

# Cystic Fibrosis why we're here

## **Cystic Fibrosis Trust** **Annual Report and Financial Statements**

For the year ended 31 March 2018

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

Fighting for a  
Life Unlimited

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**The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2018.**

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 pleased to present the Cystic Fibrosis Trust's annual report and accounts for 2017/18. This will be my final statement as Chairman, as I prepare to step down from the Board of Trustees.

The Trust has seen a great deal of change in the years since I was elected Chairman in 2012, beginning with a major rebrand and the launch of our five-year research strategy. This marked the start of an intense period of activity, during which the Trust set its sights on becoming a truly world-class organisation. This journey included a move from our long-time headquarters in Bromley to a new, purpose-designed office in Aldgate, which enabled colleagues with cystic fibrosis to get around the problem of cross-infection, and those working in the regions to remain connected and engaged. Shortly after moving, we launched our Fight for a Life Unlimited by cystic fibrosis.

This year we have looked ahead to the next chapter, consulting with our community, researchers and clinicians to develop a new research strategy for the next five years. At our September conference we announced the Trust's first Innovation Hub, at the University of Cambridge, and we will soon announce our first investments under the new strategy.

Throughout this organisational transformation the dedicated Trustees have offered guidance and firm leadership, and it has been a pleasure to work alongside such a dedicated, passionate group. The cystic fibrosis community, and the staff at the Trust, have also been a constant source of inspiration, and have made being Chairman of this organisation a privilege.

The median predicted survival for people with cystic fibrosis in the UK continues to increase, the population continues to grow and, where once it was a childhood condition, today there are more adults living with cystic fibrosis than children. While this is a testament to the wonderful clinicians, researchers and other professionals, many funded by the Trust, the changing demographics bring with them new challenges.

As precision medicines make their way to market and huge leaps forward in health technology open up new frontiers for home monitoring and telemedicine, the Trust will be at the forefront of change, seeking out new opportunities and campaigning to ensure access to all who would benefit.

The organisation I leave is well placed, financially and strategically, to deliver change for everyone affected by cystic fibrosis; and to bring about a life unlimited by the condition.

## Objectives and activities

### 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 10,400 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.

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**According to the 2016 UK Cystic Fibrosis Registry Report, the median predicted survival for people with CF in the UK is 47; however, the median age of death is just 31.**

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## 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.**

To reach our goal we:

- invest in ground-breaking research and innovation, and its application to people with CF;
- collaborate with and support the clinical community to drive up standards of care;
- provide information, advice and support for everyone affected by CF;
- campaign and influence policy affecting the CF community; and
- raise awareness of CF in the media and among the general public.

## Our vision

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

### > Measuring success

Criteria for success in 2017/18 were tracked onto our Activity Database, where individual projects and workstreams are monitored by relevant leaders within the organisation.

'SMART' measures were used where applicable, as well as data-driven analysis and narrative analysis. This explains each target's status and the steps being taken to move it in the right direction. In the achievements and performance section, we explore some of the ways individual targets were measured.

### Achievements and performance

#### > Investing in cutting-edge research and innovation

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 has the power to help deliver a life unlimited.

#### > Grant making policy

We ensure all our new research projects are strategically relevant and likely to benefit people with CF by evaluating proposals for those factors, as well as scientific excellence.

Governance for funding research at the Trust is overseen by two principle 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 of stages of life.

The SIB committee met in January to complete the review process of the Strategic Research Centres and will meet in July 2018 to discuss the governance and progress of the current Strategic Research Centres. SAB will meet in summer 2018 to complete a midterm review of the research strategy.

### >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:

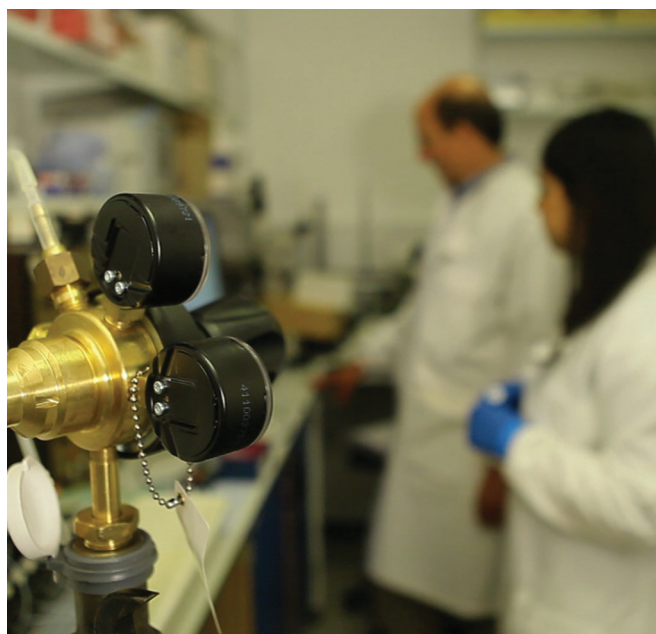
- Create clusters of world-class researchers.
- Bring experts from different disciplines together to tackle the complex problems caused by cystic fibrosis.
- Widen awareness of CF research outside the traditional biomedical disciplines and attract high-quality investigators from new research fields.
- 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.

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**We pledged £1.5 million to fund two new SRCs, as well as continuing to fund 12 existing SRCs for another year.**

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### ➡ New SRCs

#### 1. Personalised therapies for all: restoring airway function in people with CF using alternative chloride channels

##### PI: Dr Mike Gray, University of Newcastle

Cystic fibrosis is caused by a faulty protein in the cell surface (called CFTR), which leads to dehydrated, acidic, secretions in the lungs. This causes mucus to become sticky and clog the lungs, which makes them prone to infection. Although drugs have been developed to correct the most common type of faulty CFTR (F508del), the improvements are modest, and only benefit around 15% of all people with the condition.



Dr Gray and his team will use a different approach to help correct the fluid and pH imbalance in CF lungs by switching on non-CFTR 'alternative' chloride channels (ACCs) that are present in CF airway cells, in order to compensate for the lack of CFTR function. To do this, the researchers will test new compounds that increase the activity of these ACCs in lung cells from people with CF carrying both common and rare CF mutations. They will also check if combining these ACC modulators with the existing CFTR modulators has any additional benefit.

The ultimate goal of this SRC is to develop new drug-therapy approaches that can be used to restore the cellular CF defect in a patient-specific manner for all people with cystic fibrosis.



## 2. Personalised approach to *Pseudomonas aeruginosa* (PAPA)

**PI: Prof Jane Davies, Imperial College, London**

Around two in every three adults with CF have persistent *Pseudomonas aeruginosa* (Pa) chest infection, which leads to lung scarring. Since 2015, the first SRC focussing on Pa has made good progress:

- a) Creating a new structure in which scientists and clinicians from multiple disciplines (medicine, chemistry, microbiology and engineering) are focussed on one problem.
- b) Training five postgraduate students – soon to submit their PhD degree theses – who have each presented their work at international conferences and to patient/family groups.
- c) Increasing the external profile of CF research, attracting new collaborations and significant additional funding.
- d) Publishing two primary research papers (three more being considered by journals) and two reviews.



One of the striking findings has been the huge variability between Pa strains from different people with CF, making generalisation difficult.

This SRC will build on this finding with a proposed new centre, 'PAPA: The Personalised Approach to Pa'. The internal projects have been substantially co-funded, allowing the research team to bring on board new collaborators using techniques as diverse as advanced technology for breath measurement and trained 'sniffer dogs'. The cross-disciplinary team seeks to transform detection, understanding and treatment of this infection.

Meanwhile, the Trust continued the administration and monitoring of 12 existing SRCs spanning a range of topics of benefit to the whole CF community.

1. Pseudomonal infection in CF: better detection, better understanding, better treatment
2. Tackling *Mycobacterium abscessus* infection in cystic fibrosis
3. INOVCF: innovative non-CFTR approaches for CF therapy
4. EpiNet: Harnessing data to improve lives
5. The F508del-CFTR SRC
6. Personalised engineered cell therapies for cystic fibrosis
7. Cystic fibrosis-related diabetes
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. Restoration of luminal fluidity and microbiota in the gut
12. Novel therapies for *Mycobacterium abscessus*

Visit [cysticfibrosis.org.uk/src](http://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, they 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.

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**In 2017/18 we committed more than £569,000 to fund 11 new VIA projects, which brought an additional £1.75 million into CF research from external organisations.**

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New projects are tackling crucial issues such as antibiotic resistance, beating *Mycobacterium abscessus* and *Pseudomonas aeruginosa*, and the development of gene-editing tools that will work across the full spectrum of genotypes.

We continued our commitment to supporting the next generation of scientists by giving £15,000 to support 10 summer studentships in partnership with the British Lung Foundation. This scheme gives PhD 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 CF community via video link from UK CF Conference.** Viewers at home vote for their favourite presentation, and this year the winner was Sara Cuevas Ocaña for her presentation about 'INOVCF: Innovative non-CFTR Approaches for Cystic Fibrosis Therapy', an SRC led by Dr Mike Gray.

CF's got Talent shows the CF community why their fundraising is so important and what we are trying to achieve for them. It also helps develop the soft skills of researchers and provides them with a reminder of the real-world application of their everyday work and the difference it can make. The 'live' online audience of 850 was supplemented by a further 4,500 who watched some of the content later. This is an increase from the 500 views of last year's on-demand video views, and feedback about the event was very good. CF's got Talent was funded by Gilead Sciences.

## Innovation Hub

In September 2017, we announced a multimillion-pound research partnership with the University of Cambridge to create the first UK Cystic Fibrosis Innovation Hub, a world-class CF research facility centred in Cambridge but networked with collaborating centres across the UK.

Innovation hubs are an exciting new element for the Trust's portfolio of world-class research, which seek to create high-level partnerships with academic institutions while supporting research across the UK and Ireland. The Hub was set up to tackle several research areas, namely antimicrobial resistance, improved detection of pulmonary exacerbations and regenerative medicine. A further important aim of the hub is to facilitate the creation of a national network to maximise national CF research. We have committed to raising £2.0million, with an aspiration to raise a further £3.0m, which will be matched by the University of Cambridge. We have received pledges of £1.2million to date, and have already received £0.1million income.

In our financial statements there is a currently deficit balance on the corresponding designated fund as a result of the difference in timing of the commitment, costs incurred and the income received.

## Clinical Trials Accelerator Platform

Since the last report, our Clinical Trials Accelerator Platform has gone from strength to strength. We have succeeded in our ambitious aim of developing a network of CF centres across the UK to lead in the delivery of cutting-edge clinical trials. We also created the UK's only CF-specific clinical trials database, the CF Trials Tracker, which lists clinical trials and research studies open to recruitment, helping people with CF to understand the trials available and ensure that every eligible person who wants to take part has the opportunity to do so.

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**Our second round of applications to join the network was brought forward due to overwhelming interest in the programme. This was completed in May 2017 and brings our total to 20 lead CF centres, including representation from all of the devolved nations.**

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We are proud that the Trials Accelerator network now covers over 80% of the population of people with CF and is therefore positioned to facilitate access to clinical trials in a fairer manner. Almost all of the centres have a Trial Coordinator or Research Nurse in place, funded by the Trials Accelerator; it's just one way in which we are increasing CF-specific research capacity across the network.

We have also significantly increased our engagement with the pharmaceutical industry over the last six months. We are now dealing directly with several companies that have expressed an interest in working with the Trials Accelerator. We have facilitated and delivered feasibility studies for a variety of clinical trials and look forward to these opening to recruitment over the coming months. These trials will deliver opportunities for both adults and children to trial new medications in the hope of demonstrating superiority over currently available treatments.

## Clinical care

### > Clinical Fellowships for doctors and physiotherapists

The Trust's Clinical Training Fellowship programme has sponsored dozens of clinicians to specialise in CF; many of the brightest and best leaders working in CF in the UK today have benefitted from this vital support. The scheme provides specialist adult CF centres with a one-year grant to train adult physicians in the management of CF, with the aim of training up the future leaders of specialist adult CF care.

The Trust is committed to enhancing this legacy. This year, we committed to sponsoring two Clinical Training Fellows, who will undergo their training as part of a cross-London collaboration and at Sheffield, and awarded our second Physiotherapy Training Fellowship, to Ciara Long of the Royal Brompton Hospital. In the previous year, our first physiotherapy fellow capitalised on the opportunities the fellowship presented her with by gaining invaluable experience from several centres of excellence across the UK.

### > Working to promote excellent care

Clinical care features heavily in the lives of people in the CF community. By working with stakeholders, we are developing, piloting and rolling out care experience questionnaires, developing new national guidelines for all Allied Healthcare Professionals and developing a CF centre staffing audit tool to help to drive up safe and effective staffing levels in all CF centres. We support and advise on service reconfigurations across the UK. Our advance care planning work will be expanded to include specialist training for CF clinicians to ensure they feel confident in managing the difficult conversations about care preferences as people become unwell.



## SmartCareCF

During the previous year (2016–17), we ran an adult remote-monitoring study to investigate the benefits of at-home health monitoring for people with cystic fibrosis. This past year was the turn of CLIMB-CF, our multi site study to see if similar monitoring techniques could significantly improve the quality of life experienced by young people with cystic fibrosis.

We recruited 115 children and young people to participate in the study across six CF centres; 37 of those people have now completed the data-collection phase. We are proud to work alongside the Garfield Weston Foundation, which provided the funding and support required for a project of this size and complexity.

## UK Cystic Fibrosis Registry

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

We launched the first randomised CF registry-based trial in the world in May 2016, focussing on adults. This year we also launched CF START, which aims to evaluate antibiotic-prescribing methods in children, with potential long-term health implications for everyone born with cystic fibrosis.

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.

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**We were the first CF Registry in the world to publish its Annual Data Report for 2016, 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.**

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Through four drug safety studies, one observational study, and two NHS contracts, the Registry generated income of £1.8 million. A significant proportion of this income has been used to support centres in their data entry to the Registry, in the form of grants.

We also partnered with the Alan Turing Institute to develop methods to better understand Registry data using cutting-edge machine learning techniques. Additionally, a \$100,000 Vertex Circle of Care award allowed us to begin work with the London School of Hygiene and Tropical Medicine to create survival and milestone prediction tools for the CF community. Our data validation visits monitored and improved the quality of Registry data, and our Research Ethics Committee approval has been extended for a further five years and included a refresh of all our patient information sheets and consent forms.

Our CF Registry team has been moved in-house to the Cystic Fibrosis Trust, and Registry lead Rebecca Cosgriff has been re-elected as a member of the ECFS Patient Registry Executive Committee for a second term.



Rebecca Cosgriff, Registry Lead



## Registry studies

- CF START is running well, with over 50 babies recruited across 43 sites.
- VOICE study concluded early following a decision by the funder, but we are planning publications on the study methodology and interim results.
- QoL study has recruited over 80 patients and version two of the study, aiming to improve recruitment of participants, will be launched in 2019.

We also approved 25 data requests, allowing researchers to use anonymised data from the Registry for their work.

## Information and support for all

**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.

### > Grants

We awarded £282,000 to help people with CF overcome the challenges they face. This included small emergency grants, transplant grants (to help with the cost of the assessment process and recovery), health and wellbeing grants, holiday grants for over 18s and funeral grants.

In addition, we were able to provide £7,720 in homecare grants to people experiencing very poor health, including those receiving end-of-life care, enabling them to remain comfortably at home.

We were delighted to run the Helen Barrett Bright Ideas Awards again this year, awarding £10,000 in total. The awards support people with CF to build their business or career, helping them achieve financial freedom. This year, we decided to offer larger grants of up to £5,000 to increase the impact. Successful Bright Ideas included personalised printing and handmade clothes, the expansion of a music studio, and equipment for an aspiring tattoo artist.

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**We spent £59,570 on education grants awarded by the Joseph Levy Education Fund, to help people with CF pursue university courses or vocational training and further their education without being held back by financial worries.**

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### > Benefits advice

Our Welfare and Rights Advice service is now well established and respected across the country and continues to achieve great success for people with cystic fibrosis. Our adviser has supported almost 400 people with the provision of welfare advice this year. Around half of these were in relation to personal independence payments (PIP). Our service has secured over £1.6 million in benefits income for people with CF this year alone.

We also continue to offer a benefits advice service in Northern Ireland through our partnership with Citizens' Advice Bureau Belfast, who we fund to support individuals and families affected by CF in Northern Ireland.

### > Helpline

This year our helpline responded to over 3,700 enquiries from people affected by CF, providing information, support and a listening ear when people need it the most. These were evenly split between telephone and email enquiries.

Over 40% of enquiries were related to financial concerns or support, indicating the devastating impact that the financial burden of CF has on individuals and families.

### > 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.

### > Information

This year, we have continued to produce a diverse and wide-ranging information offering, including:

- A range of resources around transplants
- A series of practical leaflets on physiotherapy techniques
- Two printed books and an animation for children whose parents have CF
- A series of printed resources and an animation for young people leaving school
- Updated clinical guidance on good practice for the physiotherapy management of CF and the prevention and control of *Mycobacterium abscessus*

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**We were also proud to be awarded first place in the 'Aid to decision making' category of the British Medical Association patient information awards this year for our 'Starting a family' pack.**

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### > Youth project

The youth engagement project aims to ensure that the Trust is relevant to all people with CF, and that the voices of children and young people under 25 are represented throughout our work. The project has had a busy and very successful year.

Our youth advisory group (YAG) is made up of under 25s with CF or with a close connection to the condition. The group has grown in number and diversity this year and continues to meet online regularly to guide and support the work of the youth project and the wider trust.

This year, YAG has worked with the Clinical Trials Accelerator Platform team to produce an animation about clinical trials for young people. This was led entirely by the group and generously funded by the Queen's Trust.



**Bahar Mustafa, Digital Outreach Officer**

We also launched our 'Building Brighter Futures' project. Funded by BBC Children in Need for three years, our digital outreach officer will produce a series of online talks and six-week workshop programmes for children and young people on a range of topics, aimed at improving overall health, wellbeing and confidence. 2017/18 saw the pilot phase of this project, with talks on applying to university and mental health, and workshops built around preparing for exams and for work.

## Campaigning hard

**The 10,000+ people with CF in the UK, and their friends and families, are a powerful force; through our campaigns we ensure that the CF community's voice is heard loud and clear by decision makers with the power to change their lives.**

This year we focussed our efforts on our Stopping the Clock campaign, which aims to pave the way for access to potentially life-changing precision medicines for cystic fibrosis. In the era of increasing personalisation in healthcare, we are fighting for people with CF in the UK to be among the first in the world to benefit from advances in treatment. More than 100 MPs have taken actions to support the campaign in the past year.

We kicked off activities with a series of protests around the country in June 2017, calling for access to new precision medicines for everyone with cystic fibrosis. The protests were held outside of the government buildings in each of the four constituent nations of the UK and were attended by 400 people. More than 115 pieces of coverage about the protests went live by broadcast, print and online media, including the moving stories of 15 people with cystic fibrosis.

In November 2017, we welcomed around 40 MPs at a drop-in session at Westminster to tell them about CF and our campaigns. As well as Trust representatives, the MPs had the opportunity to hear from 10 families affected by CF and understand why this work is so important.

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**An MP round-table meeting in February 2018 was attended by the Trust and Vertex and chaired by Ian Austin MP, with around 40 MPs represented, which helped us ensure our message was clear and effective.**

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March's Westminster Hall debate saw more than 60 MPs from across the UK represent their constituents in response to the Parliamentary Petition that raced to over 100,000 signatures in 10 days. These actions ensure that their political representatives know that we may be few, but together we have influence and phenomenal support.

This progress has been underpinned by year-round engagement work with politicians in every jurisdiction, including a petition to the Welsh Assembly, which gathered over 5,000 signatures, and a cross-party letter to the Minister in Northern Ireland, supported by 66 Members of the Legislative Assembly (MLAs).

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**All this work is supported by superb press coverage; our campaigning message has been carried in 25% of all media cover secured by the Trust, ensuring our message is heard not just in the political sphere, but also by thought leaders and influencers around the UK.**

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We are pleased to see meaningful negotiations begin between the pharmaceutical company behind one of these precision medicines – Orkambi – and NHS England, with their first meeting taking place in April 2018. We will continue to do we can to ensure that the year ahead will see breakthroughs in negotiations that secure access to precision medicines across the UK.

## Raising awareness effectively engaging with our community

Cystic fibrosis was in the press over 2,000 times over the course of the year, with more than 10% of this coverage appearing in national newspapers. These articles covered a wide range of issues, campaigns and personal stories to spread the word about our work and raise awareness of the condition.

We have been working hard to talk about where money raised for the Trust goes; we've secured fantastic coverage throughout the year describing our research and impact, including articles in the likes of the Lancet, Health Service Journal and nearly 100 national and regional articles. Dr Janet Allen made a significant contribution on an article about a phase three trial of a potential new combination therapy, tezacaftor-ivacaftor, which was published in the world-leading New England Journal of Medicine.

CF Week, our annual awareness week, took place in June 2017, focussing on demonstrating the impact of our work to our core supporters who make it all possible. We demonstrated how their money is used and the difference it is making to people with CF across the country, and ended the week with our annual Wear Yellow Day. The best performing content in terms of reach and engagement was our 'What is CF?' video, which was watched and shared throughout the week by our community, closely followed by our Research Funding graphics.



This year, Wear Yellow Day outperformed the Virgin Money London Marathon (which is annually our best performing day across social media) on every social media channel except Facebook. Throughout the year, our social media accounts have continued to grow and we are seeing increased engagement across all channels. The press team achieved coverage in the Portsmouth News as the Spinnaker Tower turned yellow. In addition, Knutsford in Cheshire turned their whole town yellow, gaining attention from local media, the 'Knutsford Guardian'.

### > **Celebrity and ambassadors**

Over the course of the year we developed relationships with new influencers and celebrities, like James Dunmore from 'Made in Chelsea'. Their stories about how CF has affected their lives have helped us reach new audiences and secure national media coverage.



### > **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 2017 conference took place over two days at the East Midlands Conference Centre in Nottingham, and brought together more than 500 healthcare professionals, researchers and other leading experts from around the world. The first day focussed on potential new treatments to improve lung health in people with CF, with international speakers from both academic and clinical backgrounds sharing their latest research.

The second day was open to those affected by CF, with all sessions streamed live online for people to enjoy, with a particular focus on the role of clinical trials in improving treatment, and of our Clinical Trials Accelerator Platform in particular. The second year of 'CF's got Talent' was a great success, with early-career CF researchers presenting their work with the CF community via video-link, hosted by celebrity supporter Roger Black. There were 750 live streams of the conference, with almost 600 viewing content subsequently on demand, reflecting the conference's significance beyond the event itself.

### > **Communicating with supporters as individuals**

In 2017/18 we began a number of complementary projects using automation and personalisation to deliver more relevant and timely communications and content to our supporters. The aim is to enable the Trust to better support and engage with our supporters, and to offer a unique supporter experience. This included more tailored emails, adapting the content and message to specific demographic or psychographic groups. Work began on optimising the supporter journey and enabling relevant and related content to be made more visible to the individual. This work will continue, including web development, into 2018/19.

### > **CF Insight Survey**

We developed the CF Insight Survey alongside the CF community so that we could better understand, and hopefully improve, their everyday lives. From access to benefits, fears and hopes for the future, aging and the impact of CF on work and social life, this anonymous survey provides rich information from over 1,000 responders that is not available from other sources.

This was the second year of the survey and the number of responses increased significantly from the previous year. The survey highlights the significant challenges related to growing old with CF, uncertainty due to the impact of CF on earnings, the cost of living with the condition and worries around access to the best treatments as key concerns this year. A detailed report on content from the first two surveys will be published prior to UKCFC.



## Community involvement

We involved 367 individuals affected by CF in our activities during the year, in projects such as the Clinical Trials Accelerator Platform, the Youth Advisory Group, campaigns, Insight Survey planning, developing our information resources and sharing stories to help us engage with the community and the public in general.

**Many of these are new opportunities, which enabled us to increase the number of people from the CF community we worked with by 83.5% overall.**

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. We established the Trust-Wide Involvement Group – an internal network – to share best practice across the organisation and to coordinate involvement more effectively.

### >Volunteering

Our fantastic volunteers have provided unending commitment to our vision of a life unlimited for everyone with cystic fibrosis. Over the past year we have updated our volunteering policy, which now also includes involvement. Our focus has been on improving the volunteering process and reducing risk. Based on feedback from Trust employees we have moved to ensure we recruit based on need, and taken a step back from reactionary recruitment.

Our update included the induction process, rewriting our handbook and adapting our staff policies for volunteers. We have also created detailed guidance for those managing volunteers. With new policies in place we were able to mobilise over 100 ad hoc volunteers at our biggest annual fundraising event, the Virgin Money London Marathon, receiving positive feedback from the runners themselves as to the difference it made.

We have 173 regular volunteers and hundreds of fundraising volunteers, although this number fluctuates. We have also created application and recruitment systems to support compliance with the new General Data Protection Regulation (GDPR), as well as to fine-tune our outreach, allowing us to find high-quality volunteers to support our vital work.

**We have developed our ability to support remote volunteers and induct them effectively, enabling the mutually beneficial inclusion of people with CF on our list of volunteers.**

## Developing an effective organisation

During this year, we completed the first cycle of an integrated delivery management framework with visible Key Performance Indicators across all teams, to ensure our delivery of the operational plan. We also reviewed our strategic objectives to produce a new organisational planning framework, founded on the key pillars of 'We are all great fundraisers' and 'We are a great organisation'. During the year we undertook a review of the Trust's benefits, which showed that these were comparable with similar organisations. We did make minor improvements to our maternity pay and sickness provision for new starters. We have sought 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

Linked to this we undertook extensive Equality and Diversity training and launched a new Learning and Development policy. We reviewed and have published a new Safeguarding policy. In preparing for the introduction of the General Data Protection Regulations in May 2018 we developed a range of new policies around data management and information security and have trained all employees in these areas.

## 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 by cystic fibrosis. To acknowledge the key role they play, the Trust has been focussed on improving our supporters' experiences at every interaction.

Using feedback collected from fundraisers either face to face, online or offline, we are constantly reviewing how we thank them, ensure they have the right materials for their fundraising, and explain how their hard work is making a real difference to the lives of people living with cystic fibrosis. Providing an exceptional supporter experience will continue to be a key focus.

The Trust received 50 complaints in 2017–18, up from 36 the previous year and less than the 64 complaints in 2015–16. Complaints are closely monitored and reviewed on an ongoing basis. We have made it easier for people to give us feedback and complaints are closely monitored and reviewed on an ongoing basis.

## Fundraising

We would like to thank the many individual donors, organisations, charitable trusts, foundations and corporate partners who support our work. The Cystic Fibrosis Trust receives no government funding; this kind support makes our efforts towards creating a life unlimited by CF possible.

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**Through this extraordinary generosity, we have raised £8.78 million; an increase of nearly £300,000 from the 2016-17 financial year.**

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We are proud of this achievement, especially considering the challenging external environment, with more regulatory requirements and negative press concerning charity fundraising.

We have strong ambition to grow income over the next few years in order to have even greater impact for people with cystic fibrosis.

## >Community and Events

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**Over 5,000 people took part in a challenge event for the Trust this year, and over 1,000 community events took place across the country.**

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The Trust continued to work with corporate partners, including HSBC Private Banking and Proxima, to raise funds and awareness of cystic fibrosis. This year, we also secured a number of new supporters, including the law firm Bird & Bird, with whom we have developed a multiyear partnership. The Trust was also delighted to secure a Radio 4 charity appeal, which will be broadcast in June 2018. UKCFC continues to be a popular event, with ongoing support via sponsorship from the pharmaceutical industry raising nearly £65,000. We have gained a number of valuable regional 'Charity of the Year' partnerships with companies including the Royal Bank of Scotland Mortgage Centre, Greenock, Café Nero branches across the East, and Public Health Wales.

The Philanthropy team continued to work with charitable trusts, foundations and individual supporters to fund the work of the Trust. The team was really pleased to secure new multiyear grants, including support from The Queen's Trust, BBC Children in Need and Sport England, and to build on existing relationships with trusts and generous individuals who are long-standing supporters of our work. This includes major grants from the Garfield Weston Foundation supporting our CLIMB-CF project, the Robert Luff Foundation supporting one of the *Mycobacterium abscessus* Strategic Research Centres, the Joseph Levy Foundation supporting our Information and Support work, the Eranda Rothschild Foundation supporting our *Pseudomonas aeruginosa* Strategic Research Centre and the Vertex CF Circle of Care Awards supporting a pilot project in end-of-life care. We have received generous pledges totalling £1.2 million to date from AJN Steelstock, the Robert Luff Foundation and generous individuals for the first UK Cystic Fibrosis Innovation Hub, which has been created in partnership with the University of Cambridge.

Membership of our Sixty Five Roses Club continues to grow year on year, and many members attended and enjoyed our annual event in October 2016.

Support from people taking part in our events, community and branch activities is a significant part of our income. The Virgin Money London Marathon, our biggest fundraising event of the year, raised £339,000, with our Great Strides 65 series of events becoming our second biggest. This year, nearly 600 walkers raised over £250,000 (not including Gift Aid). Our new Ultra Marathon, which took place alongside the Great Strides 65 event in Surrey, raised an impressive £11,000. Our Chief Executive, David Ramsden, took on our annual Ben Nevis challenge alongside 32 others, in the final year before the event becomes part of the Great Strides series.



We had a strong presence at the Born Survivor events owing to our charity partnership; participants wouldn't have been able to miss our branding and staff at the event! Our Resolutions campaign inspired many sign-ups for events and activities taking place later in the year.

Many events run by the Trust or its supporters saw an increase in value and participation this year, including Carols by Candlelight, Great North Run and the Hillside Nursery Grotto in Belfast.

Our 'Wear Yellow Day' campaign during CF Week saw the number of community events quadruple year-on-year to 117 events, with an income of over £40,000 driven by an integrated marketing campaign driven by the Community and Engagement teams. People, pets, schools and towns were turned yellow, attracting attention from local media and a fun way to raise awareness of our work.

Both the Trust and the CF community work tirelessly to come up with innovative fundraising initiatives. This year, we collaborated with fundraising platform Everyday Hero for our first Trust-organised virtual event, 24 Hours for CF, 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.

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**We received notification that 87 of our supporters generously included a gift in their will for the Trust. We would like to express our gratitude to those people for thinking of us in this special way.**

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The response to our Gifts in Wills campaign continues to grow and many thanks are also due to supporters who have responded with notification of a future legacy.

Regular monthly donations provide invaluable ongoing support for which we are grateful, as it allows us to plan effectively for the future. Our Christmas campaign ran throughout November and December, highlighting the research funded by supporters through the voice of a man with CF who wants to live a long life to be there for his five-year-old daughter. Income from this campaign totals £196,000 to date. Our digital and hard-copy Resolutions campaign followed, inspiring sign-ups for events and activities taking place later in the year. In addition, the Trust launched a new weekly lottery in partnership with Sterling Management Centre Ltd, regulated by the Gambling Commission. Over 400 supporters have already joined the lottery.

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**Thank you to everyone who made a donation to our summer and Christmas appeals, on our website and via our telephone appeals, raffle and lottery tickets this ongoing support is very much appreciated.**

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We are members of the Fundraising Regulator and abide by the code of fundraising practice. 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.

## Plans for the future

The Cystic Fibrosis Trust has achieved a great deal in recent years and there are some big opportunities coming up to help achieve a life unlimited.

In March 2018, the Board of Trustees approved a new Strategic Framework for the Trust and a refreshed Research Strategy.

This confirmed that at the heart of what we do will be a dynamic research portfolio. We have also identified key priority areas as being:

- Access to medicines
- Quality of clinical care
- Day-to-day support
- Reaching all people with cystic fibrosis

"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."

### Here's how we plan to keep the momentum up in years to come.

Research is at the heart of the transformational changes we have seen in CF care and treatment. We will continue the administration, management and monitoring of research awards. We will partner with new organisations to bring fresh expertise into the field of CF research, making the most of new technologies and techniques wherever possible. We will fund and deliver research programmes to better understand the condition and how to lift the limits it places on the lives of everyone who has it.

We plan to hold another 'Research Sandpit', as we did in 2016, as it was a great way to encourage the development of SRC application ideas; two of the three SRCs awarded that year stemmed from that event.

As part of the ongoing development of the Registry to ensure the data it holds is of practical use to clinical teams and people with CF, we will develop the patient-level dashboards, as well as online tools to calculate survival estimates for those who wish to access them, which will also support clinical decision making. We are working towards creating a Registry for people diagnosed as 'CFSPID', that is, people with an inconclusive CF diagnosis, which will be a vital research tool. International collaboration continues, both with the ECFS Patient Registry and comparing clinical outcomes with the US CFF Registry.

The Clinical Trials Accelerator Platform will support the development of the evidence base for new drugs being tested in people with cystic fibrosis. As all new CF medications must complete a rigorous assessment of safety and efficacy prior to being approved for clinical use, the process is completely dependent upon people with CF volunteering to participate in clinical trials; we are determined to support and facilitate them in any way we can.

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**We will continue with patient and public involvement, inviting people with CF to be involved in clinical-trial design and empowering the CF community with the information and skills they require for making informed decisions around participation.**

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We will continue to work towards creating equity of access to clinical trials by advocating for our accelerator platform centres with the pharmaceutical industry and will increase the number and capacity of centres involved in clinical trials in cystic fibrosis. We will also deliver innovation and investment to UK CF centres by continuing with our Fellowships Programme.

We will publish qualitative research on the needs and experiences of people with cystic fibrosis, which we have commissioned University College London to carry out. The findings of this research will assist us in building on the successes of the support service by enabling us to better understand the needs of the CF community and ensure that our services are meeting those needs.



We will continue to support our youth advisory group to share their views and ambitions for the Trust, including developing innovative models of peer support. We will also continue our programme of online workshops and talks for young people, including an online art therapy course.

The Information Team has plans to produce a major resource around the process of transition from paediatric to adult services. We will publish a series of leaflets on nutrition, and booklets on body image and relationships, expanding our information resources to cover even more of the issues that affect our community.

Our supporters are hugely important to us and we must ensure that we give everyone who fundraises or donates the best experience we can. We will do this by personalising their experience with the Trust. We will continue to increase engagement with our flagship campaigns, including Wear Yellow and Great Strides, while offering a diverse and exciting event portfolio. We will also work closely with our network of branches and groups, who are key to our success at a local level, and develop innovative fundraising ideas.



The Philanthropy and Corporate team will continue to focus on developing multiyear partnerships, ensuring we can invest in cutting-edge research including flagship programmes such as the Innovation Hub, alongside providing vital support, information and advice services.

Our Engagement team will explore ways to increase people's interactions with and commitment to the Trust and build their understanding of cystic fibrosis. We'll do this by taking advantage of all the digital channels available to us to share and promote our diverse range of information and resources, as well as raising the profile of CF through targeted PR and advertising. We will also improve the way we demonstrate the impact we're having and investigate innovative new ways to fundraise.

2018's UKCFC is being held in Birmingham for the first time, from 10–11 September at the Birmingham ICC, with a focus on the impact of personalised medicine during the first day and a wider focus on the issues being faced by the CF community on the second day.

Our Public Affairs team will continue to campaign for access to life-changing medicines and treatments.

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**We will keep pushing for an agreement on the price for drugs currently licenced in the UK and look to ensure that all of the new medicines on the horizon do not face the same delays we've seen to date.**

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## Financial review

### Income

The Trust's income from normal activities for the year to March 2018 was £15.2million, an increase of 15% over the previous year.

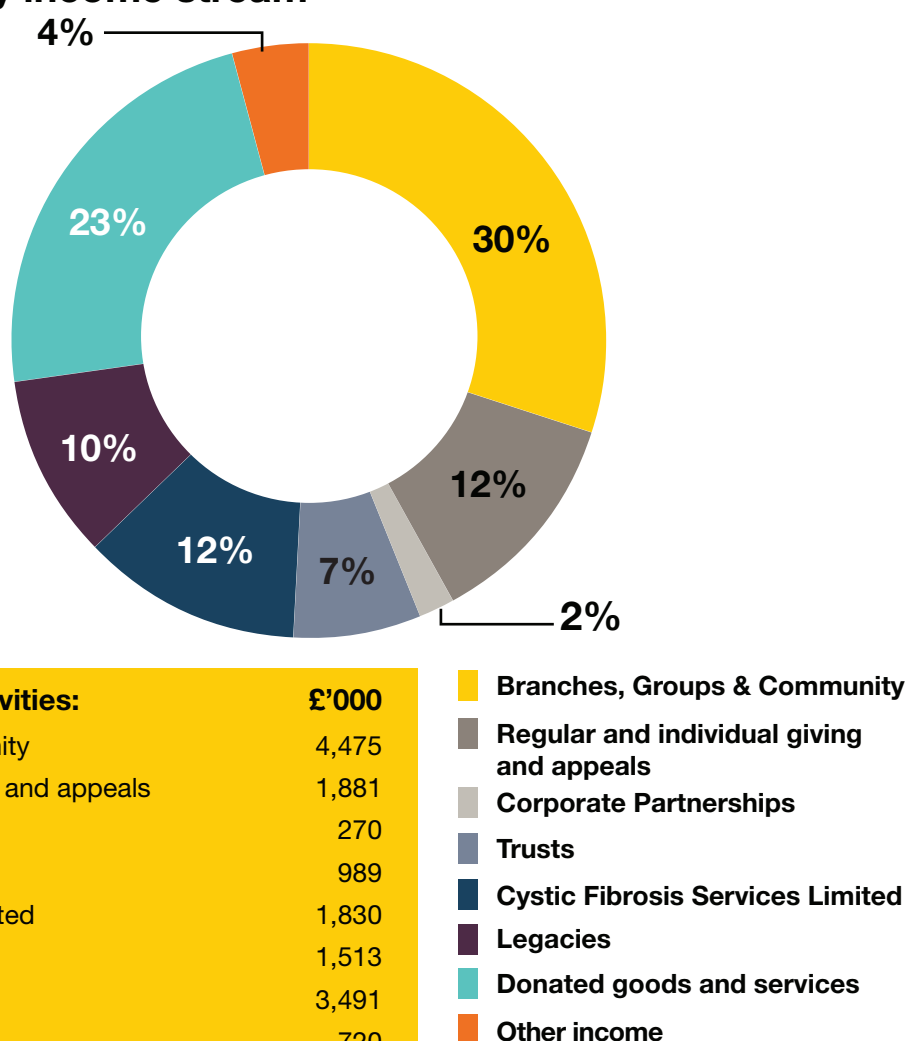
84% of the Trust's total income is made up of donations and legacies, totalling £12.8million, (2016/17 – £11.1m). This percentage is consistent with 2016-17. Donation income was again boosted by a non-monetary donation of digital advertising space from Clear Channel, which was worth £3.5 million (2016/17 – £1.9m).

Total donations and legacies excluding the donation in kind were £9.3m. Income raised by community fundraising and branches including gift aid was £4.5m which represents 48% of this figure (2016/17 – 48%), confirming the continuing importance of the volunteer network to our fundraising efforts.

There was a 7% decrease in income from Corporate Partnerships and a 1% decrease in Trusts income. Legacies decreased by 15% compared to the previous year, partly offset by a 33% increase in individual donations and a 2% increase in regular giving.

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £1.8m (2016/17- £1.7m). There were four (2016/17 – 3) long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year. Two came to an end; one in June 2017 and one in January 2018. A multi year study module contract with a pharmaceutical company commenced in October 2016 and continued throughout the year; this continues to be a growth area of business and we are actively seeking new contracts.

#### > 2017/18 income by income stream



<b>Income from normal activities:</b>	<b>£'000</b>
Branches, groups & community	4,475
Regular and individual giving and appeals	1,881
Corporate partnerships	270
Trusts	989
Cystic Fibrosis Services Limited	1,830
Legacies	1,513
Donated goods and services	3,491
Other income	720
<b>Total income from normal activities</b>	<b>15,169</b>

## Expenditure

The Trust's total expenditure for the year was £17.6m, a 13% increase compared to the previous year. The largest growth area of spend was on charitable activities at £13.7m (2016/17 – £11.8m), which comprises programmes of research, information, advice and support and clinical care.

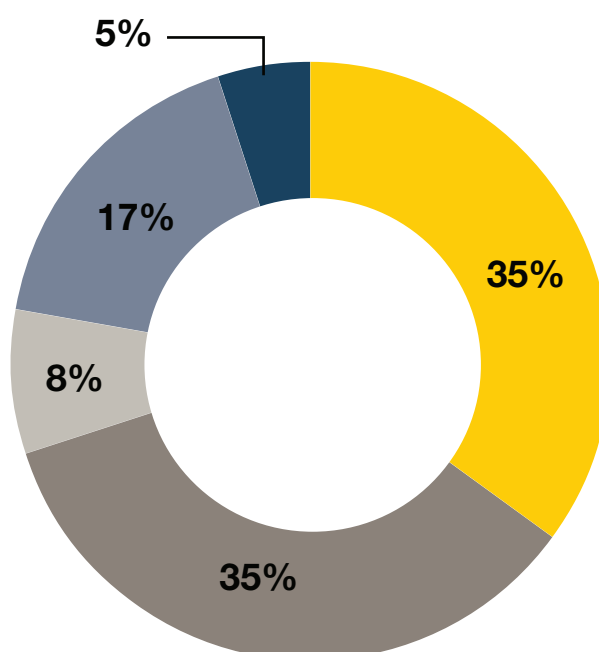
The remainder was spent on activities for generating funds, including £0.8m paid to NHS cystic fibrosis clinical centres across the UK to support the resources necessary to add patient data to the CF Registry.

Total grant commitments in the year at £5.7m were 17% higher than in the previous year. Grants worth £5.3m (2016/17 – £4.6m) were committed to a range of institutions, including £1.5m committed for two Strategic Research Centres (2016/17 – £2.3m for three Centres) and £2.0m to the first UK CF Innovation Hub at Cambridge.

The Clinical Trial Accelerator Platform flagship programme developed throughout the year, with total spend £0.3m (2016/17 – £0.5m), 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 deficit of £2.5m in the year was in line with plans, and was driven by the £2.0m Innovation Hub commitment, which the Cystic Fibrosis Trust has underwritten while we continue to appeal to donors to fund this research programme.

### > 2017/18 expenditure by cost type



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

## > 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 (2016/17: increase of £0.6 million); a 1% 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 2018 totalled £6,498,000 (2017 – £8,986,000). 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 (£130,000) 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 £0.1 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.

- A strategic reserve (£371,000) is held to fund the budgeted deficit in the 2018/19 financial year and enable the continued progress of the flagship programme in the short term (see page x)
- 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 – (£2,786,000) 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 48 months.
- Restricted income funds – (£424,000) 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.

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**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.**

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### 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.

## 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.

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This Trustees report incorporating the Strategic report was approved and authorised for issue by the Board of Trustees on **25 July 2018** and signed on its behalf by:

**George Jenkins, Chairman**

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

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2018 which comprise the Consolidated Statement of Financial Activities, the Consolidated Income and Expenditure Account, the Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

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.

### 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 2018 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 22, 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](http://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 Annual Report. 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 Annual Report (which incorporates the strategic report and the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Annual Report (which incorporates the strategic report and the directors' report) has 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 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 returns adequate for our audit have not been received from branches not visited by us; 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.

Kathryn Burton (Senior Statutory Auditor)  
for and on behalf of haysmacintyre, Statutory Auditor  
**Date 25 July 2018**

10 Queen Street Place,  
London  
EC4R 1AG



**> Consolidated statement of financial activities**

For the year ended 31 March 2018

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2018 £'000	Total Funds 2017 £'000
<b>Income and endowments from:</b>						
Donations and legacies	2	11,423	1,331	-	12,754	11,098
Other trading activities	12	1,830	-	-	1,830	1,729
Investments	2b,6	217	25	-	242	216
<b>Other income</b>						
Other income	2	343	-	-	343	139
<b>Total</b>		<b>13,813</b>	<b>1,356</b>	<b>-</b>	<b>15,169</b>	<b>13,182</b>
<b>Expenditure on:</b>						
Raising funds	3	3,902	10	3	3,915	3,711
<b>Charitable activities</b>						
Research		5,807	288	1	6,096	5,505
Clinical care	3	1,041	402	-	1,443	1,678
Information, advice & support		5,860	328	3	6,191	4,656
<b>Total charitable activities</b>		<b>12,708</b>	<b>1,018</b>	<b>4</b>	<b>13,730</b>	<b>11,839</b>
<b>Total resources expended</b>	3	<b>16,610</b>	<b>1,028</b>	<b>7</b>	<b>17,645</b>	<b>15,550</b>
<b>Net income/(expenditure) before investment gains/losses</b>		<b>(2,797)</b>	<b>328</b>	<b>(7)</b>	<b>(2,476)</b>	<b>(2,368)</b>
Realised investment gains/(losses)		4	-	-	4	39
Unrealised investment gains/(losses)		(22)	-	6	(16)	550
<b>Net investment gains/(losses)</b>		<b>(18)</b>	<b>-</b>	<b>6</b>	<b>(12)</b>	<b>589</b>
<b>Net (expenditure)/income</b>		<b>(2,815)</b>	<b>328</b>	<b>(1)</b>	<b>(2,488)</b>	<b>(1,779)</b>
Transfers between funds	17a	385	(385)	-	-	-
<b>Net movement in funds</b>		<b>(2,430)</b>	<b>(57)</b>	<b>(1)</b>	<b>(2,488)</b>	<b>(1,779)</b>
<b>Reconciliation of funds</b>						
Total funds brought forward		7,428	480	1,078	8,986	10,765
<b>Total funds carried forward</b>	17a	<b>4,998</b>	<b>423</b>	<b>1,077</b>	<b>6,498</b>	<b>8,986</b>

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

A prior year comparative Consolidated Statement of Financial Activities has been included in the notes to the accounts (note 18).

The notes on pages 29 to 49 form part of these financial statements.

	<b>All income funds 2018 £'000</b>	<b>All income funds 2017 £'000</b>
Income	<b>14,928</b>	12,966
Gains/(losses) on investments	<b>(19)</b>	517
Investment income	<b>242</b>	165
<b>Gross income in the reporting period</b>	<b>15,151</b>	13,648
Expenditure	<b>17,317</b>	15,146
Interest payable	-	-
Depreciation and charges for impairment of fixed assets	<b>320</b>	397
<b>Total expenditure in the reporting period</b>	<b>17,637</b>	15,543
<b>Net income before tax for the reporting period</b>	<b>(2,486)</b>	(1,895)
Tax payable	-	-
<b>Net Income for the financial year</b>	<b>(2,486)</b>	(1,895)

The Consolidated Summary Income and Expenditure Account is derived from the Statement of Financial Activities on page 25 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 29 to 49 form part of these financial statements.

		Consolidated		Charity	
	Notes	Total 2018 £'000	Total 2017 £'000	Total 2018 £'000	Total 2017 £'000
<b>Fixed assets</b>					
Tangible assests	5	132	450	132	450
Investments	6	5,904	5,826	5,904	5,826
		6,036	6,276	6,036	6,276
<b>Current assets</b>					
Debtors	7	1,757	1,304	1,750	1,601
Cash held as short term investment		11,351	11,308	11,351	11,308
Cash at bank and in hand		1,078	2,250	1,075	1,941
		14,186	14,862	14,176	14,850
<b>Liabilities</b>					
<b>Creditors:</b> amounts falling due within one year					
Grants payable	9	(7,276)	(6,144)	(7,276)	(6,144)
Creditors and accrued charges	10	(1,119)	(1,320)	(1,109)	(1,308)
		(8,395)	(7,464)	(8,385)	(7,452)
<b>Net current assets</b>					
		5,791	7,398	5,791	7,398
<b>Creditors:</b> amounts falling due after one year					
Grants payable	9	(5,329)	(4,688)	(5,329)	(4,688)
<b>Total net assets</b>		<b>6,498</b>	<b>8,986</b>	<b>6,498</b>	<b>8,986</b>
<b>The funds of the charity</b>					
Endowment funds	17a	1,077	1,078	1,077	1,078
Restricted income funds	17a	423	480	423	480
<b>Unrestricted funds</b>					
Designated reserves	17a	(1,363)	1,844	(1,363)	1,844
Operating reserves		3,575	3,523	3,575	3,523
Retained reserves		2,786	2,061	2,786	2,061
<b>Total charity funds</b>		<b>6,498</b>	<b>8,986</b>	<b>6,498</b>	<b>8,986</b>

The notes on pages 29 to 49 form part of these financial statements.

The net movement in funds for the Trust for the year ended 31 March 2018 was – £2,488,000 (2017: 12 months – £1,779,000). 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 **25 July 2018** and signed on their behalf by:

**George Jenkins, Chairman**

Company number 3880213

	2018 £'000	2017 £'000
<b>Net cash provided by (used in) operating activities (Note A)</b>	<b>1,277</b>	<b>4</b>
<b>Cash flows from investing activities:</b>		
Dividends and interest	242	216
Purchase of property, plant and equipment	(2)	(23)
Purchase of investments	(983)	(236)
Movement in cash awaiting investment	(1,344)	(59)
Proceeds of sales of investments	2,235	239
	<b>148</b>	<b>137</b>
Increase/(decrease) in cash held as short term investments	(43)	955
<b>Increase/(decrease) in cash (Note B)</b>	<b>1,172</b>	<b>1,096</b>
<b>Notes to Cash Flow Statement</b>		

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

	2018 £'000	2017 £'000
Net (expenditure)/income for the reporting period (as per the statement of financial activities)	(2,488)	(1,779)
<b>Adjustment for:</b>		
Fixed asset disposal gain	-	-
Depreciation charges	321	397
Dividends and interest from investments	(242)	(216)
(Gains)/losses on investments	13	(589)
Decrease/(increase) in debtors	(453)	571
Increase/(decrease) in creditors	1,572	1,620
	<b>(1,277)</b>	<b>4</b>

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

	2018 £'000	2017 £'000
Cash and cash equivalents at the beginning of the reporting period	13,558	13,417
Change in cash and cash equivalents in the reporting period	(1,172)	1,096
Decrease in short-term investments	43	(955)
<b>Cash and cash equivalents at the end of the reporting period</b>	<b>12,429</b>	<b>13,558</b>
(being cash at bank and in hand and cash held as short-term investments)		
	<b>2018</b>	<b>2017</b>
<b>Analysis of cash and cash equivalents:</b>	<b>£'000</b>	<b>£'000</b>
Cash on hand	1,078	2,250
Notice deposits (less than 3 months)	11,351	11,308
<b>Total cash and cash equivalents</b>	<b>12,429</b>	<b>13,558</b>



## **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 50. In the event of the company being wound up, the liability in respect of the guarantee is limited to £1 per member of the company.

### **c) Consolidation**

The financial statements include the results and assets and liabilities of the charity and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own Statement of Financial Activities under section 408 of Companies Act 2006. The deficit for the parent charity was £2,448,000 (2017 – deficit of £1,779,000).

### **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 UK CF Registry.

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

**f) Grants**

Grants committed and awarded during the year are expensed.

**g) Foreign currency transactions**

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

**h) Employee benefits**

- Short-term benefits – Short-term benefits including holiday pay are recognised as an expense in the period in which the service is received.
- Employee termination benefits – Termination benefits are accounted for on an accrual basis and in line with FRS 102.
- Pension scheme – The Charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Charity pays fixed contributions into a separate entity. Once the contributions have been paid the Charity has no further payment obligations. The contributions are recognised as an expense in the Statement of Financial Activities when they fall due.

**i) Taxation**

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

**j) Leases**

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

**k) Funds**

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

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

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

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

**l) Fixed assets and depreciation**

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

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

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

**m) Investments**

Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values 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 £'000	Restricted Funds £'000	<b>Total 2018 £'000</b>	Total 2017 £'000
Branches, Groups & Community	4,062	62	<b>4,124</b>	4,071
Legacies	1,351	149	<b>1,500</b>	1,766
Individual donations	242	70	<b>312</b>	234
Corporate	269	1	<b>270</b>	291
Regular giving and appeals	1,146	47	<b>1,193</b>	1,164
Trusts	113	876	<b>989</b>	994
Appeal for Innovation Hub	-	126	<b>126</b>	-
Donations in kind	3,491	-	<b>3,491</b>	1,901
Gift Aid	614	-	<b>614</b>	551
NHS National Services England	89	-	<b>89</b>	81
NHS National Services Scotland	46	-	<b>46</b>	45
<b>Total income from donations and legacies</b>	<b>11,423</b>	<b>1,331</b>	<b>12,754</b>	<b>11,098</b>

Other Income (shown separately on the Statement of Financial Activity) comprises a reclaim of partially recoverable VAT on eligible purchases, received from HMRC in the year (2017 – £139,000). The Trust is now claiming recoverable VAT on a quarterly basis.

Donations In Kind refer to non-monetary donations received from partner organisations. In 2017/18, £3,491,000 was donated in the form of digital advertising space (2016/17 – £1,901,000). This space 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 £'000	Restricted Funds £'000	<b>Total 2018 £'000</b>	Total 2017 £'000
Income from listed investments	154	25	<b>179</b>	211
Bank interest	63	-	<b>63</b>	5
<b>Total investment income</b>	<b>217</b>	<b>25</b>	<b>242</b>	<b>216</b>



## 3a. Expenditure

	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	Total 2018 £'000	Total 2017 £'000
<b>Raising funds</b>						
Fundraising	-	-	2,599	458	3,057	3,119
Trading and merchandising	-	799	59	-	858	592
<b>Charitable activities</b>						
Research	1,074	3,117	991	914	6,096	5,505
Clinical care	142	212	873	216	1,443	1,678
Information, advice & support	196	178	4,889	928	6,191	4,656
	1,412	4,306	9,411	2,516	17,645	15,550

Analysis of allocated  
Support Costs

	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	Total 2018 £'000	Total 2017 £'000
Fundraising	84	77	120	54	123	458	579
Research	168	153	239	108	245	913	1,022
Clinical care	40	36	57	26	58	217	313
Information, advice & support	171	155	243	109	250	928	511
<b>Total costs</b>	463	421	659	297	676	2,516	2,425

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.

**3a. Expenditure (continued)**

**Net (expenditure)/income in the year:**

	<b>2018</b>	2017
	<b>£'000</b>	£'000
Auditors remuneration excluding VAT	<b>20</b>	20
Auditors – tax advice	<b>38</b>	27
Depreciation	<b>320</b>	397
Operating leases – building	<b>244</b>	244
Operating leases – other	<b>6</b>	23
Trustees' travel expenses	<b>2</b>	2

**3b. Grants**

Grants were awarded during the year as follows:

	<b>2018</b>	2017
	<b>£'000</b>	£'000
Grants to institutions	<b>5,344</b>	4,552
Grants to individuals	<b>374</b>	305
	<b>5,718</b>	4,856

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.

	<b>2018</b>	2017
	<b>£'000</b>	£'000
Balance at start of year	10,832	8,967
Awarded in the year	5,719	4,856
Paid in year	(3,946)	(2,991)
<b>Balance at end of year</b>	<b>12,605</b>	<b>10,832</b>
Falling due within one year (note 9)	7,276	6,144
Falling due after more than one year (note 9)	5,329	4,688

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

	<b>2018</b>
	<b>£'000</b>
University of Cambridge/Papworth Hospital	2,065
Imperial College, London/Royal Brompton Hospital	999
University of Newcastle/Newcastle Hospital	752
Neem Biotech	100
Action Medical Research	90
Sheffield University	75
University College London	65
University of Exeter	55
Magic Bullet (with Cambridge and Microsoft)	50
Manchester University/Wythenshaw Hospital	47
University College Cork	42
ECFS – European Cystic Fibrosis Society	21

3b. Grants (continued)

James Lind Alliance/Queen's Medical Centre Nottingham	15
Queen's University Belfast	15
AMRC	9
University of Dundee	2
	<b>4,402</b>
Add: Trial Coordinator commitments made to CTAP centres (see note)	143
Add: Registry support grants made to various CF centres	799
<b>Total grants made to institutions</b>	<b>5,344</b>

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform programme. The first year cost of all those coordinators in post as at 31 March 2018 has been recognised in the accounts.

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

**4. Staff costs**

Staff costs comprise the following:

	2018 £'000	2017 £'000
Salaries	4,019	3,856
Redundancy and other termination payments	18	62
Temporary Staff	97	105
Social security costs	428	401
Other pension costs	240	220
	<b>4,802</b>	<b>4,644</b>

Redundancy and other termination payments totalling £18,000 were paid to four (2017 – £62,000 paid to two) staff members in the year. The Trust has continued to restructured teams to ensure they are fit for purpose to meet strategic priorities and efforts have been made to redeploy into new roles.

**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 £240,000 (2017 – £220,000).

**Analysis of total average monthly headcount  
by category:**

	2018 No.	2017 No.
Research	11	8
Clinical care	6	6
Information, advice & support	36	34
Fundraising	40	43
Management	7	3
Finance	5	5
IT and project management support	6	6
HR & OD	4	3
Facilities	2	3
<b>Total average monthly headcount</b>	<b>117</b>	<b>111</b>

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

	2018 No.	2017 No.
£60,001 – £70,000	2	4
£70,001 – £80,000	2	1
£80,001 – £90,000	1	1
£90,001 – £100,000	-	1
£110,001 – £120,000	1	-

Pension contributions to defined contribution pension schemes for these employees totalled £31,127 (2017 – £24,398).

Remuneration of key management personnel: The total remuneration paid to key management personnel, including pension and social security contributions, was £549,000 which relates to seven individuals who served on the Senior Leadership Team during the year (2017 – £392,000 paid to six individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. Expenses of £1,720 (2017 – £2,096) were settled on four (2017 – six) trustees.



## 5. Fixed assets

	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
<b>Cost</b>						
At 31 March 2017	630	791	243	403	183	2,250
Additions	-	2	-	-	-	2
<b>At 31 March 2018</b>	<b>630</b>	<b>793</b>	<b>243</b>	<b>403</b>	<b>183</b>	<b>2,252</b>
<b>Depreciation</b>						
At 31 March 2017	480	724	243	206	147	1,800
Charge for the year	135	47	-	102	36	320
<b>At 31 March 2018</b>	<b>615</b>	<b>771</b>	<b>243</b>	<b>308</b>	<b>183</b>	<b>2,120</b>
<b>Net book value at 31 March 2018</b>	<b>15</b>	<b>22</b>	<b>-</b>	<b>95</b>	<b>-</b>	<b>132</b>
Net book value at 31 March 2017	150	67	-	197	36	450

## 6. Investments

Group and Charity	Total 2018 £'000	Total 2017 £'000
Market value as at 31 March 2017	5,826	5,181
Additions at cost	985	236
Disposals at opening book value	(2,235)	(203)
Net gains/(losses) on investments	(17)	452
	<b>4,559</b>	<b>5,666</b>
Change in cash	<b>1,345</b>	160
Market value as at 31 March 2018	<b>5,904</b>	<b>5,826</b>

**6. Investments (continued)**

Represented by:	<b>Total 2018 £'000</b>	<b>Total 2017 £'000</b>
Equities	<b>2,475</b>	3,368
Fixed Interest and multi-asset funds	<b>1,011</b>	993
Property	<b>835</b>	841
Cash	<b>1,583</b>	624
	<b>5,904</b>	5,826

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 2018. These make up more than 5% of total investments:

	<b>Total 2018 £'000</b>
Schroder Chartity Equity fund	<b>592</b>
Schroder Emerging Market Debt	<b>762</b>
Trojan Income fund	<b>193</b>
The Equity Income Trust for Charities	<b>1,160</b>
The income trust for Charities	<b>326</b>
Charities property fund	<b>387</b>
Property income trust for charities	<b>448</b>
Ruffer charity assets Trust	<b>492</b>
Cystic Fibrosis General Fund	<b>1,257</b>

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**

	<b>Group 2018 £'000</b>	<b>Group 2017 £'000</b>	<b>Charity 2018 £'000</b>	<b>Charity 2017 £'000</b>
Trade debtors	<b>393</b>	308	-	-
Amount due from subsidiary undertaking	-	-	<b>386</b>	605
Prepayments and accrued income	<b>1,247</b>	937	<b>1,247</b>	937
Other debtors	<b>117</b>	59	<b>117</b>	59
	<b>1,757</b>	1,304	<b>1,750</b>	1,601

**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

	2018 £'000	2017 £'000
Grant creditor at 31 March 2017	10,832	8,967
Grants paid during the year	(3,943)	(2,991)
Grants approved before 31 March 2018 and payable within one year	2,564	2,841
Grants approved before 31 March 2018 and payable after one year	3,152	2,015
<b>Grant creditor at 31 March 2018</b>	<b>12,605</b>	<b>10,832</b>

## Represented by

Grants due within one year at 31 March 2018	7,276	6,144
Grants due > 12 months	5,329	4,688
	<b>12,605</b>	<b>10,832</b>

## 10. Creditors

	Group 2018 £'000	Group 2017 £'000	Charity 2018 £'000	Charity 2017 £'000
Trade creditors	357	566	349	565
Other creditors	245	89	245	89
Accruals and deferred income	517	665	515	654
	<b>1,119</b>	<b>1,320</b>	<b>1,109</b>	<b>1,308</b>

## 11. Financial Instruments (Assets and Liabilities)

	Group 2018 £'000	Group 2017 £'000	Charity 2018 £'000	Charity 2017 £'000
Financial assets measured at amortised cost (note a)	12,880	13,917	12,880	13,917
Financial assets measured at fair value (note b)	5,904	5,826	5,904	5,826
Financial liabilities measured at amortised cost (note c)	(13,600)	(12,153)	(13,600)	(12,153)
<b>Net financial assets measured at amortised cost</b>	<b>5,184</b>	<b>7,590</b>	<b>5,184</b>	<b>7,590</b>

(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 subsidiary

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:

	<b>Total 2018 £'000</b>	<b>Total 2017 £'000</b>
Sales and sundry income	<b>1,830</b>	1,729
Cost of sales and administration	<b>(858)</b>	(592)
Intercompany recharges	<b>(72)</b>	(70)
<b>Net contribution to parent charity</b>	<b>900</b>	1,067

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

	<b>Total 2018 £</b>	<b>Total 2017 £</b>
<b>Current Assets</b>		
Debtors	<b>393,351</b>	308,525
Cash at bank	<b>2,331</b>	309,007
	<b>395,682</b>	617,532
<b>Creditors:</b> amounts falling due within one year	<b>(395,680)</b>	(617,530)
<b>Net Current Assets</b>	<b>2</b>	2
<b>Net Assets</b>	<b>2</b>	2
<b>Capital and Reserves</b>		
Called up share capital	<b>2</b>	2
Profit and loss account	<b>-</b>	-
<b>Shareholder's funds</b>	<b>2</b>	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. Two shares have been allotted, which are called up and fully paid.



### 13. Leasing commitments

At 31 March 2018, the Trust's future minimum operating leases payments relating to buildings were:

	2018 £'000	2017 £'000
Within one year	271	271
Between two and five years	271	543

A 10-year property lease with a 5-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 2018, the Trust's future minimum operating leases payments relating to equipment were:

	2018 £'000	2017 £'000
Within one year	6	23
Between two and five years	24	35

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 £34,022 (2017 – £2,676). In addition, two of the trustees (2017 – two) were involved in fundraising activities carried out by regional fundraising branches.

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	Endowment funds	Other restricted	<b>2018</b>
	£'000	£'000	£'000	£'000
Tangible fixed assets	132	-	-	132
Investments	4,827	1,077	-	5,904
Current assets	14,186	-	423	14,186
Internal obligations	-	-	-	-
Current liabilities	(8,395)	-	-	(8,395)
Liabilities due in more than one year	(5,752)	-	-	(5,329)
	4,998	1,077	423	6,498

**Prior year funds**

	Unrestricted	Endowment funds	Other restricted	<b>2017</b>
	£'000	£'000	£'000	£'000
Tangible fixed assets	450	-	-	450
Investments	4,748	1,078	-	5,826
Current assets	14,862	-	-	14,862
Internal obligations	-	-	-	-
Current liabilities	(7,464)	-	-	(7,464)
Liabilities due in more than one year	(5,168)	-	480	(4,688)
	7,428	1,078	480	8,986

## 17a. Current 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
<b>Total Designated Reserves</b>	<b>1,844</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>(3,206)</b>	<b>(1,362)</b>
Operating reserve	3,523	-	-	-	52	3,575
Retained reserves	2,061	(18)	13,813	(16,610)	3,539	2,785
<b>Total General Reserves</b>	<b>5,584</b>	<b>(18)</b>	<b>13,813</b>	<b>(16,610)</b>	<b>3,591</b>	<b>6,360</b>
<b>Total Unrestricted Funds</b>	<b>7,428</b>	<b>(18)</b>	<b>13,813</b>	<b>(16,610)</b>	<b>385</b>	<b>4,998</b>
<b>Restricted Income Funds:</b>						
Innovation Hub	-	-	136	(136)	-	-
<b>Restricted funds related to research:</b>						
Gene Therapy Research	-	-	54	-	(54)	-
General Medical Research	-	-	75	(75)	-	-
Imperial College SRC: Pseudomonal infection	-	-	61	-	(61)	-
Cambridge SRC: Mycobacterium abscessus infection	-	-	75	-	(75)	-
UCL SRC: Personalised Engineered Cell Therapies	-	-	113	-	(113)	-
UCL VIA: Prenatal diagnosis for autosomal recessive conditions	-	-	5	-	(5)	-
Tim Lee (Leeds) Clinical Excellence Award: youth worker	-	-	17	-	(17)	-
P Harrison, Uni of Cork VIA011, Crispr	-	-	10	-	(10)	-
A 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
<b>Total funds related to research</b>	<b>163</b>	<b>-</b>	<b>496</b>	<b>(152)</b>	<b>(386)</b>	<b>121</b>
<b>Restricted funds related to information and support</b>						
E W Joseph/Homecare grants	59	-	9	(8)	-	60
Joseph Levy/Education Grants	14	-	35	(60)	21	10
Support services (including welfare grants)	51	-	296	(314)	-	33
CF Connect (youth and parents)	26	-	-	-	-	26
<b>Total funds related to information &amp; support</b>	<b>150</b>	<b>-</b>	<b>340</b>	<b>(382)</b>	<b>21</b>	<b>129</b>

Continued on next page

17a. Current year fund movements (continued)

Coombe Hill	-	-	29	(10)	(9)	10
Kings fund	157	-	-	-	-	157
Paediatrics	4	-	-	-	-	4
Vertex – Everest trip	6	-	-	-	(6)	-
SmartCare CF	-	-	5	-	(5)	-
Clinical Trials Accelerator Programme (CTAP)	-	-	348	(348)	-	-
North Midlands – medical equipment	-	-	1	-	-	1
Old funds – various	-	-	1	-	-	1
<b>Total Other Restricted Income Funds</b>	<b>480</b>	<b>-</b>	<b>1,220</b>	<b>(892)</b>	<b>(385)</b>	<b>423</b>
<b>Total Restricted Income Funds</b>	<b>480</b>	<b>-</b>	<b>1,356</b>	<b>(1,028)</b>	<b>(385)</b>	<b>423</b>
<b>Endowment Funds:</b>						
Ena Bennie Endowment	538	3	-	(4)	-	537
EW Joseph Endowment	178	1	-	(1)	-	178
Joseph Levy Endowment	307	2	-	(2)	-	307
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other Endowment funds	35	-	-	-	-	35
<b>Total Endowment Funds</b>	<b>1,078</b>	<b>6</b>	<b>-</b>	<b>(7)</b>	<b>-</b>	<b>1,077</b>
<b>Total Charity Funds</b>	<b>8,986</b>	<b>(12)</b>	<b>15,169</b>	<b>(17,645)</b>	<b>-</b>	<b>6,498</b>

## 17a. Funds (continued)

**Designated Funds:** The designed 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 million in the form of a research grant to Cambridge University as part of the Innovation Hub flagship programme. To date we have received £0.1 million from donors in funding for this grant (shown in the separate restricted fund line, see below), with a further £1.1 million of funding pledges secured. The Trust has underwritten this grant, but hopes 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 will be used to fund the budgeted deficit in the 2018/19 financial year. This planned excess of expenditure over income will enable the Trust to commit to continuing with strategically important activities.

**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.

**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 £0.1m to date in funding towards a £2 million 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 corresponding 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

### Strategic Research Centres:

Imperial College: Pseudomonal infection  
Cambridge: Mycobacterium abscessus infection  
Newcastle: INOVCF-Innovative non-CFTR Approaches  
Bristol: F508del0CFTR  
UCL: Personalised Engineered Cell Therapies  
Newcastle: Microbacterium abscessus infection  
Exeter: Activity & Exercise  
Newcastle: Cystic Fibrosis Related Diabetes

### Venture Innovation Awards:

UCL: Prenatal diagnosis for autosomal recessive conditions  
Imperial College: Antibacterial activity of Glatiramer acetate  
University of Cork: Crispr  
University of Liverpool: CF Start

### Clinical Excellence and Innovation Awards:

University of Leeds: Youth Worker  
Frimley Park Hospital: Exercise project  
Manchester University: Exercise and Nutrition  
Sport England funded work  
Exeter University: Helping the active stay active  
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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## 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 closely 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 studies.

**Clinical Trials Accelerator Platform** – funding this flagship programme.

**North Midlands, medical equipment** – a legacy donation received by the Cystic Fibrosis Trust which was restricted 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 Fixed Asset Reserve and the Retained Reserves in order to match the balance sheet fixed asset balance
- A transfer was made between the Operational Reserve and the Retained Reserves in order to follow the policy outlined above for the Operational Reserve balance
- 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
- Transfers were made from the endowment funds into the corresponding restricted reserves as described above. These relate to the net income arising from these endowment funds in the year.

## 17b. Prior year fund movements

	Balance					Balance
	31 March 2016 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	31 March 2017 £'000
Fixed asset reserve	824	-	-	-	(374)	450
Strategic reserve	2,050	-	-	-	(656)	1,394
<b>Total Designated Reserves</b>	<b>2,874</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>(1,030)</b>	<b>1,844</b>
Operating reserve	4,542	-	-	-	(1,019)	3,523
Retained reserves	1,767	517	12,159	(14,554)	2,172	2,061
<b>Total General Reserves</b>	<b>6,309</b>	<b>517</b>	<b>12,159</b>	<b>(14,554)</b>	<b>1,153</b>	<b>5,584</b>
<b>Total Unrestricted Funds</b>	<b>9,183</b>	<b>517</b>	<b>12,159</b>	<b>(14,554)</b>	<b>123</b>	<b>7,428</b>
<b>Restricted Income Funds Deficit:</b>						
Gene Therapy Research (Deficit)	(20)	-	-	-	20	-
<b>Other Restricted Income Funds:</b>						
<b>Restricted funds related to research:</b>						
Gene Therapy Research	171	-	56	(238)	11	-
General Medical Research	-	-	55	(55)	-	-
Imperial College SRC: Pseudomonal infection	-	-	81	-	(81)	-
Cambridge SRC: Mycobacterium abscessus infection	-	-	1	-	(1)	-
Newcastle SRC: INOVCF-Innovative non-CFTR Approaches	-	-	-	-	-	-
Bristol SRC: F508del0CFTR	-	-	-	-	-	-
UCL SRC: Personalised Engineered Cell Therapies	-	-	27	-	(27)	-
UCL VIA: Prenatal diagnosis for autosomal recessive conditions	-	-	4	-	(4)	-
Liverpool VIA: CF Start	-	-	3	-	(3)	-
Leeds Clinical Excellence Award: Youth worker	-	-	5	-	(5)	-
Imperial College VIA: Antibacterial activity of Glatiramer acetate	-	-	11	-	(11)	-
Newcastle SRC: Mycobacterium Abscessus Infection	-	-	10	-	(10)	-
Cork VIA: Crispr	-	-	-	-	-	-
Frimley Park Clinical Excellence Award: Exercise	-	-	-	-	-	-
Exeter SRC: Activity & Exercise	-	-	-	-	-	-
Newcastle SRC: Cystic Fibrosis related Diabetes	-	-	5	-	(5)	-
Genotyping – 600 Study	47	-	-	-	70	117
Genetics Repair/Editing	-	-	20	-	-	20
Other research related restricted funds	11	-	45	(31)	1	26
<b>Total funds related to research</b>	<b>229</b>	<b>-</b>	<b>323</b>	<b>(324)</b>	<b>(65)</b>	<b>163</b>

Continued on next page

17b. Prior year fund movements (continued)

	Balance					Balance
	31 March 2016 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	31 March 2017 £'000
<b>Restricted funds related to information &amp; support:</b>						
E W Joseph/Homecare grants	58	-	0	(8)	9	59
Joseph Levy/Education Grants	10	-	20	(54)	38	14
Sailing fund	33	-	-	-	(33)	-
Support services (inc. welfare grants)	46	-	86	(114)	33	51
CF Connect (youth and parents)	27	-	-	(1)	-	26
<b>Total funds related to information &amp; support</b>	<b>174</b>	<b>-</b>	<b>106</b>	<b>(177)</b>	<b>47</b>	<b>150</b>
Coombe Hill	11	-	11	(10)	(12)	-
Craig Legacy	-	-	-	-	-	-
Golf days	-	-	3	(3)	-	-
Kings Fund	157	-	-	-	-	157
Paediatrics	4	-	-	-	-	4
Peer Review	-	-	-	-	-	-
Vertex – Everest trip	6	-	-	-	-	6
SmartCareCF	-	-	-	-	-	-
Clinical Trials Accelerator Programme	-	-	474	(474)	-	-
CF Registry	-	-	55	-	(55)	-
<b>Total Other Restricted Income Funds</b>	<b>582</b>	<b>-</b>	<b>972</b>	<b>(989)</b>	<b>(85)</b>	<b>480</b>
<b>Total Restricted Income Funds</b>	<b>562</b>	<b>-</b>	<b>972</b>	<b>(989)</b>	<b>(65)</b>	<b>480</b>
<b>Endowment Funds:</b>						
Ena Bennie Endowment	507	36	27	(4)	(28)	538
EW Joseph Endowment	167	12	9	(1)	(9)	178
Joseph Levy Endowment	289	20	15	(2)	(15)	307
Robert Couper Endowment	-	-	-	-	-	-
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other endowment funds	37	4	-	-	(6)	36
<b>Total endowment funds</b>	<b>1,020</b>	<b>72</b>	<b>51</b>	<b>(7)</b>	<b>(58)</b>	<b>1,078</b>
<b>Total charity funds</b>	<b>10,765</b>	<b>589</b>	<b>13,182</b>	<b>(15,550)</b>	<b>-</b>	<b>8,986</b>

## 18. Prior year Consolidated Statement of Financial Activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2017 £'000
<b>Income and endowments from:</b>					
Donations and legacies	2	10,126	972	-	11,098
Other trading activities	12	1,729	-	-	1,729
Investments	2b,6	165	-	51	216
<b>Other income:</b>					
Other income	2	139	-	-	139
<b>Total</b>		<b>12,159</b>	<b>972</b>	<b>51</b>	<b>13,182</b>
<b>Expenditure on:</b>					
Raising funds	3	3,689	19	3	3,711
<b>Charitable activities</b>					
Research		5,205	299	1	5,505
Clinical care	3	1,204	474	-	1,678
Information, advice & support		4,456	197	3	4,656
<b>Total charitable activities</b>		<b>10,865</b>	<b>970</b>	<b>4</b>	<b>11,839</b>
<b>Total resources expended</b>	3	<b>14,554</b>	<b>989</b>	<b>7</b>	<b>15,550</b>
<b>Net income/(expenditure) before investment gains/losses</b>		<b>(2,395)</b>	<b>(17)</b>	<b>44</b>	<b>(2,368)</b>
Realised investment gains/(losses)		38	-	1	39
Unrealised investment gains/(losses)		479	-	71	550
<b>Net investment gains/(losses)</b>		<b>517</b>	<b>-</b>	<b>72</b>	<b>589</b>
<b>Net (expenditure) income</b>		<b>(1,878)</b>	<b>(17)</b>	<b>116</b>	<b>(1,779)</b>
Transfers between funds	17a	123	(65)	(58)	-
<b>Net movement in funds</b>		<b>(1,755)</b>	<b>(82)</b>	<b>58</b>	<b>(1,779)</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward		9,183	562	1,020	10,765
<b>Total funds carried forward</b>	17a	<b>7,428</b>	<b>480</b>	<b>1,078</b>	<b>8,986</b>

## Structure, governance and management

### > Patron

- HRH The Prince of Wales KG KT GCB OM

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### > Honorary President

- Dr James Littlewood OBE MO FRCP FRCPE DCH

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### > Trustees

#### Chairman

- George Jenkins OBE<sup>1</sup>

#### Vice Chairman

- Professor John Price MD FRCP FRCPCH (resigned July 2017)
- Caroline Cartellieri Karlsen<sup>1</sup>
- Peter Norris (resigned March 2018)
- David Turner QC<sup>1</sup>
- Professor Andrew Jones
- Michael Winehouse<sup>1</sup>
- Louise King<sup>1</sup>
- Hannah Begbie<sup>1</sup> (resigned December 2017)
- Ffyona Dawber
- Ryan Tohill
- Professor Rosalind Smyth (appointed July 2017)
- Sean Collins (appointed July 2017)

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### > Finance and Audit Committee

#### Chairman

- Peter Norris resigned March 2018)
- Sean Collins (appointed July 2017)

- David Turner QC
- Stephen Mullen (Independent Member)<sup>1</sup>
- David Sawyer (Independent member)
- Guy Harington (Investments Committee)
- Alistair Peel (Investments Committee)

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### > Nomination & Development Committee

#### Chairman

- George Jenkins OBE
- Professor John Price MD FRCP FRCPCH (resigned July 2017)
- Ffyona Dawber
- Louise King
- Caroline Cartellieri Karlsen
- David Turner QC<sup>1</sup>
- Professor Andrew Jones

### > Charity Management

- David Ramsden – Chief Executive
- Elizabeth Bishop FCA – Director of Finance and Resources (resigned June 2018)
- Louise Honeysett ACA – Director of Finance and Resources (appointed June 2018)
- Dr Janet Allen MD FRSE – Director of Strategic Innovation
- Dr Keith Brownlee – Director of Impact
- Anne Shinkwin – Director of Fundraising
- Oli Lewington – Director of Engagement

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### > Company Secretary

- Louise Honeysett ACA – Director of Finance and Resources

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### > Principal and Registered Office

One Aldgate  
London  
EC3N 1RE

**T** 020 3795 1555

**E** [enquiries@cysticfibrosis.org.uk](mailto:enquiries@cysticfibrosis.org.uk)

**W** [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)

Company Limited by Guarantee  
Company registration number: 3880213  
Charity registration number:  
England & Wales — 1079049  
Scotland — SC040196

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### > Auditors

haysmacintyre  
10 Queen Street Place, London EC4R 1AG

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### > Bankers

Natwest Plc  
15 Bishopsgate London EC2N 3NW

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### > Investment Managers

Cazenove Capital Management  
12 Moorgate London EC2R 6DA

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<sup>1</sup> 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.





**[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)**

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