserves policy under regular review to ensure it is set at the appropriate level to reflect changes in the business outlook as they materialise. The reserves as outlined above meet the Trust's reserves policy.

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.

Principal risks and uncertainties

The Board of Trustees is responsible for ensuring that there are effective and adequate risk management and internal control systems in place to manage the major risks to which the Charity is exposed. It discharges this responsibility through its review of the effectiveness of the Charity's risk management framework. This is designed to support informed decision making regarding the risks that affect the Charity's performance and its ability to achieve its objectives. It also provides for a consistent approach to identifying, assessing and dealing with the risks facing the Charity so as to ensure that they do not exceed the level of risk the Charity is willing to assume. It should be noted that the framework is designed to manage, rather than to eliminate, the risks to the Charity's objectives and to provide reasonable, but not absolute, assurance against material misstatement or loss.

The principal risks and uncertainties that the Trustees have identified relate to remaining engaged with, and relevant to, people with cystic fibrosis: ensuring we communicate our charitable impact effectively; embedding a sustainable financial model; data security and the risk of cyber attack; influencing external key stakeholders while maintaining autonomy; ensuring business continuity; effectively managing an appropriate response to external events; ensuring that we continue to attract and retain high-quality staff.

The COVID 19 pandemic is clearly a key risk for the Trust, impacting on all of the areas noted above, in particular on the Trust's ability to raise income through fundraising events, many of which have unfortunately been cancelled. The Board of Trustees and Senior Leadership Team have been closely monitoring the situation, meeting regularly to ensure appropriate oversight at this challenging time and to identify mitigating actions wherever possible, for example through use of the governments Job Retention Scheme (which has resulted in the furloughing of 31 members of Trust staff).

Processes in place regarding risk management and internal control include the following:

- **A risk management framework that meets the Charity Commission's requirements. A top-down risk review, by the Senior Leadership Team, and a bottom-up review, by individual functions, is undertaken through the year and the risks identified through this process are documented in a risk register.**
- **The Finance Committee receives reports from the external auditors on the effectiveness of controls and on progress against both its audit plan and the recommendations made in its reports.**
- **The Board of Trustees has received a comprehensive risk management report to assist it in ensuring that an effective process is in place. This report provided an update on the risk reviews undertaken and provided the Board with the opportunity to engage in dialogue about, and to provide input into, the evaluation and management of key risks.**
- **Formal project delivery groups are established for major projects and programmes, such as the Life Unlimited programme, to ensure that these are properly planned, managed and implemented.**
- **Projects and activities of the Trust are assessed under a consistent risk assurance framework at inception to ascertain the appropriate level of management and oversight relative to financial, resource and risk exposure.**
- **Clear and easily accessible whistleblowing procedures are in place. In addition, there are processes in place to investigate and report on any serious incidents including the implementation of required corrective actions.**

Our work with the pharmaceutical industry

Our mission is to create a world where being born with cystic fibrosis (CF) no longer means a lifelong burden of care and an early death, when everyone living with the condition will be able to look forward to a long, healthy life.

Partnerships between medical research charities and the pharmaceutical industry can help us deliver that mission and bring huge benefits to patients – from accelerating the development of new drugs, to ensuring the safety and improvement of existing treatments.

We run flagship programmes involving industry partners:

>Clinical Trials Accelerator Platform

The Clinical Trials Accelerator Platform is a UK-wide initiative to bring together CF centres to increase participation and access to CF clinical trials. This initiative is building the infrastructure and funding additional research capacity to support the pharmaceutical industry with commercial clinical trial delivery.

As part of our collaboration with industry, the Trials Accelerator offers a centralised feasibility service to support pharmaceutical companies with identification of suitable CF centres for clinical trial delivery. In 2019/20 the Trials Accelerator feasibility service was utilised for 6 clinical trials, generating an income of £19,000 for the Clinical Trials Accelerator Platform.

- The Trials Accelerator also offers a protocol review service to support pharmaceutical companies with the design, feasibility and planning of clinical trials. In 2019/20 no submissions from pharmaceutical companies were received

>The UK Cystic Fibrosis Registry

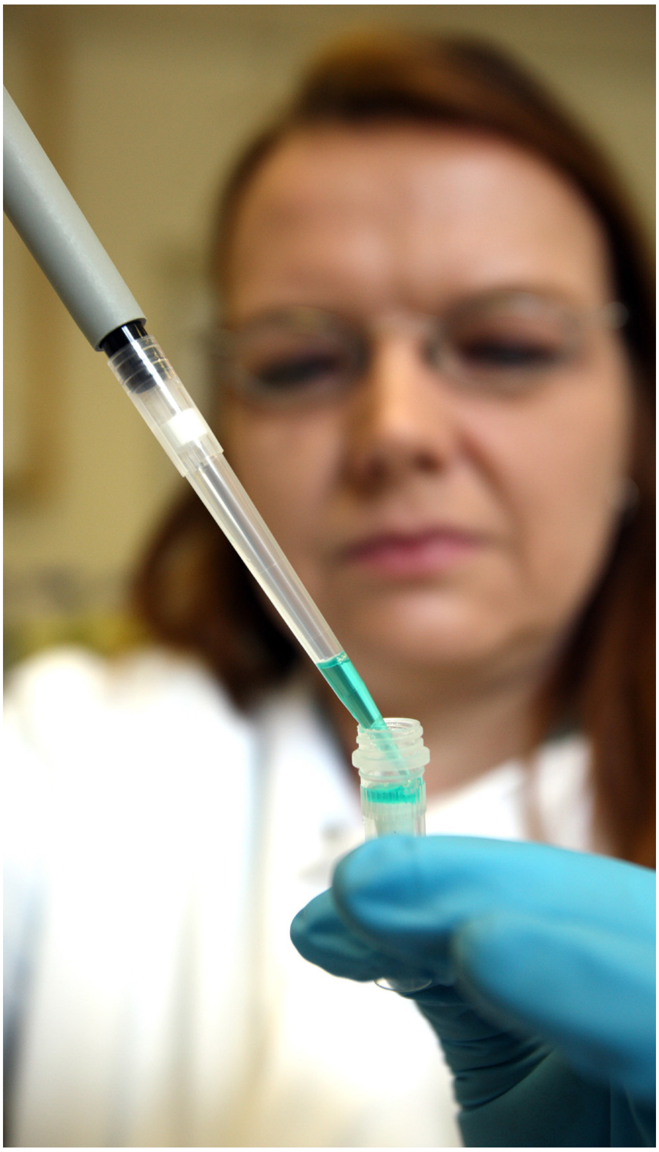
Long-term studies of drugs available to people with CF across the UK are conducted by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the Regulator of medicinal products is covered by pharmaceutical companies holding the Market Authorisation for these medicines.

You can read more about our work with industry to make medicines safer at cysticfibrosis.org.uk/registry.

In 2019/20 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £1.02 million in fees for this service. There were four long-term commercial contracts for Phase IV pharmacovigilance and health technology appraisal studies in place throughout the year.

>Venture & Innovation Awards (VIAs)

Venture and Innovation Awards support transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the pharmaceutical industry.



Sponsorship and donations

Sponsorship from pharmaceutical companies helps pay for our annual UK Cystic Fibrosis Conference, enabling us to stage a free event to keep healthcare professionals and people affected by CF informed on all aspects of clinical care and research.

In 2019/20, we received £12,000 to help pay for the costs of the UK Cystic Fibrosis Conference and would like to thank the following companies: Pari Medial and Trudell Medical.

In 2019/20 we also received £8,000 in sponsorship from Chiesi for the Annual Registry Meeting.

>Our guiding principles for working with the pharmaceutical industry
We do not do anything that prejudices the interests of people affected by CF and we will withdraw from any arrangement we believe to be against these interests, which may prejudice our mission and independence or damage our reputation.

We only enter into partnerships and contracts with pharmaceutical companies where it is in our charitable interests to do so, and we are always transparent when we do. All partnerships are based on the principles of integrity and supporting our mission and strategic aims.

We never accept funding from pharmaceutical companies to support campaigning activities. We do not promote or recommend specific treatments to individuals or influence prescribing practices for specific branded medicines.

Partnerships will not compromise the Trust's independent status and pharmaceutical companies with whom we enter into partnership will comply with ABPI code of practice when applicable **www.pmcpa.org.uk/thecode/Pages/default.aspx**.

We maintain our editorial independence so we are free to talk positively or negatively about pharmaceutical companies and their products.

Statement of Trustees' responsibilities

The Trustees, who are also directors of the Cystic Fibrosis Trust for the purposes of company law, are responsible for preparing the Trustees' report (including the Group Strategic Report) and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure, of the charitable group for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustees investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware, and

- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustees report incorporating the Strategic report was approved and authorised for issue by the Board of Trustees on **9 July 2020** and signed on its behalf by:

Richard Hunt, Chairman

Independent auditor's report to the Members and Trustees of the Cystic Fibrosis Trust

>Opinion

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2020 which comprise the Consolidated Statement of Financial Activities, the Consolidated Income and Expenditure Account, the Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 March 2020 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

>Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

>Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement (set out on page 33), the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the parent charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the parent charitable company or to cease operations, or have no realistic alternative but to do so.

>Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

>Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the group's or the parent charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

>Other information

The trustees are responsible for the other information. The other information comprises the information included in the Trustees' Annual Report and the Chair's statement. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

>Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Annual Report (which includes the strategic report and the directors' report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the strategic report and the directors' report included within the Trustees' Annual Report have been prepared in accordance with applicable legal requirements.

>Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the parent charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report (which incorporates the strategic report and the directors' report).

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charity Accounts (Scotland) Regulations (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept by the parent charitable company; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

>Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Kathryn Burton (Senior Statutory Auditor)
for and on behalf of Haysmacintyre LLP, Statutory Auditor
Date 9 July 2020

10 Queen Street Place,
London
EC4R 1AG

> Consolidated statement of financial activities

For the year ended 31 March 2020

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2020 £'000**	**Total Funds 2019 £'000**
Income and endowments from:						
Donations and legacies	2	12,657	2,539	-	**15,196**	**16,054**
Other trading activities	12	1,078	-	-	**1,078**	**1,321**
Investments	2b,6	142	7	-	**149**	**273**
Other income						
Other income	2	104	-	-	**104**	**121**
Total		13,981	2,546	-	**16,527**	**17,769**
Expenditure on:						
Raising funds	3	3,545	15	3	**3,563**	**3,517**
Charitable activities						
Research		3,346	1,085	1	**4,432**	**4,695**
Clinical care	3	1,085	1,047	-	**2,132**	**1,804**
Information, advice & support		6,082	288	3	**6,373**	**5,722**
Total charitable activities		10,513	2,240	4	**12,937**	**12,221**
Total resources expended	3	14,058	2,435	7	**16,500**	**15,738**
Net income/(expenditure) before investment gains/losses		**(77)**	**111**	**(7)**	**27**	**2,031**
Realised investment gains/(losses)		38	-	-	**38**	**-**
Unrealised investment gains/(losses)		(257)	-	(134)	**(391)**	**22**
Net investment gains/(losses)		**(219)**	**-**	**(134)**	**(353)**	**22**
Net (expenditure)/income		**(296)**	**111**	**(141)**	**(326)**	**2,053**
Transfers between funds	17a	298	(289)	(9)	**-**	**-**
Net movement in funds		2	(178)	(150)	**(326)**	**2,053**
Reconciliation of funds						
Total funds brought forward		7,087	417	1,047	**8,551**	**6,498**
Total funds carried forward	17a	**7,089**	**239**	**897**	**8,225**	**8,551**

All of the operations are continuing. There were no recognised gains or losses other than those stated above.
A prior year comparative Consolidated Statement of Financial Activities has been included in the notes to the accounts (note 18)

The notes on pages 40 to 62 form part of these financial statements.

> Consolidated income and expenditure account

For the year ended 31 March 2020

	All income funds 2020 £'000	All income funds 2019 £'000
Income	**16,378**	17,496
Gains/(losses) on investments	**(219)**	44
Investment income	**149**	273
Gross income in the reporting period	**16,308**	17,813
Expenditure	**16,476**	15,599
Interest payable	**-**	-
Depreciation and charges for impairment of fixed assets	**18**	131
Total expenditure in the reporting period	**16,494**	15,730
Net income before tax for the reporting period	**(186)**	2,083
Tax payable	**-**	-
Net Income for the financial year	**(186)**	2,083

The Consolidated Summary Income and Expenditure Account is derived from the Statement of Financial Activities on page 36 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 40 to 62 form part of these financial statements.

Cystic Fibrosis Trust

> Consolidated and charity balance sheets

As at 31 March 2020

		Consolidated		**Charity**	
	Notes	**Total 2020 £'000**	Total 2019 £'000	**Total 2020 £'000**	Total 2019 £'000
Fixed assets					
Tangible assests	5	**24**	40	**24**	40
Investments	6	**5,670**	6,031	**5,670**	6,031
		5,694	6,071	**5,694**	6,071
Current assets					
Debtors	7	**2,619**	2,313	**2,552**	2,177
Cash held as short term investment		**9,978**	11,414	**9,978**	11,414
Cash at bank and in hand		**2,939**	2,517	**2,672**	1,981
		15,536	16,244	**15,202**	15,573
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	9	**(7,135)**	(5,805)	(7,135)	(5,805)
Creditors and accrued charges	10	**(705)**	(1,261)	(699)	(1,258)
		(7,840)	(7,066)	**(7,834)**	(7,062)
Net current assets		**7,698**	9,178	**7,367**	8,511
Creditors: amounts falling due after one year					
Grants payable	9	**(5,165)**	(6,698)	(5,165)	(6,698)
Total net assets		**8,225**	8,550	**7,897**	7,883
The funds of the charity					
Endowment funds	17a	**897**	1,047	**897**	1,047
Restricted income funds	17a	**239**	417	**239**	417
Unrestricted funds					
Designated reserves	17a	(1,055)	(1,266)	(1,055)	(1,266)
Operating reserves		3,366	3,393	3,366	3,393
Retained reserves		4,778	4,961	4,450	4,295
Total charity funds		**8,225**	8,552	**7,897**	7,886

The notes on pages 40 to 62 form part of these financial statements.

The net movement in funds for the Trust for the year ended 31 March 2019 was – £655,000 (2019: 12 months +£725,000). As permitted by Section 408 of the Companies Act 2006, no separate Statement of Financial Activities or Income and Expenditure account has been presented for the charity alone.

Approved and authorised for issue by the Trustees on **9 July 2020**
and signed on their behalf by:

Richard Hunt, Chairman

Company number 3880213

Cystic Fibrosis Trust

> Consolidated Statement of cash flows

As at 31 March 2020

	2020 £'000	2019 £'000
Net cash provided by (used in) operating activities (Note A)	**(1,171)**	1,373
Cash flows from investing activities:		
Dividends and interest	**149**	273
Purchase of property, plant and equipment	**(2)**	(39)
Purchase of investments	**-**	60
Movement in cash awaiting investment	**9**	(165)
Proceeds of sales of investments	**-**	-
	156	129
Increase/(decrease) in cash held as short term investments	1,436	(63)
Increase/(decrease) in cash (Note B)	**421**	1,439

Notes to Cash Flow Statement

A. Reconciliation of net income/(expenditure) to net cash flow from operating activities

	2020 £'000	2019 £'000
Net (expenditure)/income for the reporting period (as per the statement of financial activities)	**(327)**	2,053
Adjustment for:		
Depreciation charges	**18**	131
Dividends and interest from investments	**(149)**	(273)
(Gains)/losses on investments	**352**	(22)
Decrease/(increase) in debtors	**(306)**	(556)
Increase/(decrease) in creditors	**(759)**	40
	(1,171)	1,373

B. Reconciliation of cash and cash equivalents in the reporting period

	2020 £'000	2019 £'000
Cash and cash equivalents at the beginning of the reporting period	**13,931**	12,429
Change in cash and cash equivalents in the reporting period	**424**	1,439
Increase in short-term investments	**(1,436)**	63
Cash and cash equivalents at the end of the reporting period	**12,919**	13,931
(being cash at bank and in hand and cash held as short-term investments)		

	2020	2019
Analysis of cash and cash equivalents:	**£'000**	£'000
Cash on hand	**2,941**	2,517
Notice deposits (less than 3 months)	**9,978**	11,414
Total cash and cash equivalents	**12,919**	13,931

> Notes to the Financial Statements

For the year ended 31 March 2020

1. Accounting policies

The principle accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

a) Basis of preparation
The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – (Charities SORP FRS 102), and the Companies Act 2006.

Group financial statements have been prepared in respect of Cystic Fibrosis Trust and its wholly owned trading subsidiary, Cystic Fibrosis Services Limited. In accordance with the Companies Act 2006 and SORP 2015, no separate Statement of Financial Activities is presented for Cystic Fibrosis Trust.

Cystic Fibrosis Trust meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Charity status
The charity (registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 61. In the event of the company being wound up, the liability in respect of the guarantee is limited to £1 per member of the company.

c) Consolidation
The financial statements include the results and assets and liabilities of the charity and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own Statement of Financial Activities under section 408 of Companies Act 2006. The deficit for the parent charity was £655,000 (2019 – surplus of £725,000).

The subsidiary's net surplus of £328,000 will be donated in full to the parent charity after the year end.

d) Income
All income is recognised once the charity has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably.

Donations and legacies income are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable.

Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

Investment income is recognised on a receivable basis and the amounts can be measured reliably. Dividends are recognised once the dividend has been declared and notification has been received the dividends are due.

e) Resources expended
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably.

Expenditure is recognised on an accruals basis as a liability is incurred, and includes irrecoverable VAT where applicable.

Expenditure is classified under the following activity headings:

- Expenditure on raising funds comprises those costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs
- Expenditure on charitable activities comprises those costs relating to activities where the primary aim is congruent with the objects of the charity, along with an apportionment of support costs. This includes grants made to research institutions and individuals, the provision of information and support services to people with cystic fibrosis and their families, peer reviews of cystic fibrosis centres and the development of the CF Registry.

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the estimated amount of time spent by the support area on each activity category. The basis for allocation was reviewed in the year in order to give a more accurate view of the level of support provided within different business areas. The prior year allocations have been restated in order to be consistent with the revised allocation basis.

f) Grants

Grants committed and awarded during the year are expensed.

g) Foreign currency transactions

Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the Statement of Financial Activities.

h) Employee benefits

- **Short term benefits** – Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.

- **Employee termination benefits** – Termination benefits are accounted for on an accrual basis and in line with FRS 102.

- Pension scheme – The Charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Charity pays fixed contributions into a separate entity. Once the contributions have been paid the Charity has no further payment obligations. The contributions are recognised as an expense in the Statement of Financial Activities when they fall due.

i) Taxation

No charge to taxation arises on the result for the year because the company is able to take advantage of the tax exemptions available to charities.

j) Leases

The trust recognises expenses under 'operating leases' relating to capital equipment which it does not own. The annual rentals are charged to the statement of financial activities on a straight line basis over the lease term.

k) Funds

Unrestricted reserves are those which the Trustees are free to use for any purpose in furtherance of the charitable objects.

Designated reserves are set aside out of unrestricted reserves by the Trustees, for particular purposes.

Restricted reserves are monies, which have legal restrictions on their use where donors have specified the funds can only be spent on certain of the charity's activities.

Endowed Funds are funds where the Trustees are required to hold capital, as represented by the investments, and are not entitled to spend it. Income arising from these funds is either restricted income or unrestricted income depending upon the details included with the original gift.

l) Fixed assets and depreciation

Tangible fixed assets costing £500 or more are capitalised and are depreciated by equal annual instalments over their estimated useful lives. The current estimated rates of depreciation are:

Furniture & fittings	33.33%
Computer hardware	33.33%
Computer software	33.33%
Website development	33.33%
Platform development	50%

Website and Platform development costs are capitalised on the basis that they lead to an asset that will generate funds for the Trust or where the primary aim is part of the objects of the charity. The assets are depreciated once the asset is ready for use.

m) Investments

Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values of investments are shown as unrealised gains and losses in the Statement of Financial Activities.

Profits and losses on the realisation of investments are shown as realised gains and losses in the Statement of Financial Activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired subsequent to the first day of the financial year. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value. Realised and unrealised investment gains and losses are combined in the Statement of Financial Activities.

n) Financial Instruments

The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value

- **Debtors** – Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

- **Cash at bank and in hand** – Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

- **Creditors and provisions** – Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

o) Critical accounting judgements and estimates

In preparing these financial statements, management has made judgements, estimates and assumptions that affect the application of the Charity's accounting policies and the reported assets, liabilities, income and expenditure and the disclosures made in the financial statements. Estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. The key areas that are deemed to be material for these financial statements is as follows:

- Accruing for income derived from legacies where complicated issues surrounding the measurement of the group's entitlement to income existed at the year end.

- The value of the contribution of the many thousands of hours donated by its unpaid volunteers has not been reflected in these accounts. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

p) Going Concern status

The Trustees have reviewed the financial statements and supplementary financial information and conclude that the Trust is a valid going concern.

2a. Income from donations and legacies

	Unrestricted Funds 2020 £'000	Restricted Funds 2020 £'000	**Total 2020 £'000**	Unrestricted Funds 2019 £'000	Restricted Funds 2019 £'000	**Total 2019 £'000**
Branches, Groups & Community	3,599	15	**3,614**	3,972	102	4,074
Legacies	2,875	46	**2,921**	3,470	260	3,730
Individual donations	275	54	**329**	159	872	1,031
Corporate	222	-	**222**	212	160	372
Regular giving and appeals	1,167	42	**1,209**	1,233	45	1,278
Trusts	20	1,944	**1,964**	182	1,157	1,339
Appeal for Innovation Hub	-	438	**438**	-	555	555
Donations in kind	3,833	-	**3,833**	2,962	-	2,962
Gift Aid	538	-	**538**	581	-	581
NHS National Services England	81	-	**81**	89	-	89
NHS National Services Scotland	47	-	**47**	43	-	43
Total income from donations and legacies	12,657	2,539	**15,196**	12,903	3,151	16,054

Donations In Kind refer to non-monetary donations received from partner organisations. In 2019/20 £3,833,000 was donated in the form of digital and cinema advertising space (2018/19 – £2,962,000). This was used to raise awareness of cystic fibrosis and the work of the Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, Advice and Support.

2b. Investment Income

	Unrestricted Funds 2020 £'000	Restricted Funds 2020 £'000	**Total 2020 £'000**	Unrestricted Funds 2019 £'000	Restricted Funds 2019 £'000	**Total 2019 £'000**
Income from listed investments	64	7	**71**	217	23	240
Bank interest	78	-	**78**	33	-	33
Total investment income	142	7	**149**	250	23	273

3a. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2020 £'000**
Raising funds					
Fundraising	-	-	2,506	394	**2,900**
Trading and merchandising	-	602	61	-	**663**
Charitable activities					
Research	1,629	1,269	932	602	**4,432**
Clinical care	761	138	943	290	**2,132**
Information, advice & support	174	213	5,119	867	**6,373**
	2,564	2,222	9,561	2,153	**16,500**

Analysis of allocated Support Costs – current year

	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2020 £'000**
Fundraising	78	52	101	56	108	**394**
Research	119	79	154	85	166	**601**
Clinical care	57	38	74	41	80	**291**
Information, advice & support	171	114	221	122	238	**866**
Total costs	424	283	551	302	591	**2,153**

Costs are allocated based on identifiable activities undertaken by central teams to support the wider organisation. The basis of allocation of support costs has been reviewed in the year. The prior year allocations have been restated in order to be consistent with the revised allocation basis.

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2019 £'000**
Raising funds					
Fundraising	-	-	2,475	452	**2,927**
Trading and merchandising	-	543	47	-	**590**
Charitable activities					
Research	1,046	2,089	835	725	**4,695**
Clinical care	497	94	934	279	**1,804**
Information, advice & support	167	191	4,480	884	**5,722**
Governance	-	-	-	-	**-**
	1,710	2,917	8,771	2,340	**15,738**

The net restricted grants relating to Clinical Care are negative – this is due to the release of a commitment made in a prior year. See note 3b for more information.

Analysis of allocated Support Costs – prior year

	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2019 £'000**
Fundraising	87	53	137	52	123	**452**
Research	140	86	219	83	197	**725**
Clinical care	54	33	84	32	76	**279**
Information, advice & support	171	104	267	102	240	**884**
Total costs	452	276	707	269	636	**2,340**

3a. Expenditure (continued)

Net (expenditure)/income in the year:

	2020 **£'000**	2019 £'000
Auditors remuneration excluding VAT	**21**	20
Auditors – tax advice	**-**	4
Depreciation	**18**	131
Operating leases – building	**244**	244
Operating leases – other	**6**	6
Trustees' travel expenses	**3**	2

3b. Grants

Grants were awarded during the year as follows:

	2020 **£'000**	2019 £'000
Grants to institutions	**4,402**	4,270
Grants to individuals	**385**	357
	4,787	4,627

Grants made to, and for, individuals affected by Cystic Fibrosis are for expenses such as respite care, building adaptations and equipment rental and benefited a large number of individuals throughout the Trust's network of regions and branches.

	2020 **£'000**	2019 £'000
Balance at start of year	12,503	12,605
Awarded in the year	4,787	4,267
Paid in year	(4,990)	(4,729)
Balance at end of year	12,300	12,503
Falling due within one year (note 9)	7,135	5,805
Falling due after more than one year (note 9)	5,165	6,698

During the year, grants were awarded to the following institutions:

	2020 **£'000**	2019 £'000
University of Cambridge/Papworth Hospital	856	1,525
University of Newcastle/Newcastle Hospital	750	-
University of Sheffield	749	70
Imperial College London/Royal Brompton Hospital	163	875
Kings College	157	10
Royal College of Surgeons in Ireland	97	-
Manchester University/Wythenshaw Hospital	95	84
Nottingham University	65	50
University of Exeter	58	52
Royal Hospital for Children, Glasgow	50	-
University of Liverpool	33	-
Neem Biotech	30	-
CF Europe	21	-
ECFS – European Cystic Fibrosis Society	20	21
National heart and lung institute, London	20	-
Queens University Belfast	3	65

3b. Grants (continued)

	2020 **£'000**	2019 £'000
University College London	2	100
University of Bristol	2	-
Cardiff University	2	-
St George's University of London	2	-
Institute of Cancer Sciences, Glasgow	2	-
Magic Bullet (with Cambridge and Microsoft)	-	150
University of Oxford	-	115
London School Of Tropical and Hygiene Medicine	-	65
Action Medical Research	-	52
University of Edinburgh	-	49
Owlstone Medical Limited	-	36
Queen's Medical Centre	-	35
School of Chemistry Bangor	-	20
Medicines Discovery Catapult	-	20
Leeds University	-	10
Queen Elizabeth University Hospital, Glasgow	-	2
University of Portsmouth	-	2
Ninewells Hospital and Medical School	-	2
	3,177	**3,410**
Add: Trial Coordinator commitments made to CTAP centres (see note)	616	466
Add: Registry support grants made to various CF centres	602	543
Add: Other adjustments	7	
Less: Release of grants made in previous years (see note)		-149
Total grants made to institutions	**4,402**	**4,270**

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform programme. In most cases the trial coordinators are now in their third year of funding. In addition, a new cohort of 'Affiliate Centres' were awarded funding in the year.

Various grants totalling £149,000 were released during the prior year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being succesful.

The Trust has considered the discounting of grant commitments due in more than one year, but has not made any adjustments to the figures disclosued above as the impact of discounting is negligible.

4. Staff costs

Staff costs comprise the following:

	2020 **£'000**	2019 £'000
Salaries	**4,011**	3,998
Redundancy and other termination payments	**-**	87
Temporary Staff	**232**	240
Social security costs	**416**	421
Other pension costs	**235**	232
	4,894	4,978

No redundancy and other termination payments were paid to staff (2019 – £87,000 paid to 9) staff members in the year. The prior year payments followed an organisation-wide review of the staff base to better align resources with the current strategic plan.

Pension commitments:
The Charity operates a defined contributions pension scheme. The assets of the scheme are held separately from those of the Charity in an independently administered fund. The pension cost charge represents contributions payable by the Charity to the fund and amounted to £235,000 (2019 – £232,000).

Analysis of total average monthly headcount by category:

	2020 **No.**	2019 No.
Research	**13**	11
Clinical care	**5**	6
Information, advice & support	**34**	35
Fundraising	**38**	38
Management	**4**	6
Finance	**6**	5
IT and project management support	**6**	6
HR & OD	**7**	2
Facilities	**2**	2
Total average monthly headcount	**115**	**111**

The number of employees whose total remuneration exceeded £60,000 in the year was:

	2020 **No.**	2019 No.
£60,001 – £70,000	2	2
£70,001 – £80,000	3	2
£80,001 – £90,000	-	1
£90,001 – £100,000	-	-
£110,001 – £120,000	1	1

Pension contributions to defined contribution pension schemes for these employees totalled £32,190 (2019 – £32,029).

Remuneration of key management personnel: The total remuneration paid to key management personnel, including pension and social security contributions, was £652,905 which relates to eight individuals who served on the Senior Leadership Team during the year (2019 – £579,329 paid to six individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. Expenses of £3,019 (2019 – £2,134) were settled on 4 (2019 – 4) trustees. No welfare grants were paid to trustees (2019 – 1) who have cystic fibrosis.

5. Fixed assets

	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 31 March 2019	**630**	**832**	**243**	**403**	**183**	**2,291**
Additions	-	2	-	-	-	2
At 31 March 2020	**630**	**834**	**243**	**403**	**183**	**2,293**
Depreciation						
At 31 March 2019	**630**	**793**	**243**	**402**	**183**	**2,251**
Charge for the year	-	18	-	-	-	18
At 31 March 2020	**630**	**811**	**243**	**402**	**183**	**2,269**
Net book value at 31 March 2020	**-**	**23**	**-**	**1**	**-**	**24**
Net book value at 31 March 2019	-	39	-	1	-	40

6. Investments

Group and Charity	**Total 2020 £'000**	Total 2019 £'000
Market value as at 31 March 2019	**6,031**	5,904
Additions at cost	**525**	(60)
Disposals at opening book value	**(524)**	-
Net gains/(losses) on investments	**(353)**	22
	5,679	5,866
Change in cash	**(9)**	165
Market value as at 31 March 2019	**5,670**	6,031

6. Investments (continued)

Represented by:	**Total 2020 £'000**	Total 2019 £'000
Equities	**2,952**	2,540
Fixed Interest and multi-asset funds	**468**	1,012
Property	**659**	852
Cash	**1,591**	1,627
	5,670	**6,031**

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment.

The following assets were held at 31 March 2020. These make up more than 5% of total investments:

	Total 2020 £'000
Charity Equity Income Fund	**395**
Charity Bond Fund/Rathbone Ethical Fund	**554**
Charities property fund	**321**
Property income trust for charities	**338**
Cystic Fibrosis General Fund	**1,275**
Responsible Multi Asset Fund	**2,398**

In 2014–15, the Trustees decided to exclude tobacco-related stocks from investments. This change was implemented in 2015–16 and the investment portfolio is now fully ex-tobacco.

7. Debtors

	Group 2020 £'000	Group 2019 £'000	**Charity 2020 £'000**	Charity 2019 £'000
Trade debtors	**305**	218	**-**	-
Amount due from subsidiary undertaking	**-**	-	**238**	82
Prepayments and accrued income	**2,263**	1,953	**2,263**	1,953
Other debtors	**51**	142	**51**	142
	2,619	2,313	**2,552**	2,177

8. Cash held as short term investment

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.

9. Grants Payable

	2020 £'000	2019 £'000
Grant creditor at 31 March 2019	**12,503**	12,605
Grants paid during the year	**(4,365)**	(4,728)
Grants approved before 31 March 2020 and payable within one year	**2,413**	2,023
Grants approved before 31 March 2020 and payable after one year	**1,749**	2,603
Grant creditor at 31 March 2020	**12,300**	**12,503**
Represented by		
Grants due within one year at 31 March 2020	**7,135**	5,805
Grants due > 12 months	**5,165**	6,698
	12,300	12,503

10. Creditors

	Group 2020 £'000	Group 2019 £'000	**Charity 2020 £'000**	Charity 2019 £'000
Trade creditors	**195**	802	**194**	800
Other creditors	**129**	123	**129**	123
Accruals and deferred income	**382**	336	**376**	334
	705	**1,261**	**699**	**1,257**

11. Financial Instruments (Assets and Liabilities)

	Group 2020 £'000	Group 2019 £'000	**Charity 2020 £'000**	Charity 2019 £'000
Financial assets measured at amortised cost (note a)	**13,241**	14,222	**13,241**	14,222
Financial assets measured at fair value (note b)	**5,670**	6,031	**5,670**	6,031
Financial liabilities measured at amortised cost (note c)	**(12,885)**	(14,110)	**(12,885)**	(14,110)
Net financial assets measured at amortised cost	**6,026**	6,142	**6,026**	6,142

(a) The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

(b) Financial assets held at fair value include assets held as investments.

(c) Financial liabilities measured at amortised cost include: trade creditors, other creditors, accruals, grants payable and deferred income and amounts due to group undertakings.

12. Interest in subsidary

Cystic Fibrosis Services Limited is incorporated in England (company number: 00900164) and is a wholly owned subsidiary of the Cystic Fibrosis Trust. The subsidiary's activities include medical services, information and data system support and the merchandising of marketing materials. The profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March can be summarised as:

	Total 2020 £'000	Total 2019 £'000
Sales and sundry income	**1,078**	1,321
Cost of sales and administration	**(664)**	(590)
Intercompany recharges	**(86)**	(65)
Net contribution to parent charity	**328**	666

The balance sheet of Cystic Fibrosis Services Limited at 31 March can be summarised as:

	Total 2020 £	Total 2019 £
Current Assets		
Debtors	**305,005**	217,182
Cash at bank	**269,234**	535,192
	574,239	**752,374**
Creditors: amounts falling due within one year	**(245,834)**	(86,633)
Net Current Assets	**328,405**	665,741
Net Assets	**328,405**	665,741
Capital and Reserves		
Called up share capital	**2**	2
Profit and loss account	**328,403**	665,739
Shareholder's funds	**328,405**	665,741

The charity owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd, which comprises 100 ordinary shares of £1 each. Two shares have been allotted, which are called up and fully paid.

The subsidiary's profit for the year will be donated in full to the Cystic Fibrosis Trust after the year end.

13. Leasing commitments

At 31 March 2020, the Trust's future minimum operating leases payments relating to buildings were:

	2020 £'000	2019 £'000
Within one year	**271**	**271**
Between two and five years	**1,084**	**-**

A 10 year property lease with a five year break clause was signed on 1 April 2015 for a new office in central London, with annual rent of £271,425. The break clause was not exercised and as such the remaining five years of the lease are now committed.

At 31 March 2020, the Trust's future minimum operating leases payments relating to equipment were:

	2020 £'000	2019 £'000
Within one year	**6**	**6**
Between two and five years	**24**	**24**

The charge to the Statement of Financial Activities for all of these commitments is shown in note 3a.

14. Related party transactions

The group has taken advantage of the exception which is conferred by FRS102 Section 33.1A 'Related Party Disclosures' that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

Total donation income from the Trustees in the year was £10,285 (2019 – £52,409). In addition five of the trustees (2019 – 2) were involved in fundraising activities carried out by regional fundraising branches. No Trustee (2019 – 1) who has cystic fibrosis received a welfare grant from the Cystic Fibrosis Trust during the year.

Any other transactions between the Trust and its trustees are disclosed in note 4.

15. Post balance sheet events

There were no post balance sheet events or contingent liabilities when the accounts were signed and authorised for issue.

16. Analysis of funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2020** **£'000**
Tangible fixed assets	24	-	-	24
Investments	4,773	897	-	5,670
Current assets	15,295	-	241	15,538
Internal obligations	-	-	-	-
Current liabilities	(7,480)	-	-	(7,480)
Liabilities due in more than one year	(5,718)	-	13	(5,165)
	7,075	897	254	8,227

Prior year funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2019** **£'000**
Tangible fixed assets	40	-	-	40
Investments	4,984	1,047	-	6,031
Current assets	15,827	-	417	16,244
Internal obligations	-	-	-	-
Current liabilities	(7,066)	-	-	(7,066)
Liabilities due in more than one year	(6,698)	-	-	(6,698)
	7,087	1,047	417	8,551

17a. Current year fund movements

	Balance 31 March 2019 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2020 £'000**
Fixed asset reserve	40	-	-	-	(16)	24
Appeal deficit: Innovation Hub at Cambridge	(1,306)	-	-	-	227	(1,079)
Total Designated Reserves	**(1,266)**	**-**	**-**	**-**	**211**	**(1,055)**
Operating reserve	3,393	-	-	-	(27)	3,366
Retained reserves	4,960	(219)	13,981	(14,058)	114	4,778
Total General Reserves	**8,353**	**(219)**	**13,981**	**(14,058)**	**87**	**8,144**
Total Unrestricted Funds	**7,087**	**(219)**	**13,981**	**(14,058)**	**298**	**7,089**
Restricted Income Funds:						
Appeal: Innovation Hub at Cambridge	-	-	477	(250)	(227)	-
Restricted funds related to research:						
Gene Therapy Research	-	-	45	-	-	45
General Medical Research	-	-	106	(105)	(1)	-
UCL SRC: Personalised Engineered Cell Therapies	-	-	8	-	(8)	-
Sport England – Helping the Active Stay Active	9	-	57	(57)	(9)	-
Imperial SRC: *Pseudomonas aeruginosa*	-	-	42	-	(42)	-
Targeting Immuno Theraphy for Fungal Infections-SRC15	-	-	14	-	(14)	-
RNA Interference of ENAC as Therapy for CF VIA 12	-	-	15	-	(15)	-
Life Expectancy Project	5	-	-	(25)	-	(20)
Transition Information Resources	15	-	-	-	-	15
VIA general awards	-	-	-	-	-	-
Other research related restricted funds	9	-	-	(7)	(1)	1
Total funds related to research	**38**	**-**	**287**	**(194)**	**(90)**	**41**
Restricted funds related to Information and Support						
E W Joseph/Homecare grants	62	-	2	(28)	-	36
Joseph Levy/Education Grants	(12)	-	82	(69)	12	13
Young Lives Programme	49	-	48	(91)	-	6
Support services (including welfare grants)	70	-	117	(107)	1	81
CF Connect (youth and parents)	26	-	-	-	-	26
Total funds related to Information & Support	**195**	**-**	**249**	**(295)**	**13**	**162**

Continued on next page

17a. Current year fund movements (continued)

Other funds - various categories:						
Coombe Hill	40	-	-	(15)	(17)	8
Kings fund	157	-	-	(157)	-	-
SmartCare CF	(10)	-	-	-	-	(10)
Clinical Trials Accelerator Programme (CTAP)	-	-	856	(856)	-	-
Digital Health Research Programme	-	-	647	(647)	-	-
CF Registry	1	-	-	(6)	-	(5)
Patient Reported Experience Measures	-	-	3	(1)	-	2
Consensus Documents	-	-	25	(2)	-	23
HDRUK Grant Award	-	-	-	(14)	-	(14)
Other older funds	(4)	-	2	2	31	31
Total other funds	**184**	**-**	**1,533**	**(1,696)**	**15**	**36**
Total Restricted Reserves	**417**	**-**	**2,546**	**(2,435)**	**(289)**	**239**
Endowment Funds:						
Ena Bennie Endowment	522	(67)	-	(4)	(8)	443
EW Joseph Endowment	173	(22)	-	(1)	-	150
Joseph Levy Endowment	297	(38)	-	(2)	-	257
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other Endowment funds	35	(7)	-	-	(1)	27
Total Endowment Funds	**1,047**	**(134)**	**-**	**(7)**	**(9)**	**897**
Total Funds	**8,551**	**(353)**	**16,527**	**(16,500)**	**-**	**8,225**

17a. Funds (continued)

Designated Funds: The designated fixed assets reserve matches the net book value of the charity's tangible fixed assets, the existence of which is fundamental to the charity being able to perform its charitable work and thereby achieve its charitable objectives. The value represented by such assets should not, therefore, be regarded as realisable.

Appeal Deficit: Innovation Hub at Cambridge – In 2017/18 we committed £2.0 million in the form of a research grant to Cambridge University as part of the Innovation Hub flagship programme. To date we have received £0.9m from donors in funding for this grant (shown in the separate restricted fund line, see below) as well as a further £0.4 million in funding pledges. The Trust has underwritten this grant, and we continue to work to secure additional pledges in order to fund the commitment in full and free up core funds to be made available where there is the greatest need.

General reserves: The operating reserve is held in order to provide, as a minimum, cover for six months operation costs, major fluctuations in income and contingencies for long term commitments, and any deficits arising on restricted funds.

Retained reserves are held for future initiatives.

Restricted income funds: Restricted income funds are held when donors specify a particular use for their donation. For the purposes of this report, the restricted income funds have been divided into the following categories:

- **Appeal for Innovation Hub at Cambridge:** We have received £0.9m to date in funding torwards the £2.0m commitment made to Cambridge University. As further income is received it will be recognised within this restricted fund and matched against the commitment made in 2017/18 through a transfer to the designated fund (see above).

- **Restricted funds related to research:** Donations relating to grant commitments made by the Trust to research institutions. On occasion the donations were made in a different financial year to the original grant commitment; in such cases a transfer has been made to retained reserves to back-fill the original payments.

The following funds are held related to research:

Gene Therapy Research – funds available for gene therapy related activity.
General medical research – where the donor did not specify a particular research grant award.
- Matched against selected Strategic Research Centres.
- Matched against selected Venture Innovation Awards.
- Matched against selected Clinical Excellence and Innovation Awards.

Sport England funded work – A project at Exeter University: Helping the active stay active.
CF Circle of Care – Providing accessible and personalised in formation on life expectancy in cystic fibrosis for use in clinic and to enhance reporting from the UK CF Registry.
Genotyping 600 study – funding the work required to add to the CF Registry any cystic fibrosis patients who do not currently have their genotypes recorded on the registry.
Genetic Repair/Editing – funds received for work relating to genetic editing related research.
Other research related restricted funds – including funding for grants to individuals for cystic fibrosis related summer student projects or travel to cystic fibrosis related conferences.

Continued on next page

17a. Funds (continued)

- **Restricted funds related to information and support:** Donations relating various activities supporting people with cystic fibrosis and their families.

The following funds are held related to Information and Support:

EW Joseph/Homecare grants – funding the promotion of increased care at home rather than in hospital for people with CF, and improvements in home care by education. See comments about the corresponding endowment fund below.
Joseph Levy/Education grants – funding people with cystic fibrosis in their educational studies. See comments about the corresponding endowment fund below.
Young Lives Programme – funding a youth porgramme supporting young people with cystic fibrosis. This fund is supported by Children In Need.
Support Services – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
CF Connect Youth/Parents – funding for projects to provide peer to peer telephone support service for young people with cystic fibrosis, and parents of children newly diagnosed with cystic fibrosis.

- **Other restricted funds:**
  Coombe Hill – funding education about cystic fibrosis.
  Kings College Hospital Award – funding the development of the cystic fibrosis centre at Kings College Hospital. The funds have now been accesed in full and work is in progress to refurbish the CF Adult Unit at the Kings College Hospital.
  Paediatrics – funding work in the paediatrics department at the Royal Brompton Hospital, including peer reviews.
  Vertex Everest Trip – funding an awareness-raising and fundraising trip to climb Mount Everest by a person with cystic fibrosis.
  SmartcareCF – funding the development of the SmartcareCF platform, including both adult and paediatric study.
  Clinical Trials Accelerator Platform – funding this flagship programme.
  Digital Health Research Programme – funding this flagship programme, in collaboration with Cambridge University and Papworth Hospital, on digital health monitoring.

- **Endowment funds:** The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.
  The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.
  The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home (see EW Joseph/Homecare Grants above).
  The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education (see J Levy/Education Grants above).
  The Sally Wrigley Memorial Fund.

Transfers between funds – the following transfers were made between funds:
- A transfer was made between the Appeal Innovation Hub at Cambridge and the Appeal Deficit Innovation Hub at Cambridge.
- A transfer was made to the Fixed Asset Reserve to match against the current balance on Fixed Assets.
- The balance of the Strategic Reserve was moved into Retained Reserves.
- Some transfers were made between Retained Reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been back-filled by restricted donations.

17b. Prior year fund movements

	Balance 31 March 2018 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance** **31 March 2019** **£'000**
Fixed asset reserve	131	-	-	-	(91)	40
Appeal deficit: Innovation Hub at Cambridge	(1,864)	-	-	-	558	(1,306)
Strategic reserve	371	-	-	-	(371)	-
Total Designated Reserves	**(1,362)**	**-**	**-**	**-**	**96**	**(1,266)**
Operating reserve	3,575	-	-	-	(182)	3,393
Retained reserves	2,785	44	14,595	(14,156)	1,692	4,960
Total General Reserves	**6,361**	**44**	**14,595**	**(14,156)**	**1,510**	**8,353**
Total Unrestricted Funds	**4,998**	**44**	**14,595**	**(14,156)**	**1,510**	**7,087**
Restricted Income Funds						
Appeal for Innovation Hub at Cambridge	-	-	558	-	(558)	-
Restricted funds related to research:						
Gene Therapy Research	-	-	47	21	(68)	-
General Medical Research	-	-	239	(239)	-	-
Imperial College SRC: Pseudomonal infection	-	-	2	-	(2)	-
UCL SRC: Personalised Engineered Cell Therapies	-	-	39	-	(39)	-
Exeter SRC: Activity & Exercise	-	-	35	-	(35)	-
Sport England – Helping the Active Stay Active	-	-	52	(43)	-	9
Project Breathe	-	-	150	(150)	-	-
Glasgow Clinical Excellence and Innovation: story telling podcast	-	-	8	-	(8)	-
Liverpool SRC: luminal fluidity in the gut	-	-	748	-	(748)	-
Genotyping – 600 Study	105	-	-	-	(105)	-
Imperial SRC: *Pseudomonas aeruginosa*	-	-	32	-	(32)	-
Newcastle SRC: Alternative Chloride Channels	-	-	1	-	(1)	-
Cambridge RSDF: Advanced analytics	-	-	10	-	(10)	-
Life Expectancy Project	-	-	76	(71)	-	5
Transition Information Resources	-	-	15	-	-	15
Venture Innovation Award programme general	-	-	10	(10)	-	-
Other research related restricted funds	16	-	11	(19)	1	9
Total funds related to research	**121**	**-**	**2,034**	**(511)**	**(1,606)**	**38**

Continued on next page

17b. Prior year fund movements (continued)

	Balance 31 March 2018 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2019 £'000**
Restricted funds related to Information & Support:						
E W Joseph/Homecare grants	**60**	-	8	(6)	-	62
Joseph Levy/Education Grants	10	-	35	(57)	-	(12)
Support services (inc. welfare grants)	33	-	326	(240)	-	119
CF Connect (youth and parents)	26	-	-	-	-	26
Total funds related to Information & Support	**129**	**-**	**369**	**(303)**	**-**	**195**
Other funds – various categories:						
Coombe Hill	10	-	30	-	-	40
Kings Fund	157	-	-	-	-	157
Paediatrics	4	-	-	-	-	4
Vertex – Everest trip	-	-	-	-	-	-
SmartCareCF	-	-	25	(35)	-	(10)
Clinical Trials Accelerator Programme	-	-	693	(693)	-	-
North Midlands – medical equipment	1	-	-	-	-	1
Old funds – various	1	-	23	(32)	-	(8)
Total funds – various categories	**173**	**-**	**771**	**(760)**	**-**	**184**
Total Other Restricted Reserves	**423**	**-**	**3,174**	**(1,574)**	**(1,606)**	**417**
Total Restricted Reserves	**423**	**-**	**3,174**	**(1,574)**	**(1,606)**	**417**
Endowment Funds:						
Ena Bennie Endowment	537	(11)	-	(4)	-	522
EW Joseph Endowment	178	**(4)**	-	(1)	-	173
Joseph Levy Endowment	307	**(7)**	-	(3)	-	297
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other endowment funds 3	35	-	-	-	-	35
Total endowment funds	**1,077**	**(22)**	**-**	**(8)**	**-**	**1,047**
Total charity funds	**6,498**	**22**	**17,769**	**(15,738)**	**-**	**8,551**

18. Prior year Consolidated Statement of Financial Activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2019 £'000**	**Total Funds** 2018 £'000
Income and endowments from:						
Donations and legacies	2	12,903	3,151	-	**16,054**	12,754
Other trading activities	12	1,321	-	-	**1,321**	1,830
Investments	2b,6	250	23	-	**273**	242
Other income:						
Fixed asset disposals gain	6	-	-	-	**-**	-
Other income	2	121	-	-	**121**	343
Total		14,595	3,174	-	**17,769**	15,169
Expenditure on:						
Raising funds	3	3,513	-	4	**3,517**	3,915
Charitable activities						
Research		4,237	457	1	**4,695**	6,096
Clinical care	3	992	812	-	**1,804**	1,443
Information, advice & support		5,414	305	3	**5,722**	6,191
Total charitable activities		10,643	1,574	4	**12,221**	13,730
Total resources expended	3	14,156	1,574	8	**15,738**	17,645
Net income/(expenditure) before investment gains/losses		**439**	**1,600**	**(8)**	**2,031**	(2,476)
Realised investment gains/(losses)		-	-	-	**-**	4
Unrealised investment gains/(losses)		44	-	(22)	**(22)**	(16)
Net investment gains/(losses)		**44**	**-**	**(22)**	**22**	(12)
Net (expenditure) income		**483**	**1,600**	**(30)**	**2,053**	(2,488)
Transfers between funds	17a	1,606	(1,606)	-	**-**	-
Net movement in funds		2,089	(6)	(30)	**2,053**	(2,488)
Reconciliation of funds:						
Total funds brought forward		4,998	423	1,077	**6,498**	8,986
Total funds carried forward	17a	**7,087**	**417**	**1,047**	**8,551**	6,498

Structure, governance and management

Patron
- HRH The Prince of Wales KG KT GCB OM

Honorary President
- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees
Chairman
- Richard Hunt

- Caroline Cartellieri Karlsen[1] (resigned September 2019)
- David Turner QC[1] (resigned September 2019)
- Professor Andrew Jones
- Michael Winehouse[1]
- Louise King[1]
- Ffyona Dawber
- Professor Rosalind Smyth
- Sean Collins
- Anne Byrne
- Richard Hoey
- David Titmuss
- Michelle Shaw[1] (appointed September 2019)
- Joanna Barret[1] (appointed September 2019)

Finance Committee
Chairman
- Sean Collins

- David Turner QC (resigned September 2019)
- Anne Byrne
- Stephen Mullen (Independent Member)[1] (resigned October 2019)
- David Sawer (Independent member)
- Ed Rushton (Investments Committee)
- Nick Wood (Investments Committee)
- Anne Byrne
- Michelle Shaw[1] (appointed September 2019)

People Committe
Chairman
- Richard Hunt

- Ffyona Dawber
- Louise King
- Michael Winehouse
- Michelle Shaw[1] (appointed September 2019)
- Joanna Barrett[1] (appointed September 2019)

Charity Management
- David Ramsden – Chief Executive
- Louise Honeysett FCA —Director of Finance and Resources
- Dr Janet Allen MD FRSE – Director of Strategic Innovation
- Dr Keith Brownlee – Director of Policy, Programmes & Support
- Anne Shinkwin – Director of Fundraising
- Oli Lewington – Director of Marketing & Communications
- Rebecca Cosgriff – Director of Data & Quality Improvement
- Dr Lucy Allen - Director of Research

Company Secretary
- Louise Honeysett FCA —Director of Finance and Resources

Principal and Registered Office
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Company registration number: 3880213
Charity registration number:
England & Wales —1079049
Scotland —SC040196

Auditors
Haysmacintyre LLP
10 Queen Street Place, London EC4R 1AG

Bankers
Natwest Plc
15 Bishopsgate London EC2N 3NW

Investment Managers
Cazenove Capital Management
12 Moorgate London EC2R 6DA

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[1] Indicates either person with cystic fibrosis, carer or close relative of someone with cystic fibrosis.

>Recruitment, induction and training of Trustees

Trustees consider the relevant skill-set required to enable effective oversight and proper governance of the organisation. New Trustees are appointed after a rigorous recruitment process which includes advertising in the national press and on the basis of recommendation.

Upon appointment to the Board, in order to help facilitate their understanding of the current issues concerning the organisation, each new Trustee is provided with specific tailored information and opportunities are also provided for the new Trustee to meet with the Chair and Chief Executive, as well as meeting staff working within their own area of specialism.

>Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Charity to the Chief Executive, David Ramsden and his Senior Leadership Team (SLT).

The Chief Executive and the SLT report to the Board both formally at the Board meetings and informally (as appropriate) throughout the year, thereby ensuring a regular flow of information to aid decision making.

The remuneration of key management personnel is determined by a recognised job evaluation framework taking into account the skills required and the complexity of individual roles. The process, including the award of annual pay uplift, is overseen by the Remuneration Panel made up of Trustees and chaired by the Chairman of the Trust .

>Public benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. In reviewing our aims, objectives and planning future activities, the Trustees have taken into account the Charity Commission's general guidance on public benefit. The Trustees ensure that activities undertaken are always in line with the charitable objectives and aims of the Cystic Fibrosis Trust.

>Legal structure

Cystic Fibrosis Trust ('the Trust') is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1964 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

The Board of Trustees ('the Board') has full legal responsibility for corporate governance and all operations of the Trust including determining the strategic direction for the Trust.

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 12 Trustees with a range of skills. Several committees such as the Finance and Audit Committee, Nomination and Development Committee, Strategic Advisory Board, Strategic Implementation Board and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Cystic Fibrosis Trust

cysticfibrosis.org.uk