Cystic Fibrosis why we're here

Cystic Fibrosis Trust
Annual Report and Financial Statements

For the year ended 31 March 2019

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

Fighting for a Life Unlimited

Contents

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2019.

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 50 and 51 also form part of the Trustees' report.

Chairman's Statement

I am delighted to present the Cystic Fibrosis Trust's annual report for 2018/19 in my first year as Chairman of the Board of Trustees.

Firstly, I would like to pay tribute to my predecessor Mr George Jenkins who was in post for the initial months of the Trust year and who did so much during his period of office to refocus the organisation and put in place the many initiatives which are now key features of the Trust's strategy. Thank you George.

Since joining the Trust last July I have been inspired, not just by its work on a daily basis, but by the passion of the whole CF community and I look forward to playing my part in helping to lead the Trust through what could be a time of huge potential.

Our fight for access to life-saving drugs has seen increased momentum over the last year including, for example, a well reported demonstration outside the Houses of Parliament, spearheaded by our tireless community, and an inquiry by the Health and Social Care Committee alongside activity in Scotland, Northern Ireland and Wales. We will continue to raise the profile of this need for access to medicines which have already been licensed (as well as those in the drugs pipeline), recognising that progress by decision makers is not as fast as it could be. We won't stop making the case and fighting for it until these transformational drugs are available to improve the lives and outlook for all those who desperately need them.

However the fight for access to medicines across the UK is just one part of a broader battle. We are continuing to fund vital basic research to better understand dangerous infections and develop more effective treatments. In addition we are continuing with the programme of work for our Clinical Trials Accelerator Platform which provides both the infrastructure and information to enable the CF community to have the earliest possible availability of the 'breakthrough' CF medicines being developed.

We know too that people with CF need support now, as well as in the future, consequently we continue to lend a hand to them and their families when they need it most through our grants programme, our helpline and through the expertise and advice of our Welfare and Rights Advisor. We also know that there are still people we have not yet reached who would benefit from these services and where we need to make further progress.

For the second year, the median predicted survival for people with CF is 47. This reflects how far we have come since the days when CF cut short most lives in childhood. That people with CF are living longer is a terrific achievement but we are still way short of where we want to be: a life unlimited. Lives with less burden of treatment. A better and wider understanding of what CF means that can lead to more influence on policy and decision makers. An aspiration shared by everyone which means that people with CF are able to live well and make their contribution to society to the same age as those without the condition.

We have had a strong financial performance this year, and are grateful to all those who contributed to this result through donations or fundraising activities on our behalf. Our total income exceeded expectations and our retained reserves have increased. However, we view a number of our gifts as exceptional and know that we must take a long term view with the management of our finances, balancing our commitment to research and other services with the need for financial sustainability.

For example, we have continued to fundraise for the £2 million commitment to our Innovation Hub in Cambridge, accounted for in the previous year, and will continue to regularly monitor financial performance before making any substantial commitments through any of our grant programmes.

One of the key roles of the Chairman is to work with the Board and the staff team to identify and manage the key risks that the Trust faces. We know that we are in uncertain economic times, which could impact on our ability to raise funds in future periods. Other vital issues, such as safeguarding and data protection, must be at the heart of our thoughts and actions. The principal risks and uncertainties that we have identified are set out in more detail on page 25 of this report.

With the help of the CF community – whether raising funds or raising its voice – we will continue to make progress. Though nothing is certain I do believe that we could soon be at the forefront of huge changes for this condition and further benefits for those who live with it every day!

Finally my thanks to all our team for their work and commitment over this past year.

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 2017 UK Cystic Fibrosis Registry Report, the median predicted survival for people with CF in the UK remains at 47 for a second year, however, the median age of death is just 31.

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 and 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

This year, we launched our new five-year strategy, titled 'Putting the person into personalised medicine'. Thanks to the success of our previous strategy, we are now well-positioned to increase our strategic investments through the development of strong partnerships with other external funders and the industrial sectors (including biopharmaceutical, biotechnology and health technology).

This will allow us to use new approaches in our research to promote our strategic priorities noted above.

The 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 a life unlimited.

>Our research investments

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

Governance for funding research at the Trust is overseen by two principal committees, the Research Strategy Implementation Board (SIB) and the Research Strategy Advisory Board (SAB). Applications for research grants 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 through all stages of life.

The SIB committee met in January to complete the review process of the Strategic Research Centres.

Strategic Research Centres (SRCs)

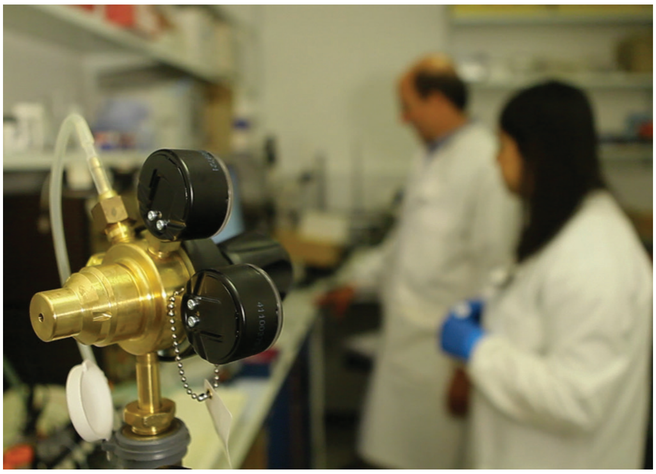
These virtual centres of excellence bring together researchers from within and outside of the field of CF, supporting scientists and other specialists around the world to work together to address specific issues arising from cystic fibrosis.

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 outside the traditional biomedical disciplines and attract high-quality investigators from new research fields; and
- recruit the brightest and best young researchers into CF research.

Each SRC 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, which 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.

We pledged £2.25 million to fund three new SRCs, as well as continuing to fund the ongoing work of 11 existing SRCs.



New SRCs

1. Gas, food and lodging; understanding the physiological and metabolic requirements of Pseudomonas aeruginosa in the cystic fibrosis airways.

Lead Investigator: Dr Martin Welch (Cambridge, UK)

Co-Investigators: Professor Soren Mölin (Denmark), Professor Helle Krogh Johansen (Denmark), Professor Susanne Häußler (Germany), Dr Dieter Jahn (Germany), Pablo Nikel (Denmark), Professor Marvin Whiteley (USA).

Pseudomonas aeruginosa is the most common bacteria involved in chronic CF airway infections and is consistently named as a top concern for people with the condition, as it causes loss of lung function and impaired quality of life. This research aims to thoroughly investigate why it is that these bacteria are so 'at home' within the lungs of people affected by CF, including exploration of the nutrients they use, the way they use them and if there are any weak points in these biochemical pathways that could be exploited to find an effective treatment.

2. Mucociliary clearance – from fundamentals to personalised treatment

Lead Investigator: Professor Pietro Cicuta (Cambridge UK, Physics of Medicine, Cavendish Laboratory)

Co-Investigators: Professor Ludovic Vallier (Cambridge), Professor Scott Randell (USA, UNC), Dr Charles Haworth (Cambridge), Professor Gerald Fuller (USA, Stanford)

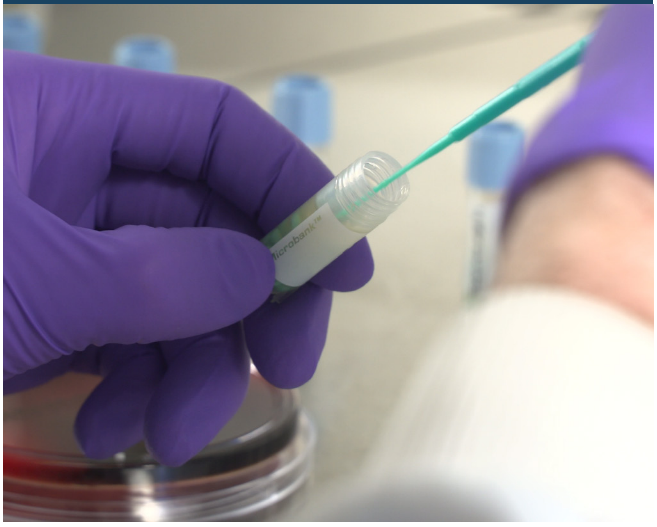
The build-up of sputum in the airways that causes infection, inflammation and lung damage is a key problem faced by people with cystic fibrosis. This SRC aims to investigate how the hairs (cilia) lining the airways work, and how genes other than CFTR influence their behaviour, with the hope of paving the way for new treatments and better detection of individuals at risk of rapid lung damage. It is also hoped that this research will shed light on why two individuals with the same CF mutations may experience such different clinical journeys.

3. Targeting immunotherapy for fungal infections in cystic fibrosis (TrIFIC)

Lead Investigator: Dr Darius Armstrong-James (Imperial College)

Co-Investigators: Professor Stuart Elborn, Professor Adilia Warris (Aberdeen), Dr Alexander Horsley (Manchester), Dr Frank van der Veerdonk (Netherlands), Dr Stuart Levitz (USA), Professor Rosemary Boyton (Imperial College)

Aspergillus fumigatus is a fungus found in the sputum of half of people with CF by the time they reach adulthood. It can cause severe infection and allergic reactions, even preventing individuals from being eligible for a lung transplant. This SRC aims to investigate whether immunotherapies, which have been used successfully in severe fungal infections, could be useful for treating these fungal infections, and which people with CF will be most likely to benefit if they are.



>Existing SRCs

The Trust continued the administration and monitoring of 11 existing SRCs spanning a range of topics of benefit to the whole CF community. **SRCs 1-3 have drawn to a close.**

4. CF-EpiNet: Harnessing data to improve lives

5. Investigating the F508del-CFTR protein

6. Personalised engineered cell therapies for cystic fibrosis

7. Cystic fibrosis-related diabetes research

8. Physical activity, exercise, sport and recreation promotion for adolescents with cystic fibrosis

9. Targeting joint disease in CF: identifying therapeutic targets in CF arthropathy

10. The impact of gut dysbiosis on lung inflammation in cystic fibrosis

11. Restoring fluidity in the gut

12. Novel therapies for *Mycobacterium abscessus*

13. Restoring airway function in CF using alternative chloride channels

14. Personalised approach to *Pseudomonas aeruginosa* (PAPA)

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 and gain additional funds for potentially transformational opportunities.

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 2018/19 we committed £606,285 to fund 14 new VIA projects, two of which are still subject to successful peer review. The estimated external leverage will total around £3.7 million (raising £6 for every £1 spent by the Trust).

These new projects focus on tackling infection, lung repair, the use of advanced analytics to improve the lives of people with CF, and much more.

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

UK Cystic Fibrosis Innovation Hub

We are now moving into the second year of the Trust's commitment to the first UK Cystic Fibrosis Innovation Hub, based at the University of Cambridge. The focus of the Hub is 'Healthy Lungs', and it has four workstreams:

1. **Pulmonary infection and inflammation**
   a) Novel approaches to developing new antimicrobial drugs to beat antimicrobial resistance
   b) Use of novel anti-inflammatories and pro-resolution therapeutics to reduce lung scarring following infection
2. **Predicting pulmonary exacerbations**
3. **Regenerative medicine using induced pluripotent stem cells**
4. **Developing a national research infrastructure to support active CF-researchers across the whole of the UK**

To support the first two years of activity the Trust committed to raising £2 million, with an aspiration to raise a further £3 million to support three further years of activity. Every pound of this funding will be matched by the University of Cambridge.

We are delighted that we have already raised over £1.41 million to support our initial commitment through the generosity of AJN Steelstock, the Robert Luff Foundation and individuals. In this first year, the Independent Scientific Advisory Board (ISAB) was formed and met, reviewing progress and advising on the best use of funding. The board includes leaders from the pharmaceutical industry and academia. They praised both the quality of the research and the rate of progress. The ISAB also made recommendations on how to support active CF researchers across the country.

Developing and supporting talent

We continued our commitment to supporting the next generation of scientists by giving £10,000 to support seven Summer Studentships in partnership with the British Lung Foundation. This scheme gives medical and basic science students experience working on world-class research relating to CF or lung health in general.

> CF's Got Talent!

Our 'CF's got Talent!' initiative sees promising early-career researchers, who are funded by the Trust, share a lay summary of their work with the live UKCFC audience and the CF community via video link. The winning presentation is then voted for by viewers at home.

In 2018, for the first time, the presentations were developed in collaboration with members of the CF community, giving people with CF an opportunity to learn more about the research, while allowing the researchers the rare opportunity to find out more about life with the condition they are investigating.

This year the winner was Afroditi Avgerinou, with her talk about investigating gene editing for treating lung disease in all forms of cystic fibrosis as part of a project led by Professor Stephen Hart at University College London. Her prize is a trip to the North America Cystic Fibrosis Conference – the largest CF conference in the world.

The 'live' online audience of 850 people was supplemented by a further 2,127 people who watched 'CF's Got Talent!' later. This is an increase from the 500 views of last year's on-demand videos, and feedback for the event was very good.

'CF's got Talent!' was funded by Gilead Sciences.

Research Innovation Workshop

Research Innovation Workshops (formerly 'research sandpits') aim to develop cross-disciplinary thinking in areas of future importance to people with cystic fibrosis. Any research generated by these discussions is intended to deliver outcomes in a minimum of four years, often longer. In light of the increasing number of people with CF living long past 40 years of age, the topic of co-morbidities (such as cancer, cardiovascular disease and diabetes) is becoming more pressing. The November 2018 workshop therefore focussed on CF and colorectal cancer (CRC), due to its elevated prevalence in people with cystic fibrosis. Representatives of Cancer Research UK and Bowel Cancer UK assisted in the selection of participants for the workshop and attended it as observers.

Outcomes include funding being set aside for research into this issue, increased awareness and interest in CF from the CRC research and clinical community, five grants awarded to scope substantial potential research programmes in this area, a new research proposal submitted to Cancer Research UK and a focus on CRC in the call for new SRC proposals.

Research Strategy Development Fund

This £250,000 fund was established to promote research with strategic importance where matched funds may or may not be available, such as the grants awarded following the research innovation workshop.

CF Syndicate in Antimicrobial Resistance

Antimicrobial resistance (AMR) is a growing concern, not just for people with CF, but for the entire population, and the NHS and the UK government have highlighted it as an urgent priority. Our new CF Syndicate in AMR, in partnership with the Medicine's Discovery Catapult, will aim to accelerate the availability of new antibiotic treatments in clinic.

To fund its research, the Syndicate will engage strategically with government and funders to leverage funds that will support the long-term delivery of the Syndicate. The Syndicate may also apply for relevant grants from national and international funding bodies.

Quality of care

We are dedicated to supporting specialist CF clinicians and helping ensure people with CF receive the best possible care. Our advance-care planning work launched this year and has had over 130 registrations, with the supporting documents downloaded over 600 times. We have also published the results of qualitative research to understand the challenges that young people with CF face.

>Clinical Fellowships for doctors and physiotherapists

The Trust's Clinical Fellowship programme has sponsored dozens of clinicians to specialise in CF care, providing specialist adult CF centres with a one-year grant to train physicians in the management of cystic fibrosis. This year, we have committed to sponsor one clinical fellow and one physiotherapy fellow.

SmartCareCF

The adult and paediatric (Climb-CF) remote monitoring studies have both completed their data-collection phase. These studies explore the possibility of using technology to monitor CF symptoms at home. The paediatric data set will be analysed using machine-learning algorithms developed during analysis of the adult dataset. We have submitted three abstracts, related to learnings from Climb-CF, to the European CF Society June 2019 meeting.

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 care team. This year saw the completion of two drug safety studies using Registry data, with three studies ongoing. These studies have generated an income of £2 million, a significant proportion of which is 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 2018/19 the Registry approved 30 requests for data, bringing the total up to 350.

CF START, a trial looking at antibiotic-prescribing methods in babies with CF, is progressing well, with over 130 people recruited across 67 study sites. As part of the Trust-funded CF-EpiNet SRC, we have securely linked data with the Welsh data safe-haven 'SAIL', which will allow researchers to analyse Registry data alongside information about wider healthcare utilisation for people with CF living in Wales. Work is ongoing to achieve similar linkage across the UK.

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. 100% of attendees who completed an evaluation form rated the meeting good, very good or excellent.

> **We were the first CF Registry in the world to publish its Annual Data Report for 2017, and also provided an accessible 'at-a-glance' summary of infographics highlighting the main trends for that period, helping people with CF and their families to understand the data contained in the report.**

We submitted anonymised 2017 data to the European Cystic Fibrosis Society Patient Registry, which published its reports here: www.ecfs.eu/projects/ecfs-patient-registry.

Access to medicines

We are committed to doing all we can to support access to medicines at every step from laboratory to medicine cabinet. This is involves investing in the cutting-edge research noted above, ensuring rapid access to clinical trials and campaigning for new drugs to be funded.

Clinical Trials Accelerator Platform

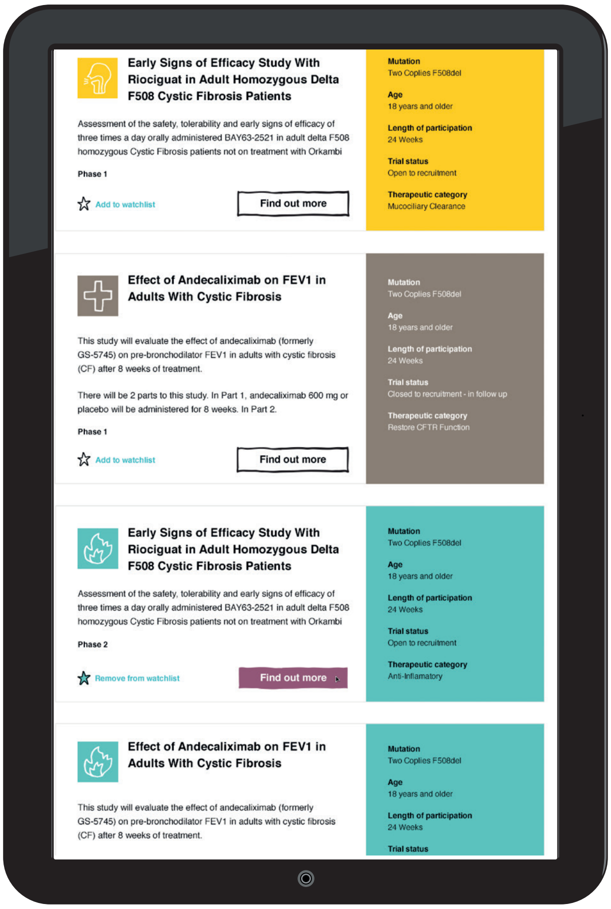
This was the first year that the Trials Accelerator was fully operational, and we saw significant progress in each of the four workstreams: the network of centres, sponsor engagement, public and patient involvement (PPI), and the Clinical Trials Digital Hub. All 20 Trials Accelerator centres opened, capturing data such as trial set-up times and recruitment and retention rates, in order to measure the success of the programme.

In the first six months of complete metric capture, the time each set-up metric takes has decreased. For example, the average time from a study opening at a Trials Accelerator centre to the first participant enrolling decreased from 7.8 weeks to 6.3 weeks, highlighting how Trials Accelerator coordinators are directly and significantly increasing the speed at which trials are set up at Trials Accelerator centres. These coordinators also increase trial activity, with increasingly high screening and enrolment rates seen at Trials Accelerator centres; during a six-month period, 250 people with CF were screened at such centres, and 151 of those enrolled onto a trial. This takes the total number of people with CF screened since launch (September 2017) to 438.

The sponsor engagement workstream has engaged with 19 clinical trial sponsors (17 pharmaceutical companies and two academic institutes), and 13 of those used the Feasibility Service, which helps sponsors ensure the best-placed centres are selected for trial delivery.

The PPI groups returned over 50 responses to sponsors. Requests to the groups included review of two commercial trial protocols, where robust feedback on trial design was given from the perspective of a person with CF to help sponsors improve the experiences of trial participants. All of the sponsors who engaged with these groups strongly agreed that involving CF representatives was worthwhile and improved the design of their trial.

The Clinical Trials Digital Hub launched on the Trust's website and has been well received by the CF community. In the 18 months since launch, the Hub has been visited 8,973 times and the Trials Tracker database has been visited 8,664 times. These statistics demonstrate that the Trust had 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.



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 Coplies 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 Coplies 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 Coplies 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 Coplies F508del
Age
18 years and older
Length of participation
24 Weeks
Trial status

> **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

This year, the voices of the over 10,500 people with cystic fibrosis, and their families and friends, have been louder than ever. Our campaign for access to life-saving drugs is currently one of the biggest political issues in health, and has warranted the involvement of the Secretary of State for Health, Health Ministers in each of the devolved nations and Prime Minister Theresa May. While there is still no routine access to Orkambi and Symkevi, we have demanded urgent agreement to end the crisis, alongside long-term reform to ensure it is never repeated.

In December 2018, we saw a breakthrough as the Scottish First Minister, Nicola Sturgeon, announced her government had agreed an arrangement with manufacturer, Vertex Pharmaceuticals, which paves the way for the medicines to become available to Scottish people with cystic fibrosis. We are keeping up the pressure to see these words fulfilled.

Talks between NHS England, Vertex, the National Institute for Health and Care Excellence (NICE) and the Secretary of State for Health have started, fallen apart, and restarted again. Meanwhile, we have built enduring and credible cross-party support in Parliament, amplifying the voices of people with cystic fibrosis in order to engage with 230 MPs and a total of 250 parliamentarians from across the political spectrum, an increase of more than double the MP engagement from 2017/18. This campaigning base is robust and resilient to political change, ensuring the durability of our campaign.

We have built and engaged a broad campaigner base through large live-streamed community events across the country and regular social media and email updates. We have also built long-lasting relationships and engagement with our most involved campaigners through focused meetings and 1:1 coaching to upskill them, creating a network of community leaders.

Twenty members of our community were invited to the Trust's parliamentary event marking three years since Orkambi was licensed, and the event was attended by over 60 supportive MPs.

We led many community actions across the year, including e-actions, contact with constituent parliamentarians and a letter-writing campaign resulting in over 1,000 handwritten letters delivered to Downing Street.

In May 2018, the Trust first met with Dr Sarah Wollaston MP, Chair of the Health and Social Care Committee, and in November 2018 this influential committee announced an inquiry into the availability of Orkambi and other CF medicines on the NHS. In March 2019, the Committee's investigation held an evidence session which summoned top officials from NHS England, NICE and Vertex. With our support, over 300 campaigners submitted their personal testimony to the inquiry, and over 200 stood alongside us and demonstrated outside the Houses of Parliament on the day of the evidence session.

The involvement of top executives has resulted in a strong increase in media and political pressure on the issue and invoked their personal responsibility to find a solution.

This year, we welcomed three Health Ministers (Secretary of State Matt Hancock in Westminster, Minister for Health and Social Services Vaughan Gething AM in Wales, and Cabinet Secretary for Health and Sport Jeane Freeman MSP in Scotland) to the campaign, representing the highest level of political involvement. We began to look beyond resolution of the immediate crisis of access to CF medicines, towards long-term reform. Since 2015, we have called for interim or managed access to CF medicines using the UK CF Registry.

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. By 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

We provided over 950 welfare grants, totalling £265,000, 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. Our welfare grants programme includes small emergency grants, transplant grants (to help with the cost of the assessment process and recovery), health and wellbeing grants, and holiday grants for over 18s and funeral grants.

> **In addition, we were able to provide £8,000 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 were delighted to run the Helen Barrett Bright Ideas Awards again this year, awarding £10,000 in total, split between eight successful applicants. The awards support people with CF to take a step forwards into self-employment, supporting them to achieve their ambitions while also being able to fit work around their health. This year, successful Bright Ideas included print making, personalised chalkboards, and health and beauty businesses.

We spent £56,231 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 an increase in enquiries from specialist CF social workers this year has enabled us to broaden our reach. Our adviser has supported 356 people with the provision of welfare advice this year. Personal Independence Payment (PIP) remains a key focus of the service, and this year we have seen an increase in queries relating to Universal Credit.

In the financial year 2018–19, the Cystic Fibrosis Trust helped people to access at least...

£1.1 million

in benefits.

Our service has secured over £1.1 million in benefits income for people with CF this year alone. We also continue to offer a benefits advice service in Northern Ireland through a specialist partnership, providing expert advice to navigate the benefits system in Northern Ireland.

>Information

This year, we have built on our extensive information library with a suite of leaflets on both physiotherapy and nutrition, developed in collaboration with specialist CF clinicians. These resources are now being widely used in CF centres, both in hard copy format and as downloads. In addition, we have been progressing the development of specialist resources on the transition to adult CF care, and body image, both of which will be launched in 2019/20.

>Helpline

This year our helpline responded to over 3,300 enquiries from people affected by CF, providing information, support and a listening ear on a wide range of topics. Around 60% of enquiries were received by email, and 40% 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 has continued to put parents of children with CF in touch via phone or email with others who have experience of the issues they are going through.

>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, and has also provided feedback on a number of Trust-wide activities.

YAG 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. 18 young people have actively participated in workshops this year, with an additional 600+ online video views. A recent 'gaming night' saw over 170 young people join online, providing the opportunity to safely 'meet' others who have cystic fibrosis.

Reaching all people

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

This year, we obtained almost 2,000 pieces of news coverage, worth almost £7 million in advertising value and reaching an aggregate audience of around 676 million people. Highlights include:

- 149 pieces of national print coverage across all outlets (Guardian, Times, Daily Telegraph, Express, Daily Mail, Mirror, Sun, Metro).
- 250 pieces of broadcast coverage (national and regional) worth £2.1 million and reaching an aggregate audience of 97 million people.
- These figures include extensive coverage of all aspects of our work and campaigns and included coverage on all major broadcasters.

>Social media
In terms of reach, our most successful piece of social media content was a video featuring Becky Whitfield, which we shared on Boxing Day 2018. Becky is the mother of Elle, who featured in our fundraising campaigns, most notably our 2016 'Be A Star' Christmas campaign. Sadly, Elle died in early 2018 and this video was made to highlight the upcoming first anniversary of her death and Becky's continual fundraising in her memory. We are very grateful to Becky, and others like her, who share their stories to spread the word about CF and support the Trust.

Our continued fight for life-saving drugs was our most significant topic over the year. Our biggest year-on-year audience increase has been on Instagram, which has grown by 61%, thanks to increased efforts to engage with our younger audience through specific content and activities such as takeovers by members of the CF community, highlights of creative work and working more closely with third-party influencers.

Although Facebook and Twitter are growing at a slower rate, we are still increasing our following at twice (Facebook) and three-times (Twitter) the average rate. With audiences of 87,000 and 25,000 respectively, we are reaching an expected 'plateau' and our focus is now on engaging with our existing followers.

>CF Week and Wear Yellow Day 2018

Leading up to CF Week, we increased our following and engagement on Instagram by building relationships with popular influencers who agreed to post their ‘Style It Yellow’ outfits on Wear Yellow Day, resulting in 31,640 engagement actions (comments, likes and shares).

Wear Yellow Day was our highest-performing day of CF Week across all channels, with more than 70,000 impressions on Twitter, nearly 2,000 views on LinkedIn and a reach of nearly 12,000 on Instagram.

>Celebrity strategy

During this period, we have developed a new celebrity strategy, which will be implemented in 2019. The strategy aims to attract more celebrities and increase the impact of the work our celebrity ambassadors do for the Trust.

>UK Cystic Fibrosis Conference (UKCFC)

Our annual flagship event continues to be the UK’s largest event devoted to the care and treatment of cystic fibrosis. The 2018 conference took place over two days at the International Convention Centre in Birmingham, and brought together more than 500 healthcare professionals, researchers and other leading experts from around the world.

The first day focussed on the latest developments in the therapeutic pipeline and personalised medicine, with speakers from both academic and clinical backgrounds sharing their latest research. We were delighted to hold another ‘CF’s Got Talent!’ as reported in the Research section.

The second day was streamed live online for all those affected by CF, focussing on the future of care and access to new medicines.

There were over 1,400 live streams of the conference, with online audiences predominantly based in the UK, but also reaching as far afield as Chile, Pakistan, America, South Africa and Macedonia.

>Community involvement

We involved 630 people affected by CF in our activities during the year, in projects such as the Clinical Trials Accelerator Platform, the development of our information resources and sharing stories to help us engage with the community and the public in general.

We exist for our community, and for us to help people with CF and their families achieve a Life Unlimited they must be at the heart of everything we do. Over the past year we have worked hard to increase that involvement and while the Trust-wide Involvement Group set up last year has been dormant, it’s clear to see that the groundwork it laid has inspired greater involvement across multiple streams of our work.

Communicating with supporters

We continue work to improve our website, with a focus on improving the user experience for those looking for information and support. The move towards improving, and personalising communications, particularly through email, is allowing us to offer a unique supporter experience and to better support and engage with our community.

This includes tailored emails and adapting the content and message of emails to specific demographic or psychographic groups.

Our supporting activity

Delivering our strategic priorities means that we have to ensure that we are a well-run and effective organisation and critically that we are generating the funding to support our ambitions.

Developing an effective organisation

Our integrated delivery-management framework, introduced during 2018, helps to give greater certainty over our delivery of the operational plan, which focusses on making the most difference we can across a number of areas affecting people with CF: access to medicines, information and support, the development of and involvement in cutting-edge research and the quality of the day-to-day care they receive. Underpinning this plan are the key pillars of 'We are all great fundraisers' and 'We are a great organisation'.

We are continuing to engage employees more fully with our values:

- We are champions for the cause
- We are respectful
- We are collaborative
- We are professional
- We are focussed and driven

This year, we introduced a new employee recognition scheme based on exemplifying these values, and a new sabbatical policy for staff who have been at the Trust for more than three years; three staff have so far benefited from this.

We monitor key measures such as staff turnover, sickness absence, staff with personal development plans and our benefits, and these have remained comparable with other similar organisations. We also ran a staff attitude survey during the year, which will become an annual event. There were encouraging responses in areas such as knowledge of cystic fibrosis, how individuals' roles contribute to our mission, pride felt about working at the Trust, flexible working arrangements and commitment to equality and diversity and employee health, safety and wellbeing. Less positive areas, which we have subsequently been working to improve, included having up-to-date job descriptions and personal development plans.

Unfortunately, as a result of these changes, seven employees left the Trust on the grounds of redundancy and overall headcount was reduced by four.

We have also introduced a new management leadership and development programme that will reach all managers over the coming year.

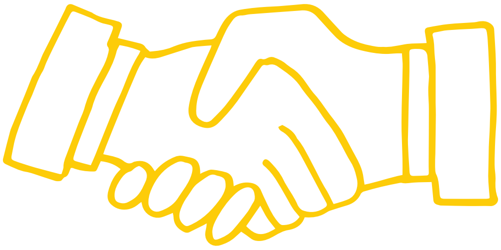
>Volunteering

The Trust values the vital contribution our volunteers continue to make to our vision of a Life Unlimited for everyone affected by cystic fibrosis. Without their support and commitment, we wouldn't be able to make such a difference, particularly in running events that bring the community together and raise much-needed funds.

As part of the wider organisational restructure, there have been changes to the staffing team supporting volunteering and we are putting in place processes to provide more direct and personal support to volunteers and the managers of the areas they are contributing to, building on the guidance resources that are available.

We are improving our ability to match business needs with volunteering offers and doing less 'just-in-case' recruitment as a result of feedback from volunteers themselves. Volunteers at events continue to be vital for us, with around 100 involved supporting the fantastic people running on behalf of the Trust at our biggest annual fundraising event, the Virgin Money London Marathon.

In total we have nearly 200 registered volunteers and hundreds of fundraising volunteers.



>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 46 complaints in 2018–19, down from 50 in 2017-18, although up from the 36 in 2016-17. 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 the 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 and 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**

Thanks to the extraordinary generosity of our supporters, in 2018-19 we have had our most successful fundraising year ever, raising over £12.1 million, an increase of £3.4 million from the 2017–18 financial year.

This fantastic achievement enables the Trust to have an even greater impact on the lives of people with cystic fibrosis. This has been driven by growth across all fundraising areas, in particular from legacies (which accounted for 29% of our total income) and major donors.

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.

>Gifts in wills

We received news of 77 supporters who had generously included a gift in their will for the Trust. 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.

>Fundraising events and activities

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

The Virgin Money London Marathon, our biggest fundraising event of the year, raised £390,000. The second most popular event is the Great North Run, which has a total of 388 runners raising £121,000.

Our 'Wear Yellow Day' campaign during CF Week continues to grow in popularity and saw the number of community events increase from 127 to 157 events, generating an income of over £41,000, 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 cystic fibrosis. The #CFYelfie component of the day raised over £9,000.

This year, our Christmas campaign asked, 'Who's Your Reason?', highlighting a personal story and our fight for access to medicines. The campaign has raised over £200,000 thanks to the fantastic support it has received.

Both the Trust and the CF community work tirelessly to come up with innovative fundraising initiatives. This year, working in collaboration with supporter Steven Taylor, who walked from Land's End to John o' Groats, and working with fundraising platform Everyday Hero, the Trust set up the Great Strides virtual trek, which proved a popular way to include people with CF as there is no risk of cross-infection. It also attracted people who can't necessarily take a day out of their routine to complete a challenge event all in one go – for example, new parents with a child with cystic fibrosis.

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

We would like to express our thanks to our loyal regular monthly donors who provide invaluable ongoing support that allows us to plan effectively for the future. We currently have approximately 5,000 people supporting us in this way, and raised £868,000 in 2018/19 (including Gift Aid).

The Trust used Ethicall for telephone fundraising in October. Their policy is to ensure that all donors are treated with respect and dignity. If they feel that a call is to a vulnerable person, then it is turned into a thank-you call, or a quality control call is made following any agreement, to check complete understanding. This campaign led to a pledged income of around £8,840 in the first 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, and BBC Children in Need and The Queen's Trust, which supports our work with young people, and Sport England. In addition, we have worked with generous individuals who are long-standing supporters of our work, including an individual with a close connection to the cause who gave an extraordinary six-figure donation.

We have received generous pledges for the Innovation Hub from AJN Steelstock, the Robert Luff Foundation and generous individuals, totalling £1.41 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 2018.

A number of high-profile balls took place this year including events organised by the Cardiff and Vale Branch, Pembrokeshire Branch, Life Unlimited Ball and 65 Roses Ball, with over £300,000 raised from gala events. We also received a very generous donation from Tim Cross and the J Van Mars Foundation.

>Corporate partnerships

The Trust continues to work in partnership with companies including Bird & Bird and Proxima to raise funds and awareness of CF, as well as to maximise pro bono and gift-in-kind opportunities.

This year, we were delighted to secure new partnerships with Madison Brook and Redsquid, who will be supporting us during 2019, and LendInvest who, among others, are raising funds towards the Innovation Hub. Corporate Partnerships will be a key area of growth for the Trust as we continue working to secure multi-year relationships with companies.

We also saw continued support from the pharmaceutical industry for UKCFC, securing £72,000 in sponsorship for the event.

Any commercial activities where the Trust benefits from the sale of products operate with a written agreement, funds proceed through Cystic Fibrosis Services Limited and are monitored closely.

>Celebrity support

Celebrity supporter James Dunmore and five friends took on their Kilimanjaro Trek as part of the 2018 Resolutions campaign, raising in excess of £35,000. The Resolutions campaign this year had a heroes theme, and continues to inspire signups for events and activities taking place throughout the year. Many events run by the Trust or its supporters saw an increase in value and participation this year.

James Dunmore

During CF Week in June 2018, we delivered a Radio 4 charity appeal, read by our celebrity ambassador Jenny Agutter. The appeal raised both funds and awareness of CF among a new audience.

Plans for the future

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

>Research and innovation

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.

In 2019 we will hold UKCFC in London for the first time, and focus on the tremendous progress that had been made in the last 30 years. We will aim to continue the trend of increasing our engagement with the online community as well as the physical audience.

>Quality of care

We will continue to support CF clinicians in delivering the best care possible with our fellowship programmes, by updating and adding to our consensus documents and with quality-improvement initiatives. We will position ourselves to support people with CF in the additional challenges they will face in the future, such as growing older, mental health issues and gaining and maintaining employment.

The UK CF Registry will publish a special edition of the annual report for the European Cystic Fibrosis Conference. A new Registry dashboard will be launched, allowing clinical teams to monitor the care they provide and the quality of their data, as well as offering a way to share Registry data with people with cystic fibrosis.

The Quality Improvement team will also work closely with care teams to collect 'patient-reported experience measure' data across the UK in order to monitor and improve the quality of care received by people with cystic fibrosis. The UK CF Registry will be presenting three posters at the 2019 European Cystic Fibrosis Society Conference. One demonstrates the ability of the Registry to measure the burden of treatment for people with cystic fibrosis. The second shows that updates to Registry software have led to an improvement in the timeliness of Annual Reviews. The third one reports on the latest programme of data validation visits, which have shown that key information on the Registry is accurate in 99% of cases.

>Access to medicines

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

The Clinical Trials Accelerator Platform will focus on optimising the inclusivity of the programme by planning expansions to the network of centres. The reputation of the programme has led to new centres wishing to sign up, which would help bring trial opportunities to more of the UK CF community. We will also 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, an increasingly important challenge given the UK's current political climate.

>Day to day support

We will build on the findings from a qualitative research project to continue a detailed scoping exercise to ensure we're best supporting people with CF with our information and support services in key areas such as older adulthood and mental health. We'll develop resources and services based on clearly defined needs and develop a solid evidence base for future work. Alongside this we will continue to expand and promote our existing services, ensuring we can reach everyone with CF – particularly 'harder to reach' groups. We also plan to update our suite of clinical guidelines to support best practice in CF clinical care, and produce new guidelines in key areas such as palliative care and mental health.

>Reaching all people with cystic fibrosis

We will continue to find novel ways to involve people affected by CF in our work, with a focus on the areas where involvement has shown the biggest impact. This includes audience research, product and message testing and development and sharing their stories in our campaigns.

Our Youth Advisory Group will continue to help us shape a relevant youth work programme that responds to the changing needs of young people with CF as they navigate the challenges of adolescence.

We will develop a suite of targeted health information resources for young people, as well as further developing our resources to help support young people with CF in understanding and accessing clinical trials.

>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 are also focusing on increasing engagement in our flagship activities such as CF Week, Great Strides™, Christmas and Resolutions while offering a diverse and exciting event portfolio. Increasing the number of people who have pledged to leave a gift in their will is a key element in enabling future fundraising growth.

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

We will be forging stronger relationships with our core supporters like Jenny Agutter and Roger Black and garnering new support from high-profile celebrities for a more impactful celebrity offering in the future. Over the forthcoming year we will be increasing our focus on enhancing our supporters' experiences with the Trust. We will be looking at developing new and innovative approaches to our fundraising and improving our website to make donating easier.

One initiative has been to run a series of regional Information Evenings, giving the CF community the opportunity to hear the latest from the world of CF and the Cystic Fibrosis Trust from a panel of Trust staff, researchers and local CF clinicians and see the impact of their fundraising support.

Jenny Agutter

>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. We will ensure we're at the top of our game by continuing the people management and leadership programme, addressing issues raised in the staff survey and introducing a mental health first aid programme for employees.

The way we support volunteers and their managers will also be under continuous review and improvement.

Financial review

Income

The Trust's income from normal activities for the year to March 2019 was £17.8million, an increase of 17% over the previous year.

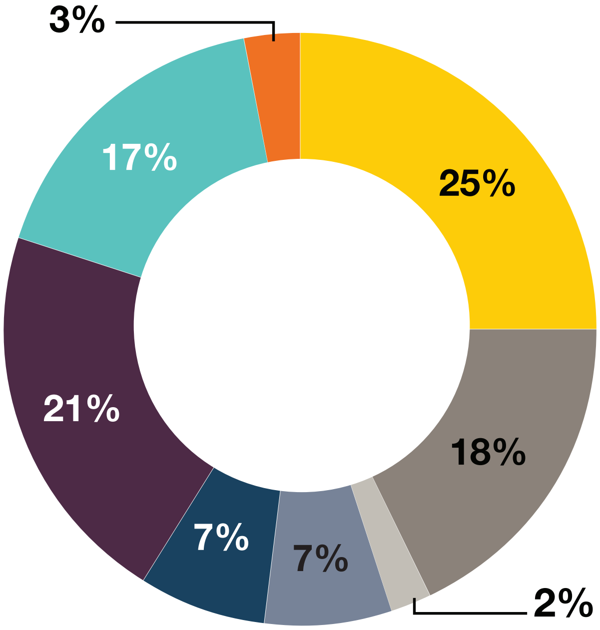
91% of the Trust's total income is made up of donations and legacies, totalling £16.1million, (2017/18 – £12.8m). This percentage is 7% higher than in the previous year, with the increase driven by a number of generous gifts from donors and through gifts in wills. Donation income was again boosted by a non-monetary donation of digital advertising space, which was worth £3.0 million (2016/17 – £3.5m).

Total donations and legacies excluding the donation in kind were £13.1m (2017/18 – £9.3m). 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 £4.4m, which represents 33% of the total (2017/18 – 48%).

Income from Corporate Partnerships and Trusts each grew by just over a third during the year. Legacy income more than doubled, driven by several large gifts in wills, and accounted for 29% of the total (2017/18 – 13%).

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £1.3m (2017/18 – £1.8m). There were 3 (2017/18 – 4) long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year. A multi year study module contract with a pharmaceutical company ended during the year. We continue to actively seek new contracts in this area.

> 2018/19 income by income stream



Income from normal activities:	£'000
Branches, groups & community	4,366
Regular and individual giving and appeals	3,137
Corporate partnerships	373
Trusts	1,339
Cystic Fibrosis Services Limited	1,321
Legacies	3,745
Donated goods and services	2,962
Other income	526
Total income from normal activities	**17,769**

Expenditure

The Trust’s total expenditure for the year was £15.7m, an 11% decrease compared to the previous year. The largest area of spend was on charitable activities at £12.2m (2017/18 – 13.7m), accounting for 78% of total spend. This comprises programmes of research, information, advice and support and clinical care.

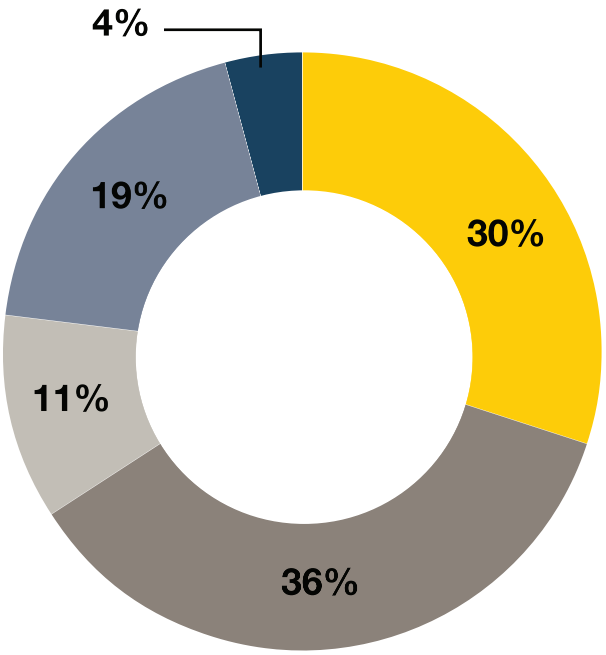
The remainder was spent on activities for generating funds, including £0.6m paid to NHS cystic fibrosis clinical centres across the UK to support the resources necessary to add patient data to the CF Registry.

Total grant commitments in the year were £4.6m (2017/18 – £5.7m), of which £4.3m (2017/18 – £5.3m) were committed to a range of institutions, including £2.3m committed for three Strategic Research Centres (2017/18 – £1.5m for two Centres). The remaining £0.4m (2017/18 – £0.4m) was committed to individuals through our ongoing Welfare Grants progamme.

The Clinical Trial Accelerator Platform flagship programme developed throughout the year, with total spend £0.7m (2017/18 – £0.3m), and we continue to receive significant investment from the CF Foundation in the US, with whom we are working in partnership on this programme.

The overall surplus of £2.1m in the year exceeded expectations. This will partly be used to backfill the deficit that arose in the previous year following a £2.0m commitment to the Innovation Hub at Cambridge, and otherwise will be carried forward within Retained Reserves and enable continued activity in key strategic areas.

2018/19 expenditure by cost type



Expenditure:	**£’000**
Research	4,695
Information, advice & support	5,722
Clinical Care	1,804
Charitable activities total	**12,221**
Costs of raising funds	2,927
Cystic Fibrosis Services Limited	590
Total expenditure	**15,738**

- ■ **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 increased by £0.1 million in the year (2017/18: increase of £0.1 million); a 2% rise in value. Income generated on investments totalled £0.2million, while realised and unrealised losses on the investment portfolio totalled £0.01 million.

>Reserves

The Trust's reserves as at 31 March 2019 totalled £8,552,000 (2018 – £6,498,000). 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 (£40,000) 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 £0.7 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 (£3,393,000) 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

- Operating reserve – held at a value (£3,575,000) 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 – (£4,961,000) 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 are expected to be utilised through a managed spend programme over the next 36 months.

- Restricted income funds – (£417,000) 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.

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 2018/19 the Trials Accelerator feasibility service was utilised for 11 clinical trials, generating an income of £18,500 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 2018/19 the protocol review service was utilised by two pharmaceutical companies, generating an income of £18,500.

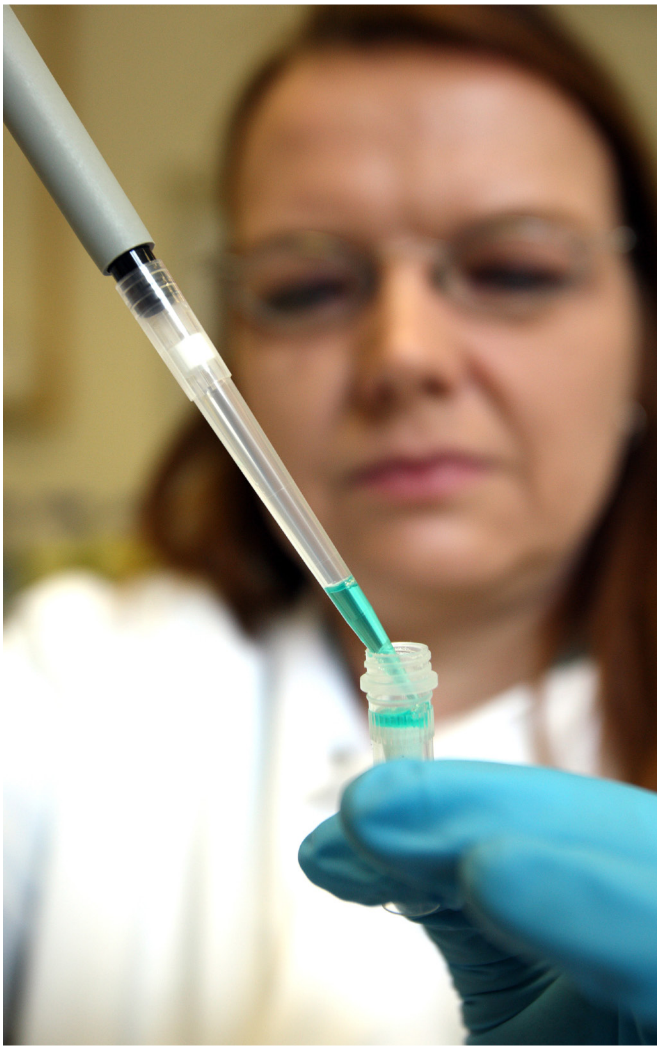
>The UK Cystic Fibrosis Registry
Long-term studies of drugs available to people with CF across the UK are conducted by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the Regulator of medicinal products is covered by pharmaceutical companies holding the Market Authorisation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

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

In 2018/19 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £1.3 million in fees for this service. There were four long-term commercial contracts for Phase IV pharmacovigilance 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.

On average, for every pound spent by the Trust to fund a VIA, an additional four pounds is leveraged. In 2018/19 we invested in two new research projects with Diagnostig Ltd and Owlstone Medical Ltd which leveraged an additional £208,000.



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 2018/19, we received £51,755 to help pay for the costs of the UK Cystic Fibrosis Conference and would like to thank the following pharmaceutical companies: Chiesi, Galapagos, Gilead, Proteostasis and Vertex.

In 2018/19 we also received a Vertex Circle of Care award of £76,052 for a project to provide accessible and personalised information on life expectancy in CF for use in clinic and to enhance reporting from the UK CF Registry.

>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 **16 August 2019** 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 2019 which comprise the Consolidated Statement of Financial Activities, Consolidated Income and Expenditure Accounts, Group and Charity Balance Sheets, Consolidated Cashflow Statement 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 2019 and of the group'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 28, 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 16 August 2019

10 Queen Street Place,
London
EC4R 1AG

> Consolidated statement of financial activities

For the year ended 31 March 2019

	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 expenditure	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**

All of the operations are continuing. There were no recognised gains or losses other than those stated above.

The notes on pages 31 to 55 form part of these financial statements.

> Consolidated income and expenditure account

For the year ended 31 March 2019

	All income funds **2019** **£'000**	All income funds 2018 £'000
Income	**17,496**	14,928
Gains/(losses) on investments	**44**	(19)
Investment income	**273**	242
Gross income in the reporting period	**17,813**	15,151
Expenditure	**15,599**	17,317
Interest payable	**-**	-
Depreciation and charges for impairment of fixed assets	**131**	320
Total expenditure in the reporting period	**15,730**	17,637
Net income before tax for the reporting period	**2,083**	(2,486)
Tax payable	**-**	-
Net Income for the financial year	**2,083**	(2,486)

The Consolidated Summary Income and Expenditure Account is derived from the Statement of Financial Activities on page 31 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 35 to 55 form part of these financial statements.

> Consolidated and charity balance sheets

As at 31 March 2019

		Consolidated		Charity	
	Notes	**Total 2019 £'000**	Total 2018 £'000	**Total 2019 £'000**	Total 2018 £'000
Fixed assets					
Tangible assests	5	**40**	132	**40**	132
Investments	6	**6,031**	5,904	**6,031**	5,904
		6,071	6,036	**6,071**	6,036
Current assets					
Debtors	7	**2,313**	1,757	**2,177**	1,750
Cash held as short term investment		**11,414**	11,351	**11,414**	11,351
Cash at bank and in hand		**2,517**	1,078	**1,981**	1,075
		16,244	14,186	**15,572**	14,176
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	9	**(5,805)**	(7,276)	(5,805)	(7,276)
Creditors and accrued charges	10	**(1,261)**	(1,119)	(1,255)	(1,109)
		(7,066)	(8,395)	**(7,060)**	(8,385)
Net current assets		**9,178**	5,791	**8,512**	5,791
Creditors: amounts falling due after one year					
Grants payable	9	**(6,698)**	(5,329)	(6,698)	(5,329)
Total net assets		**8,551**	6,498	**7,885**	6,498
The funds of the charity					
Endowment funds	17a	**1,047**	1,077	**1,047**	1,077
Restricted income funds	17a	**417**	423	**417**	423
Unrestricted funds					
Designated reserves	17a	(1,266)	(1,363)	(1,266)	(1,363)
Operating reserves		3,393	3,575	3,393	3,575
Retained reserves		4,960	2,786	4,294	2,786
Total charity funds		**8,551**	6,498	**7,885**	6,498

The notes on pages 35 to 55 form part of these financial statements.

The net movement in funds for the Trust for the year ended 31 March 2019 was £2,053,000 (2018: 12 months – £2,488,000). 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 **16 August 2019** and signed on their behalf by:

Richard Hunt, Chairman

Company number 3880213

Cystic Fibrosis Trust

> Consolidated Statement of cash flows

As at 31 March 2019

	2019 **£'000**	2018 £'000
Net cash provided by (used in) operating activities (Note A)	**1,373**	1,277
Cash flows from investing activities:		
Dividends and interest	**273**	242
Purchase of property, plant and equipment	**(39)**	(2)
Purchase of investments	**60**	(983)
Movement in cash awaiting investment	**(165)**	(1,344)
Proceeds of sales of investments	**-**	2,235
	129	148
Increase/(decrease) in cash held as short term investments	**(63)**	(43)
Increase/(decrease) in cash (Note B)	**1,439**	1,172

Notes to Cash Flow Statement

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

	2019 **£'000**	2018 £'000
Net (expenditure)/income for the reporting period (as per the statement of financial activities)	**2,053**	(2,488)
Adjustment for:		
Fixed asset disposal gain	**-**	-
Depreciation charges	**131**	321
Dividends and interest from investments	**(273)**	(242)
(Gains)/losses on investments	**(22)**	13
Decrease/(increase) in debtors	**(556)**	453
Increase/(decrease) in creditors	**40**	1,572
	1,373	(1,277)

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

	2019 **£'000**	2018 £'000
Cash and cash equivalents at the beginning of the reporting period	**12,429**	13,558
Change in cash and cash equivalents in the reporting period	**1,439**	(1,172)
Increase in short-term investments	**63**	43
Cash and cash equivalents at the end of the reporting period	**13,931**	12,429
(being cash at bank and in hand and cash held as short-term investments)		

	2019	2018
Analysis of cash and cash equivalents:	**£'000**	£'000
Cash on hand	**2,517**	1,078
Notice deposits (less than 3 months)	**11,414**	11,351
Total cash and cash equivalents	**13,931**	12,429

Cystic Fibrosis Trust

> Notes to the Financial Statements

For the year ended 31 March 2019

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 56. 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 surplus for the parent charity was £2,053,000 (2018 – deficit of £2,448,000).

The subsidiary's net surplus of £609,000 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 £1,000 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.

2a. Income from donations and legacies

	Unrestricted Funds 2019 £'000	Restricted Funds 2019 £'000	**Total 2019 £'000**	Unrestricted Funds 2018 £'000	Restricted Funds 2018 £'000	**Total 2018 £'000**
Branches, Groups & Community	3,972	102	**4,074**	4,062	62	4,124
Legacies	3,470	260	**3,730**	1,351	149	1,500
Individual donations	159	872	**1,031**	242	70	312
Corporate	212	160	**372**	269	1	270
Regular giving and appeals	1,233	45	**1,278**	1,146	47	1,193
Trusts	182	1,157	**1,339**	113	876	989
Appeal for Innovation Hub	-	555	**555**	-	126	126
Donations in kind	2,962	-	**2,962**	3,491	-	3,491
Gift Aid	581	-	**581**	614	-	614
NHS National Services England	89	-	**89**	89	-	89
NHS National Services Scotland	43	-	**43**	46	-	46
Total income from donations and legacies	12,903	3,151	**16,054**	11,423	1,331	12,754

Donations In Kind refer to non-monetary donations received from partner organisations. In 2018/19 £2,962,000 was donated in the form of digital and cinema advertising space (2017/18: £3,491,000). 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 2019 £'000	Restricted Funds 2019 £'000	**Total 2019 £'000**	Unrestricted Funds 2018 £'000	Restricted Funds 2018 £'000	**Total 2018 £'000**
Income from listed investments	217	23	**240**	154	25	179
Bank interest	33	-	**33**	63	-	63
Total investment income	250	23	**273**	217	25	242

3a. Expenditure

Total costs – current 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**
	1,710	2,917	8,771	2,340	**15,738**

Analysis of allocated Support Costs – current 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**

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 2018 £'000**
Raising funds					
Fundraising	-	-	2,599	458	**3,057**
Trading and merchandising	-	799	59	-	**858**
Charitable activities					
Research	1,074	3,117	991	914	**6,096**
Clinical care	142	212	873	216	**1,443**
Information, advice & support	196	178	4,889	928	**6,191**
	1,412	4,306	9,411	2,516	**17,645**

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 2018 £'000**
Fundraising	84	77	120	54	123	**458**
Research	168	153	239	108	245	**913**
Clinical care	40	36	57	26	58	**217**
Information, advice & support	171	155	243	109	250	**928**
Governance	-	-	-	-	-	**-**
Total costs	463	421	659	297	676	**2,516**

3a. Expenditure (continued)

Net (expenditure)/income in the year:

	2019 **£'000**	2018 £'000
Auditors remuneration excluding VAT	**20**	20
Auditors – tax advice	**4**	38
Depreciation	**131**	320
Operating leases – building	**244**	244
Operating leases – other	**6**	6
Trustees' travel expenses	**2**	2

3b. Grants

Grants were awarded during the year as follows:

	2019 **£'000**	2018 £'000
Grants to institutions	**4,270**	5,344
Grants to individuals	**357**	374
	4,627	5,718

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.

	2019 **£'000**	2018 £'000
Balance at start of year	12,605	10,832
Awarded in the year	4,627	5,719
Paid in year	(4,729)	(3,946)
Balance at end of year	12,503	12,605
Falling due within one year (note 9)	5,805	7,276
Falling due after more than one year (note 9)	6,698	5,329

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

	2019 **£'000**	2018 £'000
University of Cambridge/Papworth Hospital	1,525	2,065
Imperial College, London/Royal Brompton Hospital	875	999
Magic Bullet (with Cambridge and Microsoft)	150	50
University of Oxford	115	-
University College London	100	65
Manchester University/Wythenshaw Hospital	84	47
University of Sheffield	70	75
London School Of Tropical and Hygiene Medicine	65	-
Queens University Belfast	65	15
University of Exeter	52	55
Action Medical Research	52	90
Nottingham University	50	-
University of Edinburgh	49	-
Owlstone Medical Limited	36	-
Queen's Medical Centre	35	-
ECFS – European Cystic Fibrosis Society	21	21

3b. Grants (continued)

	2019 **£'000**	2018 £'000
School of Chemistry Bangor	20	-
MDC	20	-
Leeds University	10	-
Kings College	10	-
Queen Elizabeth University Hospital, Glasgow	2	-
University of Portsmouth	2	-
Ninewells Hospital and Medical School	2	-
King's College	-	-
University of Dundee	-	2
AMRC	-	9
Neem Biotech	-	100
University College Cork	-	42
James Lind Alliance/Queen's Medical Centre Nottingham	-	15
University of Newcastle/Newcastle Hospital	-	752
	3,410	**4,402**
Add: Trial Coordinator commitments made to CTAP centres (see note)	466	143
Add: Registry support grants made to various CF centres	543	799
Less: Release of grants made in previous years (see note)	-149	
Total grants made to institutions	**4,270**	5,344

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 second year of funding.

Various grants totalling £149,000 were released during the 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:

	2019 **£'000**	2018 £'000
Salaries	**3,998**	4,019
Redundancy and other termination payments	**87**	18
Temporary Staff	**240**	97
Social security costs	**421**	428
Other pension costs	**232**	240
	4,978	4,802

Redundancy and other termination payments totalling £87,000 were paid to 9 (2018 – £18,000 paid to 4) staff members in the year. This follows an organisation-wide review of the staff base to better align resources with the current strategic plan and ensure all teams have the most appropriate structures in place to work effectively and meet objectives.

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 £232,000 (2018 – £240,000).

Analysis of total average monthly headcount by category:

	2019 **No.**	2018 No.
Research	**11**	11
Clinical care	**6**	6
Information, advice & support	**35**	36
Fundraising	**38**	40
Management	**6**	7
Finance	**5**	5
IT and project management support	**6**	6
HR & OD	**2**	4
Facilities	**2**	2
Total average monthly headcount	**111**	**117**

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

	2019 **No.**	2018 No.
£60,001 – £70,000	2	2
£70,001 – £80,000	2	2
£80,001 – £90,000	1	1
£90,001 – £100,000	-	-
£110,001 – £120,000	1	1

Pension contributions to defined contribution pension schemes for these employees totalled £32,029 (2018 – £31,127).

Remuneration of key management personnel: The total remuneration paid to key management personnel, including pension and social security contributions, was £579,329 which relates to 6 individuals who served on the Senior Leadership Team during the year (2018 – £549,000 paid to 7 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. Expenses of £2134 (2018 – £1,720) were settled on 4 (2018 – 4) trustees. A welfare grant of £350 was paid to 1 Trustee (2018 – Nil) who has 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 2018	**630**	**793**	**243**	**403**	**183**	**2,252**
Additions	-	39	-	-	-	39
At 31 March 2019	**630**	**832**	**243**	**403**	**183**	**2,291**
Depreciation						
At 31 March 2018	**615**	**771**	**243**	**308**	**183**	**2,120**
Charge for the year	15	22	-	94	-	131
At 31 March 2019	**630**	**793**	**243**	**402**	**183**	**2,251**
Net book value at 31 March 2019	**-**	**39**	**-**	**1**	**-**	**40**
Net book value at 31 March 2018	15	22	-	95	-	132

6. Investments

Group and Charity	**Total 2019 £'000**	Total 2018 £'000
Market value as at 31 March 2018	**5,904**	5,826
Additions at cost	**(60)**	985
Disposals at opening book value	**-**	(2,235)
Net gains/(losses) on investments	**22**	(17)
	5,866	4,559
Change in cash	**165**	1,345
Market value as at 31 March 2019	**6,031**	5,904

6. Investments (continued)

Represented by:	**Total 2019 £'000**	Total 2018 £'000
Equities	**2,540**	2,475
Fixed Interest and multi-asset funds	**1,012**	1,011
Property	**852**	835
Cash	**1,627**	1,583
	6,031	**5,904**

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 2019. These make up more than 5% of total investments:

	Total 2019 £'000
Schroder Chartity Equity fund	**601**
Schroder QEP Global	**824**
Trojan Income fund	**211**
Charity Equity Income Fund	**395**
Charity Bond Fund/Rathbone Ethical Fund	**322**
Charities property fund	**223**
Property income trust for charities	**291**
Ruffer charity assets Trust	**479**
Cystic Fibrosis General Fund	**1,266**

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 2019 £'000	Group 2018 £'000	**Charity 2019 £'000**	Charity 2018 £'000
Trade debtors	**218**	393	**-**	-
Amount due from subsidiary undertaking	**-**	-	**82**	386
Prepayments and accrued income	**1,953**	1,247	**1,953**	1,247
Other debtors	**142**	117	**142**	117
	2,313	1,757	**2,177**	1,750

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

	2019 £'000	2018 £'000
Grant creditor at 31 March 2018	**12,605**	10,832
Grants paid during the year	**(4,728)**	(3,943)
Grants approved before 31 March 2019 and payable within one year	**2,023**	2,564
Grants approved before 31 March 2019 and payable after one year	**2,603**	3,152
Grant creditor at 31 March 2019	**12,963**	**12,605**
Represented by		
Grants due within one year at 31 March 2019	**5,805**	7,276
Grants due > 12 months	**6,698**	5,329
	12,503	12,605

10. Creditors

	Group 2019 £'000	Group 2018 £'000	Charity 2019 £'000	Charity 2018 £'000
Trade creditors	**802**	357	**800**	349
Other creditors	**123**	245	**123**	245
Accruals and deferred income	**336**	517	**334**	515
	1,261	**1,119**	**1,255**	**1,109**

11. Financial Instruments (Assets and Liabilities)

	Group 2019 £'000	Group 2018 £'000	Charity 2019 £'000	Charity 2018 £'000
Financial assets measured at amortised cost (note a)	**14,222**	12,880	**14,222**	12,880
Financial assets measured at fair value (note b)	**6,031**	5,904	**6,031**	5,904
Financial liabilities measured at amortised cost (note c)	**(14,110)**	(13,600)	**(14,110)**	(13,600)
Net financial assets measured at amortised cost	**6,142**	5,184	**6,142**	5,184

(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 2019 £'000	Total 2018 £'000
Sales and sundry income	**1,321**	1,830
Cost of sales and administration	**(590)**	(858)
Intercompany recharges	**(65)**	(72)
Net contribution to parent charity	**666**	900

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

	Total 2019 £	Total 2018 £
Current Assets		
Debtors	**217,182**	393,351
Cash at bank	**535,192**	2,331
	752,374	395,682
Creditors: amounts falling due within one year	**(86,633)**	(395,680)
Net Current Assets	**665,741**	2
Net Assets	**665,741**	2
Capital and Reserves		
Called up share capital	**2**	2
Profit and loss account	**-**	-
Shareholder's funds	**2**	2

The charity owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd, which comprises 100 ordinary shares of £1 each. 2 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 2019, the Trust's future minimum operating leases payments relating to buildings were:

	2019 £'000	2018 £'000
Within one year	**271**	**271**
Between two and five years	**-**	**271**

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.

At 31 March 2019, the Trust's future minimum operating leases payments relating to equipment were:

	2019 £'000	2018 £'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 £52,409 (2018- £34,022). In addition two of the trustees (2018- 2) were involved in fundraising activities carried out by regional fundraising branches. One Trustee (2019 – Nil) who has cystic fibrosis received a £350 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	**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

Prior year funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2018** **£'000**
Tangible fixed assets	132	-	-	132
Investments	4,827	1,077	-	5,904
Current assets	13,763	-	423	14,186
Internal obligations	-	-	-	-
Current liabilities	(8,395)	-	-	(8,395)
Liabilities due in more than one year	(5,329)	-	-	(5,329)
	4,998	1,077	423	6,498

> Notes to the Financial Statements (continued)

For the year ended 31 March 2019

17a. Current 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)**	**1,606**	**7,087**
Restricted Income Funds:						
Appeal: 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)	-
Cambridge SRC: Mycobacterium abscessus infection	-	-	-	-	-	-
Newcastle SRC: INOVCF-Innovative non-CF-TR Approaches	-	-	-	-	-	-
Bristol SRC: F508del0CFTR	-	-	-	-	-	-
UCL SRC: Personalised Engineered Cell Therapies	-	-	39	-	(39)	-
UCL VIA:Prenatal diagnosis for autosomal recessive conditions	-	-	-	-	-	-
Liverpool VIA: CF Start	-	-	-	-	-	-
Leeds Clinical Excellence & Innovation: youth worker	-	-	-	-	-	-
Imperial College VIA: Antibacterial activity of Glatiramer acetate	-	-	-	-	-	-
Newcastle SRC: Mycobacterium abscessus infection	-	-	-	-	-	-
Uni of Cork VIA: Crispr	-	-	-	-	-	-
Frimley Park, Clinical Excellence & Innovation: Exercise	-	-	-	-	-	-
Exeter SRC: Activity & Exercise	-	-	35	-	(35)	-
Manchester Clinical Excellence & Innovation: Exercise & Nutrition	-	-	-	-	-	-
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)	-
Newcastle SRC: Diabetes	-	-	-	-	-	-

Continued on next page

17a. Current year fund movements (continued)

Genotyping – 600 Study		105	-	-	-	(105)	-
Genetics Repair/Editing		-	-	-	-	-	-
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**
Restricted funds related to information and support							
E W Joseph/Homecare grants		60	-	8	(6)	-	62
Joseph Levy/Education Grants		10	-	35	(57)	21	(12)
Support services (including 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		-	-	-	-	-	-
SmartCare CF		-	-	25	(35)	-	(10)
Clinical Trials Accelerator Programme (CTAP)		-	-	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
Robert Couper Endowment		-	-	-	-	-	-
Sally Wrigley Memorial Fund		20	-	-	-	-	20
Other Endowment funds	3	35	-	-	-	-	35
Total Endowment Funds		**1,077**	**(22)**	**-**	**(8)**	**-**	**1,047**
Total Funds		**6,498**	**22**	**17,769**	**(15,738)**	**-**	**8,551**

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 £0.7m from donors in funding for this grant (shown in the separate restricted fund line, see below) as well as a further £0.6 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.

The designated strategic reserve has been reduced to zero during the year and has been absorbed into the Retained Reserves balance going forward.

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 £0.7m 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.

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> Notes to the Financial Statements (continued)

For the year ended 31 March 2018

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.
Sailing Fund – funding sailing related holidays for people with cystic fibrosis; in 2017 the Trust received permission from the original donor to repurpose this fund towards holidays in general, as part of the welfare grants programme
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. These funds were previously committed to the hospital, however they were released back in 2015-16 as the hospital had not been able to spend them according to the original grant agreement. The Trust is now working cloesly with the hospital to find an alternative use of these funds.
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
North Midlands, medical equipment – a legacy donation received by the Cystic Fibrosis Trust which was resrticted to medical equipment in the North Midlands region.

- **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 following its merger with the Lawrence Levy Foundation. Income arising is restricted to funding education (see J Levy/Education Grants above)
The Sally Wrigley Memorial Fund was established in 2013 from a legacy from the estate of Mrs Mary Wrigley. Income arising is unrestricted.

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 2017 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2018 £'000**
Fixed asset reserve	450	-	-	-	(319)	131
Appeal deficit: Innovation Hub at Cambridge	-	-	-	-	(1,864)	(1,864)
Strategic reserve	1,394	-	-	-	(1,023)	371
Total Designated Reserves	**1,844**	**-**	**-**	**-**	**(3,206)**	**(1,362)**
Operating reserve	3,523	-	-	-	52	3,575
Retained reserves	2,061	(18)	13,813	(16,610)	3,539	2,785
Total General Reserves	**5,584**	**(18)**	**13,813**	**(16,610)**	**3,591**	**6,360**
Total Unrestricted Funds	**7,428**	**(18)**	**13,813**	**(16,610)**	**385**	**4,998**
Restricted Income Funds						
Appeal for Innovation Hub at Cambridge	-	-	136	(136)	-	-
Restricted funds related to research:						
Gene Therapy Research	-	-	54	-	(54)	-
General Medical Research	-	-	75	(75)	-	-
Imperial College SRC: Pseudomonal infection	-	-	61	-	(61)	-
Cambridge SRC: Mycobacterium abscessus infection	-	-	75	-	(75)	-
Newcastle SRC: INOVCF-Innovative non-CFTR Approaches	-	-	-	-	-	-
Bristol SRC: F508del0CFTR	-	-	-	-	-	-
UCL SRC: Personalised Engineered Cell Therapies	-	-	113	-	(113)	-
UCL VIA: Prenatal diagnosis for autosomal recessive conditions	-	-	5	-	(5)	-
Kevin Southern VIA: CF Start	-	-	-	-	-	-
Tim Lee (Leeds) Clinical Excellence & Innovation: youth worker	-	-	17	-	(17)	-
Imperial College VIA: Antibacterial activity of Glatiramer acetate	-	-	-	-	-	-
M Gray, Newcastle Uni SRC: Mycobacterium abscessus infection	-	-	-	-	-	-
P Harrison, Uni of Cork VIA011, Crispr	-	-	10	-	(10)	-
FA Higton, Frimley Park, CEA006 Exercise	-	-	9	-	(9)	-
C Williams, Exeter, SRC008 Activity & Exercise	-	-	15	-	(15)	-
A Jones, Manchester, CEA004 Exercise & Nutrition	-	-	5	-	(5)	-
Sport England – Helping the Active Stay Active	-	-	53	(53)	-	-
J Shaw, Newcastle Uni SRC: Diabetes	-	-	2	-	(2)	-
Genotyping – 600 Study	117	-	-	(12)	-	105
Genetics Repair/Editing	20	-	-	-	(20)	-
Other research related restricted funds	26	-	2	(12)	-	16
Total funds related to research	**163**	**-**	**496**	**(152)**	**(385)**	**121**

Continued on next page

17b. Prior year fund movements (continued)

	Balance 31 March 2017 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2018 £'000**
Restricted funds related to information & support:						
E W Joseph/Homecare grants	59	-	9	(8)	-	60
Joseph Levy/Education Grants	14	-	35	(60)	21	10
Support services (inc. welfare grants)	51	-	296	(314)	-	33
CF Connect (youth and parents)	26	-	-	-	-	26
Total funds related to information & support	**150**	**-**	**340**	**(382)**	**21**	**129**
Coombe Hill	-	-	29	(10)	(9)	10
Kings Fund	157	-	-	-	-	157
Paediatrics	4	-	-	-	-	4
Vertex – Everest trip	6	-	-	-	(6)	-
SmartCareCF	-	-	5	-	(5)	-
Clinical Trials Accelerator Programme	157	-	348	(348)	-	-
North Midlands - medical equipment	**0**	-	**1**	-	-	1
Other old funds fully utilised	6	-	1	-	-	1
Total Other Restricted Income Funds	**480**	**-**	**1,220**	**(892)**	**(385)**	**423**
Total Restricted Income Funds	**480**	**-**	**1,356**	**(1,028)**	**(385)**	**423**
Endowment Funds:						
Ena Bennie Endowment	538	3	-	(4)	-	537
EW Joseph Endowment	178	1	-	(1)	-	178
Joseph Levy Endowment	307	2	-	(2)	-	307
Robert Couper Endowment	-	-	-	-	-	-
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other endowment funds	**36**	**4**	**-**	**-**	**-**	35
Total endowment funds	**1,078**	**6**	**-**	**(7)**	**-**	**1,077**
Total charity funds	**8,986**	**(12)**	**15,169**	**(17,645)**	**-**	**6,498**

18. Prior year Consolidated Statement of Financial Activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2018 £'000**
Income and endowments from:					
Donations and legacies	2	11,423	1,331	-	**12,754**
Other trading activities	12	1,830	-	-	**1,830**
Investments	2b,6	217	25	-	**242**
Other income:					
Fixed asset disposals gain	6	-	-	-	**-**
Other income	2	343	-	-	**343**
Total		13,813	1,356	-	**15,169**
Expenditure on:					
Raising funds	3	3,902	10	3	**3,915**
Charitable activities					
Research		5,807	288	1	**6,096**
Clinical care	3	1,041	402	-	**1,443**
Information, advice & support		5,860	328	3	**6,191**
Total charitable activities		12,708	1,018	4	**13,730**
Total resources expended	3	16,610	1,028	7	**17,645**
Net income/(expenditure) before investment gains/losses		**(2,797)**	**328**	**(7)**	**(2,476)**
Realised investment gains/(losses)		4	-	-	**4**
Unrealised investment gains/(losses)		(22)	-	6	**(17)**
Net investment gains/(losses)		**(19)**	**-**	**6**	**(13)**
Net (expenditure) income		**(2,816)**	**328**	**(1)**	**(2,489)**
Transfers between funds	17a	385	(385)	-	**-**
Net movement in funds		(2,431)	(57)	(1)	**(2,489)**
Reconciliation of funds:					
Total funds brought forward		7,428	480	1,078	**8,986**
Total funds carried forward	17a	**4,997**	**423**	**1,077**	**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 (appointed July 2018)
  George Jenkins OBE (resigned July 2018)[1]

- Caroline Cartellieri Karlsen[1]
- David Turner QC[1]
- Professor Andrew Jones Michael Winehouse[1]
- Louise King[1]
- Ffyona Dawber
- Ryan Tohill (resigned April 2018)
- Professor Rosalind Smyth
- Sean Collins
- Anne Byrne (appointed March 2019)
- Richard Hoey (appointed March 2019)
- David Titmuss (appointed March 2019)

Finance and Audit Committee

Chairman

- Sean Collins

- David Turner QC
- Anne Byrne (appointed March 2019)
- Ryan Tohill (resigned April 2018)
- Stephen Mullen (Independent Member)[1]
- David Sawer (Independent member)
- Ed Rushton (Investments Committee)
- Nick Wood (Investments Committee)

Nomination & Development Committee

Chairman

- Richard Hunt (appointed July 2018)
  George Jenkins OBE (resigned July 2018)[1]

- Ffyona Dawber
- Louise King
- Caroline Cartellieri Karlsen
- David Turner QC[1]
- Professor Andrew Jones

Charity Management

- David Ramsden – Chief Executive
- Louise Honeysett ACA —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

Company Secretary

- Louise Honeysett ACA —Director of Finance and Resources

Principal and Registered Office

One Aldgate
London
EC3N 1RE

T 020 3795 1555
E enquiries@cysticfibrosis.org.uk
W cysticfibrosis.org.uk

Company Limited by Guarantee
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