

Cystic Fibrosis why we're here

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

For the year ended 31 March 2017

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 2017.

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.

Chairman's Statement

This year has been one of great change and great excitement for the Cystic Fibrosis Trust. The Trust's investment in the highest quality research and innovation in new therapies made possible only through the generous donations of our supporters, has ensured developments have maintained their momentum. There is a real sense of moving forward, a sense that we are making a difference. New therapies becoming available both in the here and now but also on the horizon. More researchers and pharmaceutical companies working in this area. More possibilities of a life unlimited for everyone affected by cystic fibrosis.

We are working hard with the NHS and drug companies to reach an agreement that will make these new therapies accessible to everyone who's eligible for them.

Our Information and Support services have helped ensure hundreds of people with cystic fibrosis are receiving the benefits to which they are entitled, assuaging some of the fears and doubts around the Government's introduction of the Personal Independence Payment in place of the former Disability Living Allowance.

These developments have only been possible thanks to the support of our wonderful community: the incredible fundraising efforts of people who give up their time and money to help fight for a life unlimited for people with cystic fibrosis. We must also give thanks to the clinicians and multi-disciplinary teams who dedicate their lives to caring for people with cystic fibrosis, and the best and the brightest researchers we fund across the world who will not stop until we beat CF for good.

Despite the great work that is happening, and the fact that median predicted survival has now reached 47, half of all people with cystic fibrosis who died last year were under the age of 30. That's unacceptable. Cystic fibrosis still carries with it an enormous burden of care that adds hours of treatment to people's everyday lives. It still comes with weeks every year lost to outpatient hospital appointments, inpatient stays and days taken off from work or school because of illness. And it still means an uncertain future for those living with the condition.

Together we can change and we will change this. Your Trustee Board is focussed on making change happen: we have a refreshed leadership team under our new Chief Executive, David Ramsden, a fantastic team of dynamic and dedicated staff, a UK-wide army of volunteers and fundraisers, but most importantly we have **you**, the cystic fibrosis community. Together we will beat this.

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 is a life-limiting genetic condition that destroys the lungs and digestive system. More than 10,800 people in the UK live with the condition and have to undergo a brutal daily regime of physiotherapy and can take up to 60 tablets a day, just to stay healthy. Despite these treatments, many people with cystic fibrosis will go on to require a double-lung transplant.

According to the 2015 UK Cystic Fibrosis Registry Report, the median predicted survival for people with cystic fibrosis in the UK is 47; however, the median age of death is just 28.

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 cystic fibrosis;
- collaborate with and support the clinical community to drive up standards of care;
- provide information, advice and support for everyone affected by cystic fibrosis;
- campaign and influence policy affecting the cystic fibrosis community; and
- raise awareness of cystic fibrosis 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 cystic fibrosis for good. Launched in 2015, 'Life Unlimited' is our five-year vision for achieving a life unlimited is built around five main areas of work:

- Empowering young lives
- Supporting breaths for life
- Harnessing the power of knowledge
- Making ambitions possible
- Changing lives through transformational treatments

> Measuring success

Criteria for success in 2016/17 were tracked onto our Activity Database, where individual projects and work-streams can be monitored by relevant leaders within the organisation.

SMART measures were used where applicable and, as well as using data-driven analysis, we sought to ensure there was narrative attached to each target. This explained 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 Cystic Fibrosis Trust is the biggest charity funder of research specifically for the benefit of people with cystic fibrosis 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 cystic fibrosis 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 cystic fibrosis, 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 2017 to discuss the governance and progress of the current SRCs.

SAB will meet in summer 2017 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 cystic fibrosis, 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 cystic fibrosis research outside the traditional biomedical disciplines and attract high-quality new investigators from new research fields.
- Recruit the brightest and best young researchers into cystic fibrosis research.

Each SRC includes funding for five or six early-career researchers who work alongside experts, building a life-long interest in the field. These centres investigate the big issues affecting people with cystic fibrosis, such as cystic fibrosis-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.

The Trust called for submissions for new SRCs in the year and committed £2.25 million to launch three new SRCs, including two as a result of a Trust-funded research sandpit (below) to tackle some of the effects of cystic fibrosis on the digestive system.

> Research sandpit

In February 2016, the Trust held a research sandpit bringing together digestive-system researchers and experts in cystic fibrosis to consider some of the digestive issues affecting people with the condition. Two of the three SRCs awarded in 2016/17 stem from this event, and will tackle this huge issue that affects many people with cystic fibrosis.

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

This SRC aims to investigate how altering the make-up of bacteria within the gut to increase the production of short chain fatty acids could reduce lung inflammation and improve lung health. It will work by studying the relationship between declining lung health, bacterial populations in the gut and the levels of short chain fatty acids in the digestive system, as well as exploring the effect of antibiotics on these bacteria in people with cystic fibrosis. Finally, a study will examine the effect of dietary supplementation with short chain fatty acids and/or fermentable fibre on inflammation in the lungs and rest of the body.

2. Restoration of luminal fluidity and microbiota in the gut

Slowed movement of digested food through the gut frequently leads to constipation and blockages that require hospital treatment and even surgery in people with cystic fibrosis. Existing treatments are limited in their success. This centre will investigate using licensed drugs and peptides to reduce the amount of sodium and water absorbed by the gut lining, to improve the movement of matter through the digestive system. This will include the use of lab-grown mini-guts called 'organoids' and result in a large clinical trial for the best treatment identified.

3. Novel therapies for *Mycobacterium abscessus*

Mycobacterium abscessus is a type of bacteria that can cause devastating lung infections in people with cystic fibrosis. It is very difficult to treat and is growing in frequency around the world. This SRC aims to use a mixture of existing expertise and cutting-edge technologies developed for other applications to develop new antibiotics and other ways of preventing and fighting these infections, and to strengthen existing treatments.

Meanwhile, the Trust continued the administration and monitoring of nine existing SRCs spanning a range of topics of benefit to the whole CF community. These amount to over £6.3m in investment into these vital areas of research over the last three years.

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 cystic fibrosis 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 cystic fibrosis: identifying therapeutic targets in CF arthropathy

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

> Venture and Innovation Awards

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.

In 2016/17 we committed more than £587,000 to fund nine new VIA projects and bought an additional £1.6 million into cystic fibrosis research from external organisations as a result. New projects are tackling issues such as the effect of diet on CF-related diabetes, the effect of pollution on infections and drug discovery.

We also committed £500,000 to continue our support of the Gene Therapy Consortium at University of Oxford, University of Edinburgh and Imperial College London.

We continued our commitment to supporting the next generation of scientists with £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 cystic fibrosis or lung health in general.



CF's Got Talent

Our first ever 'CF's Got Talent!' competition saw six early-career researchers funded by the Trust present their work to an online audience of people with cystic fibrosis and their families as well as everyone in attendance at our flagship annual conference (see p9).

Clinical Trials Accelerator Platform

In September we announced the launch of the £2 million Clinical Trials Accelerator Platform, a flagship programme by the Trust designed to improve access to cutting-edge treatments for people with CF. The process of developing new drugs is sometimes hampered by a lack of clinical trial participants, often caused by people with cystic fibrosis not being given opportunities to take part. Supported by the Cystic Fibrosis Foundation, this programme will build a national network of CF centres and fund new research posts to support CF centres to grow their CF clinical trial portfolio; along with the creation of an educational clinical trials digital hub to be launched from the Trust website. All this means that people with CF will have increased access to clinical trial opportunities and feel empowered to take part in such opportunities.

In this financial year we ran the first of two competitive selection rounds for CF centres, with 14 CF centres applying to be part of the initial network, 10 of which were successful. Successful centres represent over 6,000 people across England and Scotland (over half the UK population of people with CF), with the intention of covering the vast majority of the rest of the population in the next round of selection, taking place in June 2017.

Clinical care

> Clinical Excellence & Innovation Awards

In 2016, we launched the first Clinical Excellence & Innovation Awards – a competitive grants programme, investing in new and progressive ideas in clinical care. We made six awards across the country and doubled our financial impact, as each project was match-funded by a separate source. In March 2017 we committed to funding a second round of Clinical Excellence and Innovation Awards.

> Clinical Fellowships for doctors and physiotherapists

The Trust's Clinical Fellowship Programme has sponsored dozens of clinicians to specialise in CF and many of the best and brightest 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 cystic fibrosis (CF), and aims to train the future leaders of specialist adult CF care.

The Trust is committed to enhancing this legacy and this year we sponsored a Clinical Fellow in London. We also opened applications for our first ever fellowship in the physiotherapy specialism, which was awarded to Newcastle Hospital.

> Advance Care Planning

This year, we developed Advance Care Plans, a tool for people with CF to help record their preferences and wishes for their family and CF team to refer to when they become more unwell and reach the end of their life.

Advance care planning allows people with cystic fibrosis to hope for the best, but plan for the worst. These discussions make it easier to express concerns and make requests about future care. We're also producing Advance Care Plan resources to help people with cystic fibrosis and their CF teams manage some of the difficult decisions they have to make at this time.

> Patient/carer experience survey

This year, we began a project to further drive up standards of care in all CF centres across the UK's specialist centres and network. In consultation with external professional CF special interest groups, as well as parent and patient representatives, we are developing a patient/carer experience survey to provide feedback on standards of care.

Our clinical care team has provided active involvement and advice during the working groups to reconfigure the West Midlands and Wessex adult CF services, and the Hull/York services.

We continue to give talks on patient experience and clinical care work at regional CF team meetings with CF professionals.



SmartCareCF

The adult remote monitoring study, led by Professor Andres Floto at Papworth hospital, concluded recruitment this year with 148 participants in total joining the study. The paediatric remote monitoring study, known as CLIMB-CF and led by Professor Jane Davies, recruited six centres, with a target of 120 participants to recruit. Royal Brompton is the lead centre, and is joined by Great Ormond Street, Alder Hey, Brighton, Newcastle, and North of Scotland Network. Due to the remoteness of patients from their centres in the North of Scotland, we believe it will be a particularly useful examination of the use of technology.

UK Cystic Fibrosis Registry

The UK CF Registry is a world-class database that includes over 99% of people with cystic fibrosis in the UK, who have consented to their data being submitted by their care team. The new Registry platform, launched last financial year, is a bespoke, flexible and adaptable platform that is easier for CF teams to use.

This year, we launched My CF Registry, a portal into the Registry to allow people with CF to add their own quality of life and wellbeing data.



We launched the first randomised CF registry-based trial in the world in May: CF START aims to evaluate antibiotic-prescribing methods in children, a topic 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.

We were the first CF Registry in the world to publish its Annual Data Report for 2015, and alongside the full report we provided an accessible ‘at a glance’ summary of infographics highlighting the main trends for that period.

Through four drug safety studies, one observational study, and two NHS contracts, the Registry generated income of £1.6 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.

Information and support for all

> Grants

Cystic fibrosis doesn't just take its toll on the lungs and the rest of the body, it can place families under financial strain too. So we spent over £240,000 on grants for people with CF, including small emergency grants, transplant grants (to help with the cost of the assessment process), health and wellbeing grants, holiday grants for over 18s and funeral grants. Feedback from recipients tells us that these grants provide hope and help lighten the burden of CF at difficult times.

We awarded £10,800 through the Helen Barrett Bright Ideas Awards to young people with CF who have the ambition of turning their hobby or passion into a business idea, helping them achieve financial freedom. Full-time employment can be difficult when you are juggling treatments and your health fluctuates – this programme helps inspire people with CF to consider being self-employed and take advantage of some of the flexibility that can allow.

We also spent £54,300 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 money worries.

> Benefits advice

Our new Welfare and Rights Advisor has supported 418 people with welfare advice provision this year, which has secured over £1.3million in benefits income for our beneficiaries, and we spent more than £6,600 on a pilot scheme providing benefits advice through a partnership with Citizens' Advice Bureau Belfast, supporting 228 individuals and families affected by CF in Northern Ireland.



Sangeeta Enright, Welfare and Rights Advisor

> Helpline

This year our helpline responded to over 3,700 calls and emails from people affected by CF, providing information, support and a listening ear when people need it the most. The expertise shared by our team has helped point people towards the services and information described in this report, ensuring that we reach as many people who could benefit as possible.

> CF Connect

As part of our commitment to offer support for everyone affected by cystic fibrosis, the CF Connect programme has established around 20 peer-to-peer contacts. The scheme puts parents of children with CF in touch via phone or email with others who have experience of the issues they may be going through. We also trained nine CF Connect volunteers in a special session aimed at providing parents with support on education issues.

> Information

We published new clinical guidelines on nutritional management of cystic fibrosis, a complex area for both clinicians and people with CF to get to grips with, yet one that can make such a difference to day-to-day life by supporting people with the condition to be strong enough to fight off infections and live the lives they want to.

We published comprehensive information resources to support people with CF during the difficult process of considering starting a family, and for families of children starting primary school.

With plenty of other specialist informative resources in the pipeline, we hope to ensure everyone affected by cystic fibrosis has access to accurate information about all aspects of the condition.

Campaigning hard

This year we have continued to campaign hard on the issues that matter, and have made some valuable ground, extending access to life-changing precision medicines to two-to-five year-olds as well as people with additional mutations.

Our public affairs activities brought issues around CF care and treatment into the public eye, particularly as our Stopping the Clock campaign continued throughout the year. As part of this, over 6,000 members of the CF community wrote to their MPs using our e-action to call for fair access to the precision medicines.

This action led to our parliamentary debate in Westminster, putting pressure on the Government to break the deadlock over pricing between the pharmaceutical company behind one of these precision medicines – Orkambi – and the NHS. The debate received cross-party support, and put stories from people with CF in front of the decision makers, resulting in the Government agreeing to meet with representatives from the Trust for meaningful discussions about a way forward.

Over seven million people watching BBC Breakfast heard about the plight of people with CF who are still waiting for Orkambi, and our digital workshop in December helped encourage people from the CF community to be more politically active.

In March, the Trust met with Health Minister Lord O'Shaughnessy; John Stewart, Acting Director of Specialised Commissioning; and Nicole Mather, Director at the Office of Life Sciences. The Minister paid tribute to the campaigning by the Trust and the community, agreed to re-open the door to negotiations with Vertex and confirmed that NHS England is considering how a solution proposed by the Trust could make use of UK CF Registry data and help break the deadlock and provide a fair and sustainable model for future CF treatments.

Raising awareness and more effectively engaging with our community

> CF Week

June 2016 saw a new look for CF Week, a nationwide week of awareness, this time focussed on the incredible research into CF happening both in the UK and across the globe. We broke down some of our most complex research projects into simple summaries and infographics and celebrated breakthroughs and young scientists specialising in the field.

> UKCFC

The UK Cystic Fibrosis Conference (UKCFC), our flagship event, is the UK's largest gathering devoted to cystic fibrosis. This year it took place in a new venue in Nottingham and brought together clinicians, healthcare professionals, researchers, academics and other leading experts from around the world. The first day was designed to inspire conversation, innovation and learning between experts in CF care and research, with the second day catering to a non-scientific audience.

We also launched 'CF's Got Talent', a new satellite event that saw six early-career researchers explain what they are working on to the CF community via video-link, hosted by celebrity supporter Roger Black. Nearly 1,000 people tuned in to watch online, and on-demand videos of the talks were watched nearly 500 times, demonstrating the impact of the conference beyond the audience present on the day.

> Clear Channel

We have developed our corporate partnership with Clear Channel, which is now running into its second year and providing incredible reach, including 10,000 posters in bus shelters across the UK and significant time across digital screens in London and Manchester, with a total value of over £1,898,000.

> New email marketing platform

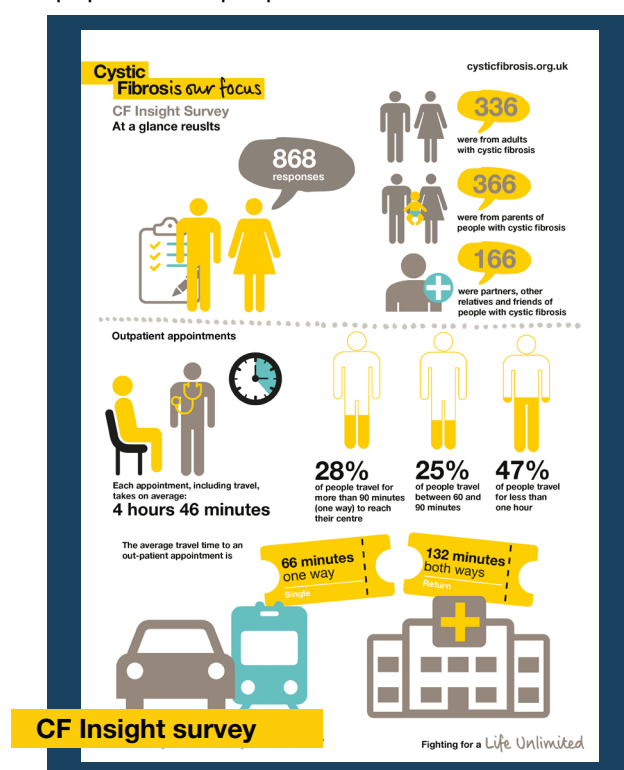
With our striking brand, varied communications and commitment to contacting our supporters in the way that's best for them, email marketing is a crucial part of our work to get right. We signed off on a new platform to allow us to be more consistent with our brand, more agile with our emails and more accurate and efficient with the way we use contact data.

> CF Life

In September we re-launched our magazine, using feedback from readers to shape the new look and content, and inviting our community to name the new publication. Over 20,000 people receive the new-look CF Life magazine (formerly 'Is'), and the response to the two editions in this year have been very positive, praising the way the stories have brought to life the varied experiences of all kinds of people affected by cystic fibrosis.

> CF Insight Survey

Nearly 1,000 people responded to the CF Insight Survey, which was co-developed with the community, telling us about their everyday lives and experiences; information that cannot be gleaned from other formal sources. Topics covered included employment and education, travel time to hospital, experience of clinical trials, use of technology and apps, plus preferences around discussing CF in new situations. This is a great foundation for us to build on for next year's survey, which we hope will capture the views of the population of people with CF in the UK.



Community involvement

We exist for our community, and to help them achieve a life unlimited they have to be at the heart of everything we do. The scope of community involvement in our projects increased greatly this year. We involved nearly 200 people with CF, in addition to family members and people otherwise affected by the condition, in 18 projects. This included the development of the Clinical Trials Accelerator Platform (see page 6), the CF Insight Survey, the Christmas Card competition, UK CF Registry development, Activity Unlimited development and the creation of various support and information packs. In addition to many of these projects, My CF Registry, Trials Accelerator PPI advocate roles and development of the Insight Survey should ensure we build on this progress next year.

The Trust also promoted involvement in a range of externally facilitated opportunities, including the James Lind Alliance work to understand which areas of CF research are the highest priority to the community. The main areas of interest include reducing the burden of treatment for people with CF, digestive issues, lung disease, antibiotics and infection, CF-related diabetes, exercise and adherence to treatment, which are reflected in our range of research programmes.

> Volunteering

We have 619 active volunteers, and have continued to grow our new volunteer support across the organisation this year. We would like to thank all our fantastic fundraising volunteers for their hard work and endless commitment to the Trust throughout this year. We provided support and training to CF Connect volunteers (see page 8) to extend the remit of the service to support calls around primary and secondary education. We delivered 602 hours of learning through our accredited Volunteer Management course and marketed it to other charities, bringing in £3,767 in income.

We provided seven summer work placement opportunities from June–September 2016. These volunteers were recruited from local schools, universities and internationally through the American Intern Service. The departments involved included Communications, Youth programme, Conferences and the website. These placements not only provided valuable work experience, but also enhanced the projects/works of the various teams.

Our partnership with Queen Mary University, the Q-Projects, went from strength to strength. This service provides students with fixed-term one-week placements. Due to the popularity of the service with various departments, and the excellent feedback we received from students, the Trust was used as a case study for the Q-Projects promotional video.

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 assure 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'. We launched our new HR system this year, bringing payroll in-house, saving money and giving us greater control of employee records.

We have a close relationship with a number of organisations, such as CDL, Born Survivor and Run 4 Wales, who provide us with support and services that help us reach our goals effectively.

> Supporter Experience

As part of our commitment to the CF community, we have reviewed our complaints process and reporting structure, so that all feedback is better able to drive excellence and to enhance our focus on the people who support us.

Our thanking processes have been improved to better reflect our depth of gratitude. We have introduced a new process to capture and analyse feedback from all channels; digital, verbal and written. Reporting and acting on this feedback, good and bad, will enable us to drive the exceptional stewardship that we are aiming for.

We have re-evaluated our Key Performance Indicators to facilitate exceeding Fundraising Regulator standards and improved our reporting structure to improve transparency. By raising accountability levels, reviewing and analysing complaints regularly, we can ensure we're always improving our interactions with supporters. Supporting this, Nationwide has kindly continued its Customer Service Excellence training for team members at the Trust.

> New Chief Executive

We said goodbye and thank you to Ed Owen, after five years as the Chief Executive of the Trust. After a recruitment process involving people with CF at every stage, we welcomed our new Chief Executive David Ramsden, who is looking forward to working with the whole community to do all we can to transform the lives of people with cystic fibrosis.

Fundraising

The Cystic Fibrosis Trust receives no government funding, and we would like to thank the many individual donors, organisations, charitable trusts, foundations and corporate partners without whose generous support none of our life-changing work for people with CF could take place. Donations and legacies raised for the Cystic Fibrosis Trust during 2016/17 totalled £11.1 million with income from our community continuing to grow.

Over 6,000 people took part in a challenge event this year, thanks to sponsorship from organisations like the Community Foundation for Surrey's Gold-i Innovation Fund, which supported our iconic Great Strides 65 South event in the form of a sponsorship package of £2,000.

Income from Trusts and Foundations continues to be one of our strongest growth areas with ongoing grants received to support a wide variety of projects, such as the My CF Registry portal, our Strategic Research Centres and our Information and Support programmes, over many years. This includes major grants from the Garfield Weston Foundation and the Masonic Charitable Foundation supporting our SmartCareCF projects, the Robert Luff Foundation supporting one of the *Mycobacterium abscessus* Strategic Research Centres and the Joseph Levy Foundation supporting our Information and Support work.

The Trust was delighted to receive a number of gifts from generous donors supporting both our core activities and specific projects, which are vital to funding our work. Membership of our Sixty Five Roses Club continues to grow and was extended to Scotland this year. Many new and existing supporters attended our annual event in October 2016.

Support from our corporate partners, including Champneys, has enabled us to raise both money and awareness of cystic fibrosis with new audiences. Our partnership with Clear Channel continues with generous in kind advertising allowing us to promote the work of the Trust and increase awareness of the condition. It was our most successful year at the UK Cystic Fibrosis Conference, securing over £51,000 sponsorship from a range of industry partners.

Support from people taking part in our events, community and branch activities is a significant part of our income. The Virgin Money London Marathon raised £369,000, and together with our community we manned 16 cheer points supporting our runners on the big day. Community activities have grown by over 50% on the previous year and there are a growing number of regional corporate relationships. We were the Charity of the Year for Hillsborough Oyster Festival, Hillside Nursery and Costain, among others, making regional partnerships of this kind worth £300,000. Wear Yellow Day 2016 was a great success, raising £4,000 via #cfyelfie images and donations, with £10,000 raised by community events as part of our annual CF Week activity. Christmas was also a particularly successful time for the community.

We had an exciting and varied portfolio of over 100 challenge events and our generous participants increase in number each year, taking part in activities such as marathons, cycles, walks and even sky dives and abseils to raise money. The hugely successful New Year's Resolutions Campaign in January, showcasing all our activities for the year, saw an average 35% increase in sign-ups for our events.



A number of new events were introduced, including two new walks under the Great Strides brand and our first ever virtual event.

We were also advised that average individual donation on Just Giving per activity is above average for the sector at £29 per donation.

We received notification that 56 of our supporters generously included a gift in their will for the Trust. We would like to express our gratitude for their support and thinking of us in this special way. The response to our Gifts in Wills campaign continues to grow and many thanks are also due to the 65 very kind supporters who 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. In addition, thank you to everyone who made a donation to our summer and Christmas appeal, via our web site, responded to our telephone appeals, bought a raffle ticket or played our lottery. Your ongoing support is very much appreciated.

We are members of the Fundraising Regulator and abide by the code of fundraising practice. The Trust used Ethicall for telephone fundraising during its Christmas campaign and an audit of their practices and procedures was carried out by the Director of Fundraising in February 2017 to ensure that we were happy regarding their approach. 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.

The Trust received 36 complaints in 2016–17, down from 64 the year before. Complaints are closely monitored and reviewed on an ongoing basis.

Plans for the future

The Cystic Fibrosis Trust has achieved a great deal in recent years and there are some big opportunities to help achieve a life unlimited coming up. Our simple strategic plan will allow us to grab those opportunities with both hands, while operating effectively and efficiently to overcome the challenges and avoid risks we inevitably face.

Since launching our vision for a 'Life Unlimited' in 2015, we have made progress on achieving the goals we set for ourselves. 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 most of the transformational changes we have seen in CF care and treatment. We will continue the administration, management and monitoring of research awards, streamlining the process with the introduction of grants management software. 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, for example exploring the effects of the environment on the rate of disease progression in people with CF, applying complex mathematics to some of the data available about the condition and exploring new ways to understand symptoms affecting the digestive system.

The My CF Registry portal will be further developed, to give the CF community an insight into both the Registry and their own clinical care records. The publication of academic papers will raise the profile of our Registry and world-leading pharmacovigilance programme. By appointing an Impact Advisor, we'll showcase the difference we are making to the lives of people with cystic fibrosis, driving support from the community and funders.

Research relies on clinical trials, and with a limited population of people with CF who can participate and at times a seemingly complex process, the Clinical Trials Accelerator Platform will be a vital resource. The team will spend the next year setting up the remaining Trials Accelerator centres (to be selected in May 2017), executing our Patient & Public Involvement (PPI) strategy and overseeing development of the clinical trials digital hub, to include digital information resources about the value of research and an online searchable clinical trials database – the CF Trials Tracker – to help people with CF identify and take part in relevant trials.

Clinical care features heavily in the lives of people in our community. By working with stakeholders, we will develop, pilot and roll out the patient/carer experience survey, develop new national guidelines for all Allied Healthcare Professionals and also develop a CF centre staffing audit tool to help to drive up safe and effective staffing levels in all CF centres. We will also continue to be involved in service reconfiguration across the UK. We will also deliver innovation and investment to UK CF centres by continuing with our Fellowships Programme and the Clinical Excellence and Innovation Awards.

Advances in treatment and care mean that people with CF have increasingly been able to take on big life challenges, such as leaving school or undergoing a lung transplant, for which we will develop the resources to help them understand the risks and opportunities involved. We'll launch a series of online events to help young people with CF build essential life skills, promoting our commitment to helping them achieve their ambitions. We're not only focusing on the good times, though – we need to be there for our community whatever they are going through. 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.

To make sure we're on the same page as the people we work so hard to support, we'll involve more people with CF and their friends and family, and develop new ways of ensuring our work is relevant to the entire population of people with CF in the UK. We'll explore potential questions for the next Insight Survey with the people who will be filling it in, and develop our volunteering programme to provide high-quality work experience for people with cystic fibrosis.

Our Public Affairs team will continue to campaign for access to life-changing medicines and treatments, and highlight the work we are doing to tackle the increasing threat posed by bacterial resistance to antibiotics. We're aiming to continue to build on the success we had in mobilising the CF community to raise their voices with us on political matters this year. We will also fight for access to new medicines and technologies by contributing high-quality, evidence-based information to Health Technology Appraisals in the UK, reflecting the evidenced views and motivations of people with cystic fibrosis.

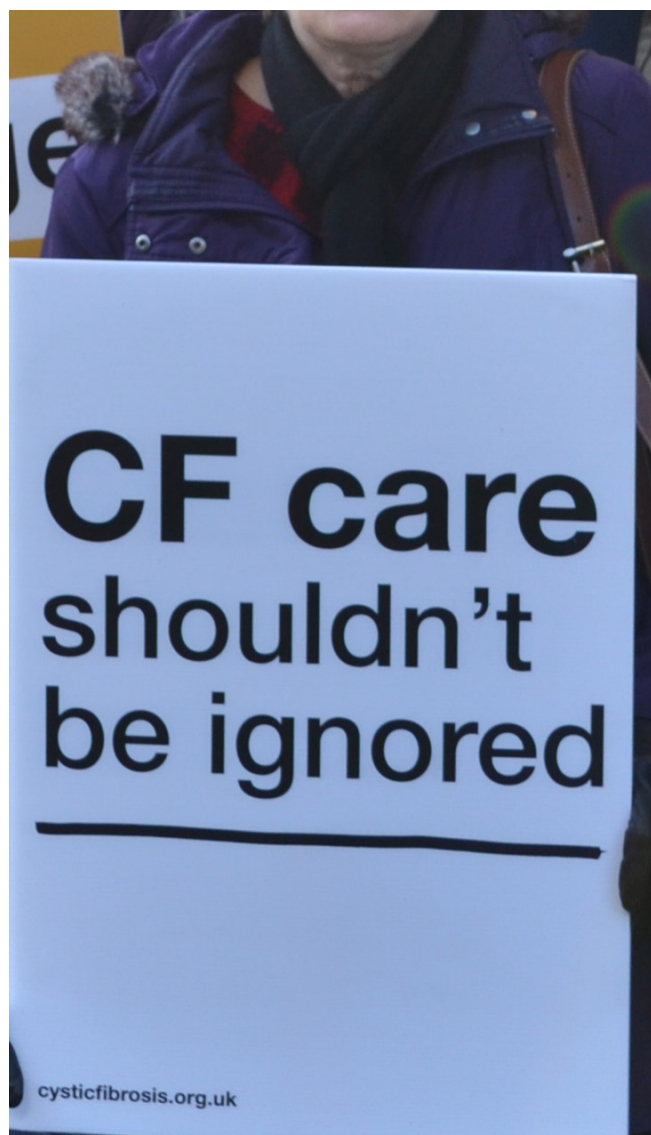
The people supporting us are the driving force behind all of our achievements, and their engagement and experience with us continues to be crucial to our success. We will offer an exciting portfolio of events and activities to inspire people to support us and provide support for all the fantastic individuals, branches, regional corporates and schools through their fundraising activities. We will launch new ways to allow our supporters to donate money, including a weekly lottery, and use digital and social media activities to enhance our existing fundraising activities. We are committed to ensuring that we are collecting appropriate consent to allow us to provide continued support and communication.

We will continue to develop strong relationships with companies, trusts and foundations, and high net worth individuals in order to increase our impact for people with CF, as well as growing the network of supporters who join the Sixty Five Roses Club.

In order to deliver on these future plans, we will continue working with clearly defined objectives, and ensure they are built on the fundamental pillars of being both a great organisation and great fundraisers. Being a great organisation also means being a great place to work. The Trust continues to invest in developing its employees and will be introducing a new on-line learning platform during the year to complement the new HR and personal development planning systems implemented during 2016/17.

Our Engagement team will explore ways to increase people's interactions with and commitment to the Trust and awareness of cystic fibrosis. We'll do this with social media, by driving people to resources on our website and continuing to run broadcast days for key campaigning moments, which helped us reach millions of people this year. We will also improve the way we demonstrate the impact we're having and investigate innovative new ways to fundraise, including mass-participation events, to support our fundraising team in their goals. Although the Supporter Experience Project is about to close the learnings and outcomes have informed other areas of improvements for our supporters.

As we move forward, we will put the views and insights of people CF at the heart of everything we do. A lot has been achieved, but much more remains to be done; too many lives are still too tough and too short.



Financial review

Income

The Trust's income from normal activities for the year to March 2017 was £13.2 million, an increase of 16% over the previous year.

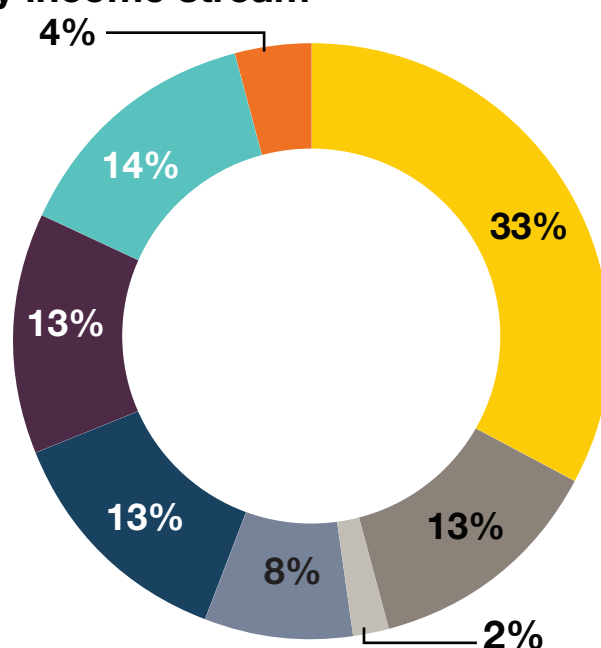
84% of the Trust's income from normal activities was donations and legacies, bringing in £11.1 million, (2015/16: £9.6 million). This increase was driven by a non-monetary donation of digital advertising space from Clear Channel, which was worth £1.9million.

Total donations and legacies excluding the donation in kind were £9.2 million. Income raised by community fundraising and branches including Gift Aid was £4.4million, which represents 48% of this figure (2015/16: 40%), confirming the continuing importance of the volunteer network to our fundraising efforts.

At £1.3 million, income from Trusts & Foundations and Corporate Partnerships was 36% lower than in the previous year. However, this was partly offset by a 3% increase in income from individuals and legacies.

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £1.7 million (2015/16: £1.3 million). There were three (2015/16: three) long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, with a fourth contract commencing in the final quarter and a fifth currently under negotiation. In addition a multi-year study module contract with a pharmaceutical company commenced in October 2016, and there were several shorter-term contracts for specific projects in place during the year. This continues to be a growth area of business and we are actively seeking new contracts.

> 2016/17 income by income stream



| Income from normal activities: | | £'000 |
|--|--|---------------|
| Branches, groups & community | | 4,373 |
| Regular and individual giving and appeals | | 1,647 |
| Corporate partnerships | | 291 |
| Trusts | | 994 |
| Cystic Fibrosis Services Limited | | 1,729 |
| Legacies | | 1,766 |
| Donated goods and services | | 1,901 |
| Other income | | 481 |
| Total income from normal activities | | 13,182 |

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

Expenditure

The Trust's total expenditure for the year was £15.6 million, a 14% increase compared with the previous year. The largest growth area of spend was on charitable activities at £11.8 million (2015/16: £8.9 million), which comprises programmes of research, information, advice and support and clinical care.

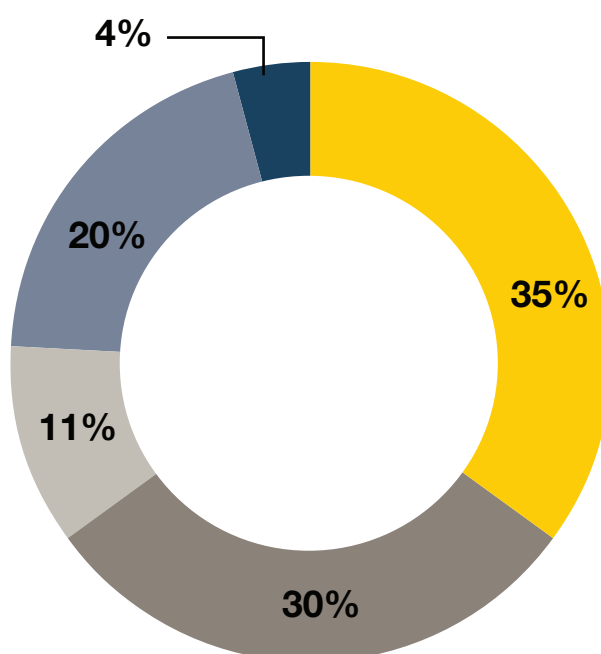
The remainder was spent on activities for generating funds, including £0.6 million paid to NHS CF clinical centres across the UK to support the resources necessary to add patient data to the UK CF Registry.

Total grant commitments in the year at £4.9 million were 7% higher than in the prior year. Grants worth £4.6 million (2015/16: £3.8m) were committed to a range of institutions, including £2.3 million (2015/16: £2.6m) committed for three Strategic Research Centres.

Work on the flagship SmartCareCF and CF Registry Platform Development programmes has continued, with total spend on these programmes of £0.5 million (2016/17: £1.0 million). The Clinical Trials Accelerator Platform flagship programme launched, with total spend in the year of £0.5 million (2015/16: £0.2m). This programme has received significant investment from the CF Foundation in the US, with whom we are working in partnership.

The overall deficit of £1.8 million in the year was in line with plans, and represents strategic utilisation of reserves according to the five-year business plan.

> 2016/17 expenditure by cost type



| Expenditure: | £'000 | |
|------------------------------------|---------------|---|
| Research | 5,505 | Research |
| Information, advice & support | 4,656 | Information, advice and support |
| Clinical Care | 1,678 | Clinical Care |
| Charitable activities total | 11,844 | Costs of raising funds |
| Costs of raising funds | 3,119 | Cystic Fibrosis Services Limited |
| Cystic Fibrosis Services Limited | 592 | |
| Total expenditure | 15,550 | |

> 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 £0.6 million in the year (2015/16: decrease of £0.2 million); a 12% rise in value. Income generated on investments totalled £0.2million, while realised and unrealised gains on the investment portfolio totalled £0.6 million.

> Reserves

The Trust's reserves as at 31 March 2017 totalled £8,986,000 (2016: £10,765,000). 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:

- Operating reserve – held at a value (£3,523,000) 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 – (£2,061,000) 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 – (£480,000) 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.

- 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 (£450,000) is held to ensure these funds are not considered to be realisable
 - A strategic reserve (£1,394,000) is held to fund the budgeted deficit in the 2017/18 financial year and enable the continued progress of the flagship programme in the short term (see page 6)

Principal risks and uncertainties

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

The principal risks and uncertainties that the Trustees have identified relate to remaining engaged with, and meeting the expectations of people with cystic fibrosis; ensuring we communicate our charitable impact effectively; meeting income targets and investment risk; data security and the risk of cyber attack; risks relating to the external research environment and Government policy; and ensuring that we continue to attract and retain high-quality staff.

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

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

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:

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 judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

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

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

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

- there is no relevant audit information of which the company and the group's auditors are unaware, and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustees report incorporating the Strategic report was approved and authorised for issue by the Board of Trustees on **12 July 2017** and signed on its behalf by:

George Jenkins, Chairman

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 2017 which comprise Consolidated Statement of Financial Activities, the Group Income and Expenditure Account, the Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows and the related notes. 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.

> Respective responsibilities of trustees and auditor

As explained more fully in the Trustees' Responsibilities Statement, 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.

We have been appointed auditor under the Companies Act 2006 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

> Scope of the audit of the financial statements

A description of the scope of an audit of financial statements is provided on the Financial Reporting Council's website at www.frc.org.uk/auditscopeukprivate.

> Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the group's and the parent charitable company's affairs as at 31 March 2017 and of the group's and the parent charitable company's net movement in funds, including the group's and the parent 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 (as amended).

> Opinion on other matters prescribed by the Companies Act 2006

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

- The information given in the Trustees' Annual Report (which 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 Trustees' Annual Report (which incorporates the strategic report and the directors' report) has been prepared in accordance with applicable legal requirements.

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

> Matters on which we are required to report by exception

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

- the charitable company and group have not kept adequate and sufficient accounting records, or returns adequate for our audit have not been received from branches not visited by us; or
- the consolidated 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 12 July 2017

26 Red Lion Square
London
WC1R 4AG

> Consolidated statement of financial activities

For the year ended 31 March 2017

| | Note | Unrestricted Funds £'000 | Restricted Funds £'000 | Endowment Funds £'000 | Total Funds 2017 £'000 | Total funds 2016 £'000 |
|--|------|--------------------------------|------------------------------|-----------------------------|---------------------------------------|------------------------------|
| Income and endowments from: | | | | | | |
| Donations and legacies | 2 | 10,126 | 972 | - | 11,098 | 9,617 |
| Other trading activities | 12 | 1,729 | - | - | 1,729 | 1,264 |
| Investments | 2b,6 | 165 | - | 51 | 216 | 281 |
| Other income: | | | | | | |
| Other income | 2 | 139 | - | - | 139 | 224 |
| Total | | 12,159 | 972 | 51 | 13,182 | 11,386 |
| Expenditure on: | | | | | | |
| Raising funds | 3 | 3,689 | 19 | 3 | 3,711 | 4,695 |
| Charitable activities | | | | | | |
| Research | | 5,205 | 299 | 1 | 5,505 | 5,461 |
| Clinical Care | 3 | 1,204 | 474 | - | 1,678 | 496 |
| Information, advice & support | | 4,456 | 197 | 3 | 4,656 | 2,931 |
| Total charitable activities | | 10,865 | 970 | 4 | 11,839 | 8,888 |
| Total resources expended | 3 | 14,554 | 989 | 7 | 15,550 | 13,583 |
| Net income/(expenditure) before investment gains/losses | | (2,395) | (17) | 44 | (2,368) | (2,197) |
| Realised investment gains/(losses) | | 38 | - | 1 | 39 | (41) |
| Unrealised investment gains/(losses) | | 479 | - | 71 | 550 | (283) |
| Net investment gains/(losses) | | 517 | - | 72 | 589 | (324) |
| Net (expenditure)/income | | (1,878) | (17) | 116 | (1,779) | (2,521) |
| Transfers between funds | 17a | 123 | (65) | (58) | - | - |
| Net movement in funds | | (1,755) | (82) | 58 | (1,779) | (2,521) |
| Reconciliation of funds: | | | | | | |
| Total funds brought forward | | 9,183 | 562 | 1,020 | 10,765 | 13,286 |
| Total funds carried forward | 17a | 7,428 | 480 | 1,078 | 8,986 | 10,765 |

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 22 to 47 form part of these financial statements.

| | All income funds 2017 £'000 | All income funds 2016 £'000 |
|---|--|--|
| Income | 12,966 | 11,105 |
| Gains/(losses) on investments | 517 | (218) |
| Investment income | 165 | 230 |
| Gross income in the reporting period | 13,648 | 11,117 |
| Expenditure | 15,146 | 13,302 |
| Interest payable | - | - |
| Depreciation and charges for impairment of fixed assets | 397 | 281 |
| Total expenditure in the reporting period | 15,543 | 13,583 |
| Net income before tax for the reporting period | (1,895) | (2,466) |
| Tax payable* | - | - |
| Net Income for the financial year | (1,895) | (2,466) |

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

All income and expenditure is derived from continuing activities.

The notes on pages 22 to 47 form part of these financial statements.

| | | Consolidated | | Charity | |
|---|-------|---------------------------------|------------------------|---------------------------------|------------------------|
| | Notes | Total 2017 £'000 | Total 2016 £'000 | Total 2017 £'000 | Total 2016 £'000 |
| Fixed assets | | | | | |
| Tangible assests | 5 | 450 | 824 | 450 | 824 |
| Investments | 6 | 5,826 | 5,181 | 5,826 | 5,181 |
| | | 6,276 | 6,005 | 6,276 | 6,005 |
| Current assets | | | | | |
| Debtors | 7 | 1,304 | 1,875 | 1,601 | 1,973 |
| Cash held as short term investment | | 11,308 | 12,263 | 11,308 | 12,263 |
| Cash at bank and in hand | | 2,250 | 1,154 | 1,941 | 1,060 |
| | | 14,862 | 15,292 | 14,850 | 15,296 |
| Liabilities | | | | | |
| Creditors: amounts falling due within one year | | | | | |
| Grants payable | 9 | (6,144) | (4,940) | (6,144) | (4,940) |
| Creditors and accrued charges | 10 | (1,320) | (1,565) | (1,308) | (1,569) |
| | | (7,464) | (6,505) | (7,452) | (6,509) |
| Net current assets | | 7,398 | 8,787 | 7,398 | 8,787 |
| Creditors: amounts falling due after one year | | | | | |
| Grants payable | 9 | (4,688) | (4,027) | (4,688) | (4,027) |
| Total net assets | | 8,986 | 10,765 | 8,986 | 10,765 |
| The funds of the charity | | | | | |
| Endowment funds | 17a | 1,078 | 1,020 | 1,078 | 1,020 |
| Restricted income funds | 17a | 480 | 562 | 480 | 562 |
| Unrestricted funds | | | | | |
| Designated reserves | 17a | 1,844 | 2,874 | 1,844 | 2,874 |
| Operating reserves | | 3,523 | 4,542 | 3,523 | 4,542 |
| Retained reserves | | 2,061 | 1,767 | 2,061 | 1,767 |
| Total charity funds | | 8,986 | 10,765 | 8,986 | 10,765 |

The notes on pages 22 to 47 form part of these financial statements.

The net movement in funds for the Trust for the year ended 31 March 2017 was – £1,779,000 (2016: 12 months – £2,521,000). 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 **12 July 2017** and signed on their behalf by:

George Jenkins, Chairman

Company number 3880213

| | 2017 £'000 | 2016 £'000 |
|---|---------------|----------------|
| Net cash provided by (used in) operating activities (Note A) | 4 | (1,151) |
| Cash flows from investing activities: | | |
| Dividends and interest | 216 | 281 |
| Purchase of property, plant and equipment | (23) | (816) |
| Purchase of investments | (236) | (2,448) |
| Movement in cash awaiting investment | (59) | 104 |
| Proceeds of sales of investments | 239 | 2,302 |
| | 137 | (577) |
| Increase/(decrease) in cash held as short term investments | 955 | (2,559) |
| Increase/(decrease) in cash (Note B) | 1,096 | (4,287) |
| Notes to Cash Flow Statement | | |

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

| | 2017 £'000 | 2016 £'000 |
|--|---------------|----------------|
| Net (expenditure)/income for the reporting period (as per the statement of financial activities) | (1,779) | (2,521) |
| Adjustment for: | | |
| Fixed asset disposal gain | - | - |
| Depreciation charges | 397 | 281 |
| Dividends and interest from investments | (216) | (281) |
| (Gains)/losses on investments | (589) | 324 |
| Decrease/(increase) in debtors | 571 | (1,322) |
| Increase/(decrease) in creditors | 1,620 | 2,368 |
| | 4 | (1,151) |

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

| | 2017 £'000 | 2016 £'000 |
|--|---------------|---------------|
| Cash and cash equivalents at the beginning of the reporting period | 13,417 | 15,145 |
| Change in cash and cash equivalents in the reporting period | 1,096 | (4,287) |
| Decrease in short term investments | (955) | 2,559 |
| Cash and cash equivalents at the end of the reporting period | 13,558 | 13,417 |
| (being cash at bank and in hand and cash held as short term investments) | | |
| | 2017 | 2016 |
| Analysis of cash and cash equivalents: | £'000 | £'000 |
| Cash on hand | 2,250 | 1,154 |
| Notice deposits (less than 3 months) | 11,308 | 12,263 |
| Total cash and cash equivalents | 13,558 | 13,417 |

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 xx. 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 £1,779,000 (2016- deficit of £2,521,000)

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 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 | Total 2017 £'000 | Total 2016 £'000 |
|---|--------------------------------|------------------------------|---------------------------------|------------------------|
| Branches, Groups & Community | 4,029 | 42 | 4,071 | 3,863 |
| Legacies | 1,754 | 12 | 1,766 | 1,192 |
| Individual donations | 166 | 68 | 234 | 565 |
| Corporate | 280 | 11 | 291 | 667 |
| Regular giving and appeals | 1,115 | 49 | 1,164 | 1,259 |
| Trusts | 204 | 790 | 994 | 1,273 |
| Donations in kind | 1,901 | - | 1,901 | 105 |
| Gift Aid | 551 | - | 551 | 568 |
| NHS National Services England | 81 | - | 81 | 81 |
| NHS National Services Scotland | 45 | - | 45 | 44 |
| Total income from donations and legacies | 10,126 | 972 | 11,098 | 9,617 |

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 (2016: £178,000). Going forward, the Trust will continue to make claims for recoverable VAT on a regular basis.

The remaining £Nil within Other Income (2016 – £48,000) comprises ad hoc sources of income that do not fit under the other categories shown above or on the face of the Statement of Financial Activities.

2b. Investment Income

| | Unrestricted Funds £'000 | Restricted Funds £'000 | Total 2017 £'000 | Total 2016 £'000 |
|--------------------------------|--------------------------------|------------------------------|---------------------------------|------------------------|
| Income from listed investments | 160 | 51 | 211 | 219 |
| Bank interest | 5 | - | 5 | 62 |
| Total investment income | 165 | 51 | 216 | 281 |

3a. Expenditure

| | Grants Restricted £'000 | Grants Unrestricted £'000 | Direct costs £'000 | Support costs £'000 | Total 2017 £'000 | Total 2016 Restated £'000 |
|-------------------------------|-------------------------------|---------------------------------|--------------------------|---------------------------|------------------------|------------------------------------|
| Raising funds | | | | | | |
| Fundraising | - | - | 2,540 | 579 | 3,119 | 2,884 |
| Trading and Merchandising | - | 515 | 77 | - | 592 | 666 |
| Charitable activities | | | | | | |
| Research | 819 | 2,469 | 1,195 | 1,022 | 5,505 | 6,791 |
| Clinical care | 399 | 350 | 616 | 313 | 1,678 | 427 |
| Information, advice & support | 134 | 170 | 3,841 | 511 | 4,656 | 2,815 |
| | 1,352 | 3,504 | 8,269 | 2,425 | 15,550 | 13,583 |

Analysis of allocated
Support Costs

| | Governance £'000 | Finance £'000 | IT Support £'000 | People & OD £'000 | HQ & Facilities £'000 | Total 2017 £'000 | Total 2016 Restated £'000 |
|-------------------------------|---------------------|------------------|---------------------|-------------------------|-----------------------------|------------------------|------------------------------------|
| Fundraising | 92 | 101 | 188 | 65 | 133 | 579 | 658 |
| Research | 163 | 178 | 332 | 114 | 235 | 1,022 | 1,550 |
| Clinical care | 50 | 54 | 101 | 35 | 73 | 313 | 98 |
| Information, advice & support | 82 | 89 | 166 | 57 | 117 | 511 | 642 |
| Total costs | 387 | 422 | 787 | 271 | 558 | 2,425 | 2,948 |

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:**

| | 2017 | 2016 |
|-------------------------------------|--------------|-------|
| | £'000 | £'000 |
| Auditors remuneration excluding VAT | 20 | 17 |
| Auditors – tax advice | 27 | 32 |
| Depreciation | 397 | 281 |
| Operating leases – building | 244 | 245 |
| Operating leases – other | 23 | 12 |
| Trustees' travel expenses | 2 | 4 |

3b. Grants

Grants were awarded during the year as follows:

| | 2017 | 2016 |
|------------------------|--------------|-------|
| | £'000 | £'000 |
| Grants to institutions | 4,552 | 4,382 |
| Grants to individuals | 304 | 246 |
| | 4,856 | 4,627 |

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

| | 2017 | 2016 |
|---|----------------|---------|
| | £'000 | £'000 |
| Balance at start of year | 8,967 | 7,163 |
| Awarded in the year | 4,856 | 4,628 |
| Paid in year | (2,991) | (2,824) |
| Balance at end of year | 10,832 | 8,967 |
| Falling due within one year (note 9) | 6,144 | 4,940 |
| Falling due after more than one year (note 9) | 4,688 | 4,027 |

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

| | 2017 |
|--|--------------|
| | £'000 |
| University of Cambridge/Papworth Hospital | 831 |
| University of Leeds/Leeds Hospital | 750 |
| University of Liverpool | 750 |
| University of Edinburgh | 238 |
| Imperial College, London/Royal Brompton Hospital | 379 |
| University of Oxford | 158 |
| University of Sussex | 98 |
| Alder Hey Hospital | 75 |
| The Alan Turing Institute | 65 |
| Action Medical Research | 62 |
| University of Newcastle/Newcastle Hospital | 52 |

3b. Grants (continued)

| | |
|---|--------------|
| Sheffield University | 21 |
| ECFS – European Cystic Fibrosis Society | 21 |
| AMRC | 7 |
| University of Portsmouth | 3 |
| Brunel University | 2 |
| Queen Elizabeth University Hospital, Glasgow | 2 |
| Golden Jubilee Hospital | 2 |
| St George's Hospital | 2 |
| | 3,518 |
| Less: Grant commitments from previous years released in the year (see note) | (100) |
| Add: Grant commitments made to unspecified research institutions | 223 |
| Add: Trial Coordinator commitments made to CTAP centres (see note) | 396 |
| Add: Registry support grants made to various CF centres | 515 |
| Total grants made to institutions | 4,552 |

One commitment made in previous financial years were reversed in the year:

- A commitment of £100,000 made to a pharmaceutical company in 2015/16 was released. The original commitment made was for £200,000, however the scope of the project changed and the amount of funding committed by the Cystic Fibrosis Trust was reduced to £100,000.
- The Trust has committed to funding the salaries of 9.4 clinical trial coordinators as part of the Clinical Trials Accelerator Platform programme. A provision for these salaries was made at the year end while recruitment of post holders is ongoing.

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:

| | 2017 £'000 | 2016 £'000 |
|---|---------------|---------------|
| Salaries | 3,856 | 3,593 |
| Redundancy and other termination payments | 62 | 122 |
| Temporary Staff | 105 | 210 |
| Social security costs | 401 | 384 |
| Other pension costs | 220 | 192 |
| | 4,644 | 4,501 |

Redundancy and other termination payments totalling £62,000 were paid to two (2016 – £122,225 paid to 10) staff members in the year. The prior year figures include costs related to the relocation in May 2015 when some staff members chose not to relocate, giving rise to redundancies. 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 £220,000 (2016 – £192,000).

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

| | 2017 No. | 2016 No. |
|--|-------------|-------------|
| Research | 8 | 7 |
| Clinical care | 6 | 5 |
| Information, advice & support | 34 | 27 |
| Fundraising | 43 | 41 |
| Management | 3 | 2 |
| Finance | 5 | 4 |
| IT and project management support | 6 | 6 |
| HR & OD | 3 | 4 |
| Facilities | 3 | 1 |
| Total average monthly headcount | 111 | 97 |

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

| | 2017 No. | 2016 No. Restated |
|--------------------|-------------|-------------------------|
| £60,001 – £70,000 | 4 | 3 |
| £70,001 – £80,000 | 1 | - |
| £80,001 – £90,000 | 1 | - |
| £90,001 – £100,000 | 1 | 1 |

Pension contributions to defined contribution pension schemes for these employees totalled £24,398 (2016 – £27,879).

Remuneration of key management personnel: The total remuneration paid to key management personnel was £392,000 which relates to six individuals who served on the Senior Leadership Team during the year (2016 – £414,000 paid to six individuals). Prior year comparatives have been restated to include pension and social security contributions

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. Expenses of £2,096 (2016 – £3,588) were settled on six (2016 – four) trustees.

5. Fixed assets

| | Furniture & fittings £'000 | Computer hardware £'000 | Computer software £'000 | Website development £'000 | Platform development £'000 | Total £'000 |
|--|-------------------------------|----------------------------|----------------------------|------------------------------|-------------------------------|----------------|
| Cost | | | | | | |
| At 31 March 2016 | 628 | 770 | 243 | 403 | 183 | 2,227 |
| Additions | 2 | 21 | - | - | - | 23 |
| At 31 March 2017 | 630 | 791 | 243 | 403 | 183 | 2,250 |
| Depreciation | | | | | | |
| At 31 March 2016 | 345 | 656 | 243 | 104 | 55 | 1,403 |
| Charge for the year | 135 | 68 | - | 102 | 92 | 397 |
| At 31 March 2017 | 480 | 724 | 243 | 206 | 147 | 1,800 |
| Net book value at 31 March 2017 | 150 | 67 | - | 197 | 36 | 450 |
| Net book value at 31 March 2016 | 283 | 114 | - | 299 | 128 | 824 |

6. Investments

| Group and Charity | Total 2017 £'000 | Total 2016 £'000 |
|-----------------------------------|------------------------|------------------------|
| Market value as at 31 March 2016 | 5,181 | 5,463 |
| Additions at cost | 236 | 2,448 |
| Disposals at opening book value | (203) | (2,596) |
| Net gains/(losses) on investments | 452 | (353) |
| | 5,666 | 4,962 |
| Change in cash | 160 | 219 |
| Market value as at 31 March 2017 | 5,826 | 5,181 |

6. Investments (continued)

| Represented by: | 2017 £'000 | 2016 £'000 |
|--------------------------------------|---------------|---------------|
| Equities | 3,368 | 3,150 |
| Fixed Interest and multi-asset funds | 993 | 881 |
| Property | 841 | 837 |
| Cash | 624 | 313 |
| | 5,826 | 5,181 |

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 2017. These make up more than 5% of total investments:

| | Total 2017 £'000 |
|---------------------------------------|------------------------|
| Schroder Chartity Equity Fund | 1,445 |
| The Equity Income Trust for Charities | 1,923 |
| The income trust for charities | 389 |
| Charities property fund | 416 |
| Property income trust for charities | 425 |
| Ruffer charity assets Trust | 604 |
| Schroder liquidity fund | 380 |

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

7. Debtors

| | Group 2017 £'000 | Group 2016 £'000 | Charity 2017 £'000 | Charity 2016 £'000 |
|--|------------------------|------------------------|--------------------------|--------------------------|
| Trade debtors | 308 | 492 | - | - |
| Amount due from subsidiary undertaking | - | - | 605 | 590 |
| Prepayments and accrued income | 937 | 1,307 | 937 | 1,307 |
| Other debtors | 59 | 76 | 59 | 76 |
| | 1,304 | 1,875 | 1,601 | 1,973 |

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

| | 2017 £'000 | 2016 £'000 |
|--|---------------|---------------|
| Grant creditor at 31 March 2016 | 8,967 | 7,163 |
| Grants paid during the year | (2,991) | (2,823) |
| Grants approved before 31 March 2017 and payable within one year | 2,841 | 2,913 |
| Grants approved before 31 March 2017 and payable after one year | 2,015 | 1,714 |
| Grant creditor at 31 March 2017 | 10,832 | 8,967 |

Represented by

| | | |
|---|---------------|--------------|
| Grants due within one year at 31 March 2017 | 6,144 | 4,940 |
| Grants due > 12 months | 4,688 | 4,027 |
| | 10,832 | 8,967 |

10. Creditors

| | Group 2017 £'000 | Group 2016 £'000 | Charity 2017 £'000 | Charity 2016 £'000 |
|------------------------------|------------------------|------------------------|--------------------------|--------------------------|
| Trade creditors | 566 | 498 | 565 | 498 |
| Other creditors | 89 | 126 | 89 | 131 |
| Accruals and deferred income | 665 | 942 | 654 | 940 |
| | 1,320 | 1,566 | 1,308 | 1,569 |

11. Financial Instruments (Assets and Liabilities)

| | Group 2017 £'000 | Group 2016 £'000 | Charity 2017 £'000 | Charity 2016 £'000 |
|---|------------------------|------------------------|--------------------------|--------------------------|
| Financial assets measured at amortised cost (note a) | 13,917 | 13,971 | 13,917 | 13,971 |
| Financial assets measured at fair value (note b) | 5,826 | 5,181 | 5,826 | 5,181 |
| Financial liabilities measured at amortised cost (note c) | (12,153) | (10,436) | (12,153) | (10,436) |
| Net financial assets measured at amortised cost | 7,590 | 8,716 | 7,590 | 8,716 |

(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:

| | Total 2017 £'000 | Total 2016 £'000 |
|---|---------------------------------|---------------------------------|
| Sales and sundry income | 1,729 | 1,264 |
| Cost of sales and administration | (592) | (666) |
| Intercompany recharges | (70) | (67) |
| Net contribution to parent charity | 1,067 | 531 |

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

| | Total 2017 £ | Total 2016 £ |
|---|-----------------------------|-----------------------------|
| Current Assets | | |
| Debtors | 308,525 | 497,205 |
| Cash at bank | 309,007 | 94,813 |
| | 617,532 | 592,018 |
| Creditors: amounts falling due within one year | (617,530) | (592,016) |
| Net Current Assets | 2 | 2 |
| Net Assets | 2 | 2 |
| Capital and Reserves | | |
| Called up share capital | 2 | 2 |
| Profit and loss account | - | - |
| Shareholder's funds | 2 | 2 |

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

13. Leasing commitments

At 31 March 2017, the Trust's future minimum operating leases payments relating to buildings were:

| | 2017 | 2016 |
|----------------------------|-------|-------------------|
| | £'000 | Restated £'000 |
| Within one year | 271 | 271 |
| Between two and five years | 543 | 814 |

A 10 year property lease with a 5 year break clause was signed on the 1st April 2015 for a new office in central London, with annual rent of £271,425.

At 31 March 2017, the Trust's future minimum operating leases payments relating to equipment were:

| | 2017 | 2016 |
|----------------------------|-------|-------|
| | £'000 | £'000 |
| Within one year | 23 | 20 |
| Between two and five years | 35 | 73 |

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 £2,676 (2016 – £30,504). In addition, two of the trustees (2016 – three) 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 | Gene Therapy Restricted | Other restricted | 2017 |
|---------------------------------------|--------------|-----------------|-------------------------|------------------|---------|
| | £'000 | £'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 |

Prior year funds

| | Unrestricted | Endowment funds | Gene Therapy Restricted | Other restricted | 2016 |
|---------------------------------------|--------------|-----------------|-------------------------|------------------|---------|
| | £'000 | £'000 | £'000 | £'000 | £'000 |
| Tangible fixed assets | 824 | - | - | - | 824 |
| Investments | 4,161 | 1,020 | - | - | 5,181 |
| Current assets | 15,292 | - | - | - | 15,292 |
| Internal obligations | 20 | - | (20) | - | - |
| Current liabilities | (6,505) | - | - | - | (6,505) |
| Liabilities due in more than one year | (4,609) | - | - | 582 | (4,027) |
| | 9,183 | 1,020 | (20) | 582 | 10,765 |

17a. Current year fund movements

| | Balance 31 March 2016 £'000 | Investment Gains £'000 | Income £'000 | Expenditure £'000 | Transfers £'000 | Balance 31 March 2017 £'000 |
|--|--------------------------------------|------------------------------|-----------------|----------------------|--------------------|--------------------------------------|
| Fixed asset reserve | 824 | - | - | - | (374) | 450 |
| Strategic reserve | 2,050 | - | - | - | (656) | 1,394 |
| Total Designated Reserves | 2,874 | - | - | - | (1,030) | 1,844 |
| Operating reserve | 4,542 | - | - | - | (1,019) | 3,523 |
| Retained reserves | 1,767 | 517 | 12,159 | (14,554) | 2,172 | 2,061 |
| Total General Reserves | 6,309 | 517 | 12,159 | (14,554) | 1,153 | 5,584 |
| Total Unrestricted Funds | 9,183 | 517 | 12,159 | (14,554) | 123 | 7,428 |
| Restricted Income Funds Deficit: | | | | | | |
| Gene Therapy Research (Deficit) | (20) | - | - | - | 20 | - |
| Other Restricted Income Funds: | | | | | | |
| Restricted funds related to research: | | | | | | |
| 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 |
| Total funds related to research | 229 | - | 323 | (324) | (65) | 163 |

Continued on next page

17a. Current year fund movements (continued)

| | Balance 31 March 2015 £'000 | Investment Gains £'000 | Income £'000 | Expenditure £'000 | Transfers £'000 | Balance 31 March 2016 £'000 |
|--|--------------------------------------|------------------------------|-----------------|----------------------|--------------------|--------------------------------------|
| Restricted funds related to information and support | | | | | | |
| E W Joseph/Homecare grants | 58 | - | - | (8) | 9 | 59 |
| Joseph Levy/Education Grants | 10 | - | 20 | (54) | 38 | 14 |
| Sailing fund | 33 | - | - | - | (33) | - |
| Support services (including welfare grants) | 46 | - | 86 | (114) | 33 | 51 |
| CF Connect (youth and parents) | 27 | - | - | (1) | - | 26 |
| Total funds related to information & support | 174 | - | 106 | (177) | 47 | 150 |
| | | | | | | |
| 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 |
| SmartCare CF | - | - | - | - | - | - |
| Clinical Trials Accelerator Programme | - | - | 474 | (474) | - | - |
| CF Registry | - | - | 55 | - | (55) | - |
| Total Other Restricted Income Funds | 582 | - | 972 | (989) | (85) | 480 |
| Total Restricted Income Funds | 562 | - | 972 | (989) | (65) | 480 |
| Endowment Funds: | | | | | | |
| 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) | 35 |
| Total Endowment Funds | 1,020 | 72 | 51 | (7) | (58) | 1,078 |
| | | | | | | |
| Total Charity Funds | 10,765 | 589 | 13,182 | (15,550) | - | 8,986 |

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.

The designated strategic reserve will be used to fund the budgeted deficit in the 2017/18 financial year. This planned excess of expenditure over income will enable the Trust to commit to the flagship programmes and activities set out in the five year business plan.

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

Retained reserves are held for future initiatives.

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

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 deficit – All fundraising pledges made as part of the 2011 Gene Therapy appeal have now been received, reducing this deficit to £Nil.
- Gene Therapy Research – income available for future grant commitments for gene therapy related activity
- General medical research – where the donor did not specify a particular research grant award
- Strategic Research Centres:
 - Imperial College: Pseudomonas 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
- 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.

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

Craig legacy – funding restricted to cystic fibrosis related work at the Royal Brompton and Wythenshawe Hospitals

Golf days – funding restricted to running golf days as fundraising events.

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

Peer Review – supporting the costs of running the clinical peer review programme

Vertex Everest trip – funding an awareness-raising and fundraising trip to climb Mount Everest by a person with cystic fibrosis.

SmartcareCF – funding the development of the SmartcareCF platform, including both adult and paediatric study.

Clinical Trials Accelerator Platform – funding this flagship programme.

CF Registry – funding the development of the CF Registry, including provision of a 'patient portal' enabling direct access to medical data by people with cystic fibrosis.

17a. Funds (continued)

- **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 has in recent years been designated to Gene Therapy research;
- 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. Whilst the capital is maintained as an endowment fund, 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 2015 £'000 | Investment Gains £'000 | Income £'000 | Expenditure £'000 | Transfers £'000 | 31 March 2016 £'000 |
| Fixed asset reserve | 289 | - | - | - | 535 | 824 |
| Strategic reserve | 2,871 | - | - | - | (821) | 2,050 |
| Total Designated Reserves | 3,160 | - | - | - | (286) | 2,874 |
| Operating reserve | 5,435 | - | - | - | (893) | 4,542 |
| Retained reserves | 3,182 | (218) | 9,637 | (12,779) | 1,945 | 1,767 |
| Total General Reserves | 8,617 | (218) | 9,637 | (12,779) | 1,052 | 6,309 |
| Total Unrestricted Funds | 11,777 | (218) | 9,637 | (12,779) | 766 | 9,183 |
| Restricted Income Funds Deficit: | | | | | | |
| Gene Therapy Research (Deficit) | (160) | - | - | - | 140 | (20) |
| Other Restricted Income Funds: | | | | | | |
| Restricted funds related to research: | | | | | | |
| Gene Therapy Research | - | - | 257 | - | (86) | 171 |
| General Medical Research | - | - | 54 | (54) | - | - |
| Imperial College SRC: Pseudomonal infection | - | - | 26 | - | (26) | - |
| Cambridge SRC: Mycobacterium abscessus infection | - | - | 450 | - | (450) | - |
| Newcastle SRC: INOVCF-Innovative non-CFTR Approaches | - | - | - | - | - | - |
| Bristol SRC: F508del0CFTR | - | - | 1 | - | (1) | - |
| UCL SRC: Personalised Engineered Cell Therapies | - | - | 50 | (50) | - | - |
| UCL VIA: Prenatal diagnosis for autosomal recessive conditions | - | - | 13 | (13) | - | - |
| Imperial College VIA: Antibacterial activity of Glatiramer acetate | - | - | 14 | (14) | - | - |
| Genotyping – 600 Study | 300 | - | - | (183) | (70) | 47 |
| Other research related restricted funds | 11 | - | 14 | (12) | (2) | 11 |
| Total funds related to research | 311 | - | 879 | (326) | (635) | 230 |
| Restricted funds related to information & support: | | | | | | |
| E W Joseph / Homecare grants | 38 | - | - | (4) | 24 | 58 |
| Joseph Levy / Education Grants | - | - | 20 | (47) | 37 | 10 |
| Sailing fund | 27 | - | - | - | 6 | 33 |
| Leisure fund | 29 | - | - | (31) | 16 | 14 |
| Support services (inc. welfare grants) | - | - | 129 | (95) | (2) | 32 |
| CF Connect (youth and parents) | 21 | - | 9 | (3) | - | 27 |
| Total funds related to information & support | 115 | - | 158 | (180) | 81 | 174 |

17b. Prior year fund movements (continued)

| | Balance | | | | | Balance |
|--|---------------------------|------------------------------|-----------------|----------------------|--------------------|---------------------------|
| | 31 March 2015 £'000 | Investment Gains £'000 | Income £'000 | Expenditure £'000 | Transfers £'000 | 31 March 2016 £'000 |
| Coombe Hill | - | - | 24 | (10) | (3) | 11 |
| Craig Legacy | 25 | - | - | (25) | - | - |
| Kings College Hospital Award | - | - | - | 157 | - | 157 |
| Paediatrics | 8 | - | - | (4) | - | 4 |
| Peer Review | - | - | 10 | (10) | - | - |
| Vertex – Everest trip | - | - | 57 | (50) | - | 7 |
| SmartCare CF | 36 | - | 550 | (336) | (252) | (2) |
| CF Registry | - | - | 20 | (20) | - | - |
| Total Other Restricted Income Funds | 497 | - | 1,698 | (804) | (809) | 582 |
| Total Restricted Income Funds | 337 | - | 1,698 | (804) | (669) | 562 |
| Endowment Funds: | | | | | | |
| Ena Bennie Endowment | 589 | (50) | 27 | - | (54) | 512 |
| EW Joseph Endowment | 202 | (18) | 9 | - | (24) | 169 |
| Joseph Levy Endowment | 302 | (31) | 16 | - | 3 | 290 |
| Robert Couper Endowment | - | - | - | - | - | - |
| Sally Wrigley Memorial Fund | 20 | - | - | - | - | 20 |
| Other Endowment funds | 59 | (7) | (1) | - | (22) | 29 |
| Total Endowment Funds | 1,172 | (106) | 51 | - | (97) | 1,020 |
| Total Charity Funds | 13,286 | (324) | 11,386 | (13,583) | - | 10,765 |

18. Prior year Consolidated Statement of Financial Activities

| | Note | Unrestricted Funds £'000 | Restricted Funds £'000 | Endowment Funds £'000 | Total Funds 2016 £'000 |
|--|------------|--------------------------------|------------------------------|-----------------------------|------------------------------|
| Income and endowments from: | | | | | |
| Donations and legacies | 2 | 7,919 | 1,698 | - | 9,617 |
| Other trading activities | 12 | 1,264 | - | - | 1,264 |
| Investments | 2b,6 | 230 | - | 51 | 281 |
| Other income: | | | | | |
| Fixed asset disposals gain | 6 | - | - | - | - |
| Other income | 2 | 224 | - | - | 224 |
| Total | | 9,637 | 1,698 | 51 | 11,386 |
| Expenditure on: | | | | | |
| Raising funds | 3 | 4,634 | 61 | - | 4,695 |
| Charitable activities | | | | | |
| Research | | 4,779 | 682 | - | 5,461 |
| Clinical Care | 3 | 618 | (122) | - | 496 |
| Information, advice & support | | 2,748 | 183 | - | 2,931 |
| Total charitable activities | | 8,145 | 743 | - | 8,888 |
| Total resources expended | 3 | 12,779 | 804 | - | 13,583 |
| Net income/(expenditure) before investment gains/losses | | (3,142) | 894 | 51 | (2,197) |
| Realised investment gains/(losses) | | (4) | - | (37) | (41) |
| Unrealised investment gains/(losses) | | (214) | - | (69) | (283) |
| Net investment gains/(losses) | | (218) | - | (106) | (324) |
| Net income/(expenditure) | | (3,360) | 894 | (55) | (2,521) |
| Transfers between funds | 17a | 766 | (669) | (97) | - |
| Net movement in funds | | (2,594) | 225 | (152) | (2,251) |
| Reconciliation of funds: | | | | | |
| Total Funds brought forward | | 11,777 | 337 | 1,172 | 13,286 |
| Total funds carried forward | 17a | 9,183 | 562 | 1,020 | 10,765 |

Structure, governance and management

> Patron

- HRH The Prince of Wales KG KT GCB OM

> Honorary President

- Dr James Littlewood OBE MO FRCP FRCPE DCH

> Trustees

Chairman

- George Jenkins OBE¹

Vice Chairman

- Professor John Price MD FRCP FRCPCH
- Caroline Cartellieri Karlsen¹
- Peter Norris
- David Turner QC¹
- Professor Andrew Jones
- Michael Winehouse¹
- Louise King¹
- Hannah Begbie¹
- Ffyona Dawber (appointed April 2016)
- Ryan Tohill (appointed April 2016)

> Finance and Audit Committee

Chairman

- Peter Norris
- David Turner QC
- Stephen Mullen (Independent Member)¹
- David Sawyer (Independent member, appointed June 2016)
- Guy Harington (Investments Committee)
- Alistair Peel (Investments Committee)

> Nomination & Development Committee

Chairman

- George Jenkins OBE
- Professor John Price MD FRCP FRCPCH
- Ffyona Dawber (appointed April 2016)
- Louise King (appointed April 2016)
- Caroline Cartellieri Karlsen (appointed April 2016)

> Charity Management

- David Ramsden – Chief Executive
- Elizabeth Bishop FCA – Director of Finance and Resources
- 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

> Company Secretary

- Elizabeth Bishop FCA – Director of Finance and Resources

> Principal and Registered Office

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

> Auditors

haysmacintyre
26 Red Lion Square London WC1R 4AG

> Bankers

Natwest Plc
15 Bishopsgate London EC2N 3NW

> Investment Managers

Cazenove Capital Management
12 Moorgate London EC2R 6DA

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

> **Recruitment, induction and training of Trustees**

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

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

> **Senior Leadership Team**

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

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

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

> **Public benefit**

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

> **Legal structure**

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

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

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



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