

Cystic

**Fibrosis why
we're here**

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

For the year ended 31 March 2016

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

Contents

| | |
|---|----|
| About us | 3 |
| <hr/> | |
| Achievements and performance | 4 |
| Investing in cutting edge research and innovation | 4 |
| Collaborating with the clinical community to drive up standards of care | 8 |
| Reforming the Registry to harness the power of knowledge | 9 |
| Offering information and support for all | 9 |
| Campaigning hard | 10 |
| Raising awareness and more effectively engaging with our community | 11 |
| Developing an effective organisation | 12 |
| Fundraising | 12 |
| <hr/> | |
| Plans for the Future | 13 |
| <hr/> | |
| Financial Review | 14 |
| <hr/> | |
| Principal risks and uncertainties | 17 |
| <hr/> | |
| Statement of Trustees' responsibilities | 18 |
| <hr/> | |
| Independent auditor's report | 19 |
| <hr/> | |
| Financial statements | 20 |
| <hr/> | |
| Structure, governance and management | 41 |

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2016. 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 2005.

In August 2013 Parliament approved 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013'. These regulations introduce into the Companies Act 2006 a requirement for all large and medium-sized companies to prepare a separate Strategic Report. The Trustees have incorporated the requirements of the Strategic Report within their Trustees' Report.

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 slow and painful killer, a genetic condition that destroys the lungs and digestive system. More than 10,500 people in the UK live with cystic fibrosis, a life-long burden that means each day requires hours of physiotherapy and handfuls of pills, just to stay healthy. According to the 2014 UK Cystic Fibrosis Registry report, the average survival rate for cystic fibrosis in the UK is 40.1 years, however the median age at 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 carries 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 cutting-edge research and innovation, and its application to people with cystic fibrosis;
- collaborate with 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 strategy

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 strategy 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 2015/16 were tabulated and tracked on a balanced scorecard, through which individual projects and work streams could be monitored by relevant project and work stream 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 to explain its RAG status and steps being taken where necessary to move the project back to green from amber or red. Further detail on measures of success are included within activity descriptions below.

Achievements and performance

> Investing in cutting-edge research and innovation

The Cystic Fibrosis Trust is one of the biggest funders of university research specifically for the benefit of people with cystic fibrosis.

> Grant making policy

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 applications for funding. We also evaluate all proposals in terms of the existing portfolio of research-funded projects and their distribution across the aims of the research strategy to ensure we maintain a balanced portfolio of high quality research activity.

> Strategic Research Centres

These virtual centres of excellence bring together researchers from within and outside the field of cystic fibrosis, supporting scientists around the world to work together to address specific issues facing people with cystic fibrosis.

Our SRCs aim to:

- Create clusters of world class researchers.
- Bring researchers from different fields or disciplines together, to tackle the complex problems in cystic fibrosis.
- Widen awareness of cystic fibrosis research outside the traditional biomedical disciplines and so attract high quality investigators from new research disciplines.
- Recruit the brightest and best young researchers to cystic fibrosis research. Each SRC provides funding for five or six young scientists, who will work alongside the experts. Investing in these scientists at this stage in their careers leads to long-lasting interest in the field.

Following an open call in February 2015, the Trust has committed £2.6 million during this financial year to four new Strategic Research Centres, reflecting the high quality of applications, with co-funding for one SRC from the host organisation, the University of Leeds. This brings the total commitment since 2013 to £6.3 million covering nine SRCs.

1. The CFRD (Cystic Fibrosis Related Diabetes) SRC

Prof James Shaw, University of Newcastle

This study aims to unravel the primary mechanisms underlying CF-related diabetes (CFRD) by bringing together researchers from the fields of CF and diabetes based throughout the UK, Europe and USA. The study aims to establish how the genetic defects responsible for CF increase blood sugar levels, a first step in understanding the development of CFRD. By building on this initial investigation, the researchers hope to identify novel interventions for CF patients to help prevent the development of diabetes thereby reducing morbidity and increasing life-expectancy.

2. Personalised Engineered Cell Therapies for Cystic Fibrosis

Prof Stephen Hart, UCL Institute of Child Health

This project aims to prevent or repair lung damage caused by CF. The researchers will investigate two approaches to precisely repair the patient's own CF gene using an exciting new approach called 'gene editing'. Firstly, the gene editing molecules will be wrapped in a protective coating to form 'nanoparticles' which can be inhaled, correcting the CF gene in the lung. Secondly, they will take cells from the patient and treat them with gene editing in the laboratory. The patient's own corrected cells will then be delivered back into the lungs where, once there are enough cells, the lung should now be healthy. If one of these approaches is successful, it could lead to a huge improvement in lung disease that limits the lives of so many with CF.

3. Physical Activity, Exercise, Sport and Recreation Promotion for Adolescents with CF

Prof Craig Williams, University of Exeter

This project seeks to provide detailed information on how best to utilise activity for adolescents with CF. Many clinicians and their support teams, whilst valuing the role of physical activity to people with CF, are unsure how to promote it. Similarly, parents and adolescent patients are often overwhelmed with managing a busy treatment and education schedule to be able to fit sport, exercise or recreation into their lives. The researchers aim to bring together exercise specialists, psychologists, physiotherapists, engineers, clinicians, parents and adolescents to prescribe physical activity more effectively.

This SRC complements the new 'Activity Unlimited' programme of work also announced in 2015. A key component of the Trust's commitment to supporting 'breaths for life', Activity Unlimited is designed to help everyone with cystic fibrosis take control of their physical health and wellbeing through support and information on the wide range of activities that can help improve lung health.

4. Targeting Joint Disease in Cystic Fibrosis (CF): Identifying Therapeutic Targets in CF Arthropathy

Prof Michael McDermott, University of Leeds

Diseases of the joints (arthropathy) are amongst the most rapidly increasing complications of CF, but also the most overlooked. Symptoms of joint pain and disability affect more than one in ten people with CF, but effective forms of treatment are limited. The causes of CF arthropathy (CFA) are poorly understood, and there is no CF-specific method for describing and assessing joint symptoms or the effects of quality of life. The proposed research seeks to provide a systematic clinical and biological understanding of joint disease in CF, and will provide the basis for a drug trial of a novel agent for treatment of CFA.

Meanwhile, work continued apace in our current five Strategic Research Centres funded in previous years:

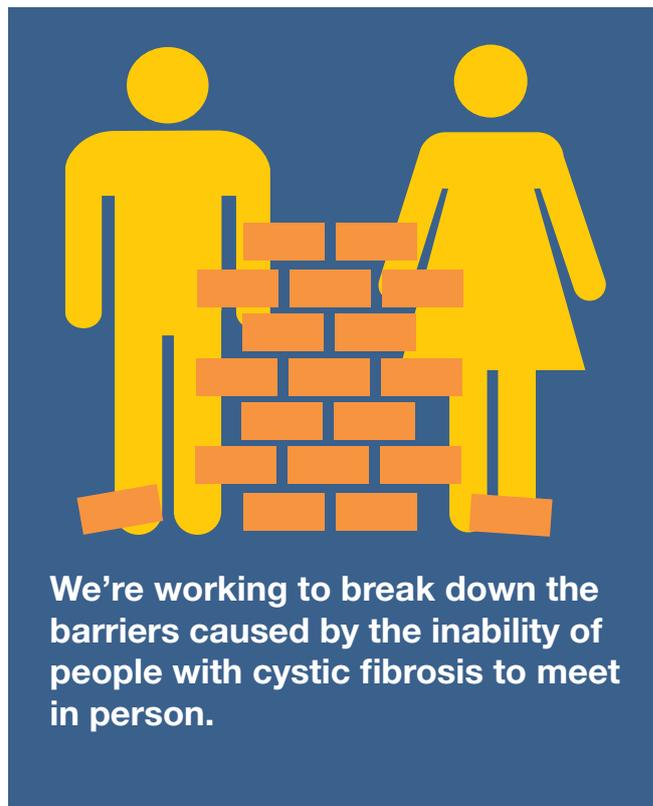
1. Pseudomonal infection in CF: better detection, better understanding, better treatment

Prof Jane Davies, Imperial College London

- Finding new, non-invasive ways to detect Pseudomonal infection by harnessing advances in technology;
- Understanding how Pseudomonas adapts to the lungs and becomes chronic, which will mean that we can identify high-risk patients and, eventually, develop novel treatments to counteract these adaptations; and
- Testing new, non-antibiotic forms of therapy: chronic Pseudomonas protects itself by forming 'biofilm' structures and this SRC will investigate molecules known to breakdown these biofilms.



By understanding Pseudomonas better and detecting it earlier, we can reduce damage from lung infection and increase the life expectancy of people with cystic fibrosis.



We're working to break down the barriers caused by the inability of people with cystic fibrosis to meet in person.

2. Tackling Mycobacterium abscessus infection in cystic fibrosis

Prof Andres Floto, University of Cambridge

- Working out how M. abscessus spreads and how we can prevent it spreading;
- Identify why some strains cause more lung damage than others; and
- Explore new leads that might be developed into drugs to treat M. abscessus infection

3. INOVCF: Innovative non-CFTR Approaches for Cystic Fibrosis Therapy

Dr Michael Gray, Newcastle University

- Understanding the role of 'bypass transporters' in fluid and pH balance in normal and cystic fibrosis lungs;
- Understanding how acidic lung pH affects natural antimicrobial agents to fight bacterial infections;
- Developing new cell models to help study these processes more easily, reducing the need to get cells from people with cystic fibrosis.



4. Harnessing data to improve lives

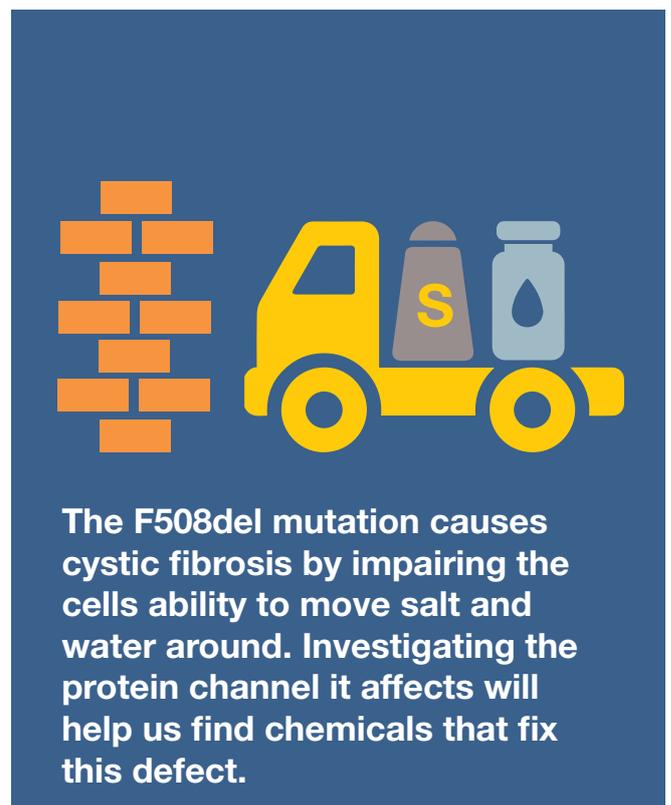
Prof Diana Bilton, Imperial College London

- Developing secure and ethical ways to make data-linkages;
- Identifying treatments that produce the most benefits in health, survival and quality of life for people with cystic fibrosis at critical stages of their lives;
- Examining how cystic fibrosis has an impact on education and work and why patients from poorer families experience more health problems.

5. Investigating the F508del-CFTR protein

Dr David Sheppard, University of Bristol

- Investigating the structure of the CFTR and how it is affected by the F508del defect; and
- Searching for chemicals that repair all the faults in CFTR caused by the F508del defect, so that the CFTR is correctly made and delivered to the cell border to form a stable gated pathway for chloride movement.



> Venture and Innovation Awards

One of the key strategic funding streams for research in 2015/16, is our Venture and Innovation Awards (VIAs) programme, which forms part of our five-year research strategy. VIAs leverage funding from external sources for transformational research projects, and enable us to respond quickly to new investment opportunities. VIA grants are awarded on a rolling basis by an internal committee who assess 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 2015/16 we committed more than £700,000 in total to 11 VIA projects covering a wide variety of aspects of cystic fibrosis, including engaging those living with cystic fibrosis in helping shape the direction of future research.

In February 2016 we held a 'research sandpit' to explore the GI tract and cystic fibrosis, one of the most significant and yet often overlooked aspects of life with cystic fibrosis. Research sandpits bring together experts in a wide range of fields, including non-CF-related, to address specific issues to do with cystic fibrosis.

This year we also continued our commitment to supporting the next generation of scientists with £10,500 to support six summer studentships, as part of a co-funded scheme with the British Lung Foundation to give emerging PhD students experience working in world-class research.

Continued investment in SmartCareCF has seen the programme hit a number of key milestones. The adult feasibility study on remote monitoring, which is led by Papworth Hospital, opened for recruitment in August 2015, and will continue to collect data for analysis until April 2017. A parallel study into the feasibility of remote monitoring for paediatric patients has been planned this year.

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).

The Research SAB met in September 2015, after the UK Cystic Fibrosis Conference in Manchester to complete a midterm review of the research strategy. In addition, SAB was asked to review proposals for changes to the strategy (particularly that of the VIA scheme) to ensure the existing research strategy is aligned to the new cooperate strategy to 2020.

> Collaborating with the clinical community to drive up standards of care

In August, the Trust announced the launch of the Excellence in Clinical Care & Innovation Awards – a new programme to support the very best ideas and innovation in cystic fibrosis clinical practice. The awards will provide funding for exciting quality improvement and clinical innovation projects. All UK CF centres are eligible to apply for awards ranging from £15,000 and up to £75,000, to be met by matched funds from an alternative source.

This year we awarded two clinical fellowships to; Kings College Hospital (£75,000) and Belfast Health & Social Care Trust (£75,000). The Cystic Fibrosis Clinical Fellowships programme is designed to encourage, develop and maintain high-quality leadership in the field of cystic fibrosis, helping develop and train the next generation of CF centre directors.

The Trust also contributed £75,000 towards a project in collaboration with the children's medical research charity Sparks to search for drugs that could benefit children with rare forms of the genetic mutation that causes cystic fibrosis. We made a contribution of £50,000 as co-funding for a study with Action Medical Research and Great Ormond Street Children's Hospital to develop a safe means of diagnosing cystic fibrosis during early pregnancy.

The Clinical Advisory Group met twice this year to advise on Cystic Fibrosis Trust publications, helpline enquiries and wider clinical issues. Chaired by Dr Keith Brownlee, Director of Impact, the group brings together representation from all the devolved nations, parent representatives and people with cystic fibrosis, as well as chairs of the Allied Health Professionals groups.

In recent years, the Trust's Peer Review programme has been an essential part of our commitment to working with people with CF, commissioners and clinicians to ensure the best care for people with cystic fibrosis. Each CF centre is reviewed every five years, to help identify areas of best practice, assess the service against service specifications and review the outcomes and experiences of a service. The peer review programme in its current form came to an end in October 2015, to allow us to evaluate the process. We are currently undertaking an extensive consultation with all interested parties, to produce a more objective, outcome-driven process that is centred on people with cystic fibrosis, and which will be more frequent and flexible.

> **Reforming the Registry to harness the power of knowledge**

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 CF care team. The Cystic Fibrosis Trust has commissioned the development of a bespoke, adaptable and flexible registry platform, which launched in February 2016, to make it easier for teams at CF centres to enter data, and to unlock the potential for the Registry's next phase of development, to which the Trust committed following a 2015 community survey. This includes enabling Registry-based clinical trials and developing a portal so that people with cystic fibrosis can view their clinical data as well as inputting their own information about their wellbeing. This has been an investment of £315,000 during 2015/16 with further investment scheduled for 2016/17.

The 2014 Annual Data Report was published in August 2015 with both a full report and 'at a glance' summary to offer a complete and an accessible snapshot of the UK CF population. The 2015 Annual Data Report will be published in August 2016 and will be similarly available on the Trust's website.

Through three pharmacovigilance and 2 NHS contracts, the Registry generated income of £1.2 million, all of which has been used either directly to support the Registry – including through grants to CF centres – or to fund research work dedicated to cystic fibrosis.

We are delighted to announce that this year saw Dr Siobhán Carr, who is a Consultant Paediatrician at the Royal Brompton Hospital, appointed as the new Chair of the Registry Steering Committee.

The Trust also held a National meeting in Nottingham for Registry users to learn, feed back, and share best practice. The meeting was attended by over 100 delegates, with 100% rating the event good, very good, or excellent.

> **Offering information and support for all**

2015/16 was a very exciting year for the Cystic Fibrosis Trust's Information and Support team, with additions to the team increasing its capacity to deliver support for those who need it most, and a commitment to give support for people at every stage of the cystic fibrosis journey.

The recruitment of a welfare and rights advisor enabled the team to offer specialist benefits and rights advice. This was boosted in Northern Ireland with the successful pilot of a benefits advice scheme, working with the Citizen's Advice Bureau.

The addition of a Youth Empowerment Officer in February 2016 enables the Trust to achieve its goal of 'Empowering young lives', and ensure that young people with cystic fibrosis have a voice in the work we do. By the end of March the YEO had developed and recruited the Trust's first Youth Advisory Group, which features people with cystic fibrosis aged 11–25 as well as siblings and friends.

In June 2015 we launched a new support pack and film aimed at parents of a child newly diagnosed with cystic fibrosis. These resources bring together stories and accounts from others who have been in that position, as well as practical advice and guidance.

We have sent out over 80 new parent packs since launch. We have also continued to expand our CF Connect scheme, putting new parents affected by cystic fibrosis in touch with trained parent volunteers who offer a listening ear, advice and support, in confidence.

This year we awarded 695 grants to individuals, totalling more than £230,000. This includes grant giving activity in partnership with the Joseph Levy Foundation, with 85 education related grants made from restricted funds.

Our health and wellbeing grants are awarded by an independent expert panel that meets every 8 weeks, and includes a person with CF, a parent and a former CF social worker. Emergency grants are processed by the Support Service team on a weekly basis.

In 2015/16 we awarded:

- 248 Health & Wellbeing grants, totalling over £63,000, to help people with the financial burden of managing and living with cystic fibrosis.
- 139 Emergency grants totalling over £19,000 to support people in moments of crisis
- 24 Transplant grants totalling £6,000 to support people going through the transplant process.
- 85 Funeral grants totalling £64,000 to help families who have lost a loved one.

Steve is just one of many grants recipients who have benefitted from our programme of support this year. Following the birth of his son in 2014, Steve was finding it more difficult to find the time to do as much exercise as he had been used to doing, and his lung function started to drop drastically. He had been working hard on getting out running, but with winter approaching he was concerned that he wouldn't be able to keep this up, so he successfully contacted us to see if we could help him with a grant for a new rowing machine.

Steve said, "Without the rowing machine, I would have been so inactive over the winter. I'm really starting to feel the benefits of having it. My physiotherapy is noticeably different after I've had a row. Thank you to the Cystic Fibrosis Trust for giving me the opportunity to give my health a boost with this new rower."

Through other programmes, we awarded:

- £28,000 through holiday grants
- £44,000 in education grants
- £7,000 of homecare grants

> Campaigning hard

Throughout 2015/16 the Trust continued to campaign on the issues most affecting people with cystic fibrosis, including access to medicines, transplantation and equal care. The cystic fibrosis community is also represented in the Westminster Parliament by an All-Party Parliamentary Group.

In November 2015 the Trust launched one of its biggest and most wide-ranging campaigns to date, 'Stopping the Clock', dedicated to ensuring that people with cystic fibrosis who could stand to benefit from life-changing precision medicines can access them on the NHS wherever they are in the UK.

Through this ongoing campaign we are amplifying the voice of our community and putting pressure on policy influencers and decision makers to work together for the good of those who are without access to these life-changing treatments.

- Almost 1,500 members of the CF community took part in our survey on attitudes to precision medicines, which informed our submission to the NICE consultation on the combination treatment Orkambi, which could benefit around half the UK CF population.
- More than 20,000 supporters signed our petition calling on the NHS across all four UK nations and drug manufacturers to take responsibility for ensuring access to precision medicines. The petition was handed in at Number 10 Downing Street. In December 2015 we worked with the Houses of Parliament's Outreach Service to organise a unique digital parliamentary debate. The service spreads awareness of the work, processes and relevance of the institution of Parliament, encouraging greater engagement between the public and the House of Commons and House of Lords. Members of the community shared videos and took to twitter to share their stories with Ian Austin MP, who raised the debate and represented the voice of the community. Following this members of UK Government met with the Trust's policy team to discuss working together to ensure greater access to medicines.
- The campaign as so far generated more than 3,000 new active supporters to the Cystic Fibrosis Trust, allowing us to better engage and understand their views, ideas and issues.

George Freeman MP, Minister for Life Sciences, said

“The Government and I wholeheartedly support the cystic fibrosis campaign’s central aim of ensuring that as many people with CF as possible will have access to personalised medicines by 2020. That sets an inspiring and clear goal and I relish the attempt to deliver it.” This is clearly a ringing endorsement of our campaign, and also offers real hope for the future for people with CF.

> Raising awareness and more effectively engaging with our community

We are responding to the changing face of marketing and communications and moving the Trust into a more digital first approach.

June 2015 saw the return of CF Week, the Cystic Fibrosis Trust’s annual week devoted to awareness and fundraising. The theme for 2015 was ‘the power of us’, and a focus on the strength and impact of the CF community themselves. People from across the community shared stories and experiences, and the Trust offered an in-depth look at some of its key projects.

In September we held the UK Cystic Fibrosis Conference, the UK’s largest conference dedicated to a multidisciplinary cystic fibrosis agenda. Bringing together clinicians, health professionals and researchers from around the world, the UK CF Conference promotes innovation, dialogue and shared learning. This year the event expanded to two days: one for a multidisciplinary clinical, research and academic audience, and a second for clinical healthcare professionals as well as those with a personal or professional interest in cystic fibrosis.

For the first time we streamed the entire conference live and recorded it for our website, so that the whole CF community were able to follow it in real time or watch key sections back later.

2015/16 saw the roll-out of ‘Life Unlimited’ a bold new era for the Trust with an exciting programme arranged around five key bodies of work. A soft launch in October introduced Life Unlimited to our core audience, followed in February with a big public event, accompanied by a world exclusive music track and powerful campaign video.

With Life Unlimited, the Trust is setting out to reach a wider audience, to boost income to allow us to do more, and achieve greater impact than ever before for the cystic fibrosis community. The public launch was aimed at attracting the attention of the wider public who know little or nothing about cystic fibrosis and the Trust.

In the first week following the launch, the video had been viewed 389,000 times, including 63,565 times on YouTube, and added 220 new subscribers to the Trust’s YouTube channel. The video and campaign secured a total of 62 pieces of media coverage, including both BuzzFeed and the Mail Online.

The launch benefitted from the support of a corporate partnership with ClearChannel, Digital Outdoor Advertising. As part of this outdoor campaign, the Life Unlimited advert appeared during rush hour at Piccadilly Circus, in London, and at 38 outdoor sites across the city, giving it an estimated audience reach of more than six million.

This year, the Trust launched a new website in order to deliver greater impact. Over a year in development, the new website that will enable the Trust to better serve its supporters and a growing audience. With 59% of traffic to the site coming via either smartphone or tablet, it was imperative to develop a mobile-responsive site with a better search function and all-round user-experience. Phase 1 of the site went live in February, with continuing development for Phase 2 extending into 2016/17. In addition to being more intuitive, the new site will allow the Trust to personalise content according to user profiles, so that users will find the content they need quickly and easily.

> Developing an effective organisation

In 2015/16 the Trust continued to expand on its volunteer programme following the award of the Investing in Volunteers accreditation in 2014.

A huge thank you to all of our volunteers who give their time and skills to help us achieve our mission, including the additional 82 volunteers we recruited across the organisation in 2015/16, which is a 10% increase on 2014/15. We have also developed new volunteer opportunities in CF connect, photography and our project placements from Queen Mary University. Volunteers work across the organisation, in areas including Content, Digital, People and Organisational Development, and Fundraising Support, and collectively giving nearly 32,000 hours of their time to support the Trust, showing just how dedicated they are to helping advance awareness of cystic fibrosis.

> Fundraising

The Cystic Fibrosis Trust receives no government funding, and we are very grateful for the ongoing support of the individual donors, organisations, charitable trusts, foundations, and corporate partners without whose generous support none of our life changing work could take place.

This year, the Trust was delighted to receive a number of gifts from high net worth individuals in support of both our core and project work, in line with plans to develop this area of income. We were also very pleased to develop warmly supportive relationships with new and existing members of the high value membership Sixty Five Roses Club at our annual flagship event in October 2015.

Income from charitable trusts and foundations continued to grow significantly in 2015/16 with income doubling in the last two years. This included two major grants totalling £500,000 from well-established grant makers the Garfield Weston Foundation and the Freemason's Grand Charity.

Corporate partnerships fundraising was given a boost in 2015/16 by securing major partnerships with HSBC Private Bank, Champneys, and Sainsbury's Central Retail Division. We were delighted to secure strategic partnerships with Simply Health and Yakult, and were selected as the charity of choice for the city focused 'Swaps Ball' held at The Dorchester, London, which raised £92,000. The successful UK CF Conference 2015 received £67,000 in sponsorship from a range of industry partners and has laid the foundation for an increase in sponsorship income for the 2016 conference. We are also very grateful for the generous in kind support from Clear Channel in helping to promote the work of the Trust.

We received notification that 52 of our supporters passed away in 15/16 who had generously included a gift in their will for the Trust. We would like to express our gratitude for thinking of us in this way. Very many thanks are also due to the 53 very kind supporters who responded to our Gifts in Wills campaign with notification of a future legacy.

Fundraising and community activities are essential to the continuing work of the Cystic Fibrosis Trust, providing opportunities to raise awareness, engage supporters and build lasting relationships, as well as generating much-needed income. This year we supported 118 challenge events, such as marathons, bike rides and treks, in the UK and beyond, raising more than £ 2,271,000. Our Community, Branches & Groups Activity also raised an amazing £2,081,000, including gift aid.

We are also very grateful to the new and existing donors who support our work through regular monthly donations via direct debit, as this ongoing support is invaluable in enabling us to plan ahead. Equally the support of everyone who made a donation to our Christmas appeal, via our web site, or in response to our telephone appeals, or who bought a raffle ticket is very much appreciated.

The Trust would like to convey our sincere and heartfelt thanks to each and every person who supported the charity's work in any way over the past year. Your support is literally a lifeline for all the Trust's innovative research, campaigning, and information and helpline services. Without your help none of our life changing work could take place.

Plans for the future

In 2015, after an intense period of planning, trustees agreed a bold and ambitious five-year strategy to deliver a step-change in the impact of the charity on the lives of people with cystic fibrosis. 2015/16 has been the first year of the “Life Unlimited” strategy and has seen much progress on a range of fronts, with significant investment in world-class research, more focused support for those who need it most and development of flagship programmes like SmartCareCF and the CF Registry.

Crucial to embarking on such a significant journey was the process of listening to all parts of the cystic fibrosis community in the UK itself, understanding their needs, concerns and goals. This engagement was and remains vital in enabling the Trust to take a leadership position on behalf of or community, and to bring together the expertise and insight that it contains within it.

Putting people with cystic fibrosis first in everything we do is a central part of our strategy, and we are seeing much greater involvement of our core beneficiaries in the shaping and delivery of our activities, with significant benefits in ensuring the projects are having maximum impact.

The revolution in genomics and personalised medicine is creating extraordinary opportunities for people with cystic fibrosis. We are determined to seize them. Transforming our work to transform the lives of those we are here for inevitably takes time and creates challenges. But we have made a good start and we are confident of further progress in the coming years.

With the community and public launches of the Life Unlimited era, the ground has been prepared for 2016/17 to see the start of a step-change for the Trust. This year we will develop and begin to roll out four flagship programmes, which will drive our work over the next five years. These world-class programmes will underpin our strategic priorities and bringing us closer to our goal of beating cystic fibrosis for good.

- **Therapeutic Development Programme:** to develop new therapies for all people with cystic fibrosis whatever their genotype and whatever the stage of their condition. This programme includes the Clinical Trials Accelerator Programme, which is design to promote equity of access to clinical trials across the UK and thereby increase opportunities for people with CF to be involved in trials
- **SmartCareCF** to identify, test and enable the deployment of innovative digital technology solutions that can improve the health and wellbeing of people living with cystic fibrosis.
- **Innovation Hubs:** to help establish new academic centres of excellence creating a focused critical mass in clinical and basic sciences research.
- **The UK Cystic Fibrosis Data Registry Phase II** – the Registry will move to a new, more efficient platform that will unlock its potential to revolutionise the way clinical trials are carried out. We will also open the CF Registry to people with cystic fibrosis so they can track their health, input their own data, and increase their involvement in research.

Other key activities for 2016/17 include:

- **Stopping the Clock** – the campaign will continue, including engagement with the NHS in England and Scotland over Orkambi
- **CF Week in May**, engaging the community with the impact of research and their role in helping shape the future.
- **CF Yelfie Day** on 1 July
- **The UK Cystic Fibrosis Conference** in September, which this year will run to three days including a satellite event designed to engage our community with research
- **The announcement of up to three new Strategic Research Centres**, as well as new VIAs and other programmes, and a new round of summer studentships
- **New Information & Support materials**, aimed at parents of children with cystic fibrosis starting school, and a fertility pack for adults with CF considering starting a family.

Financial review

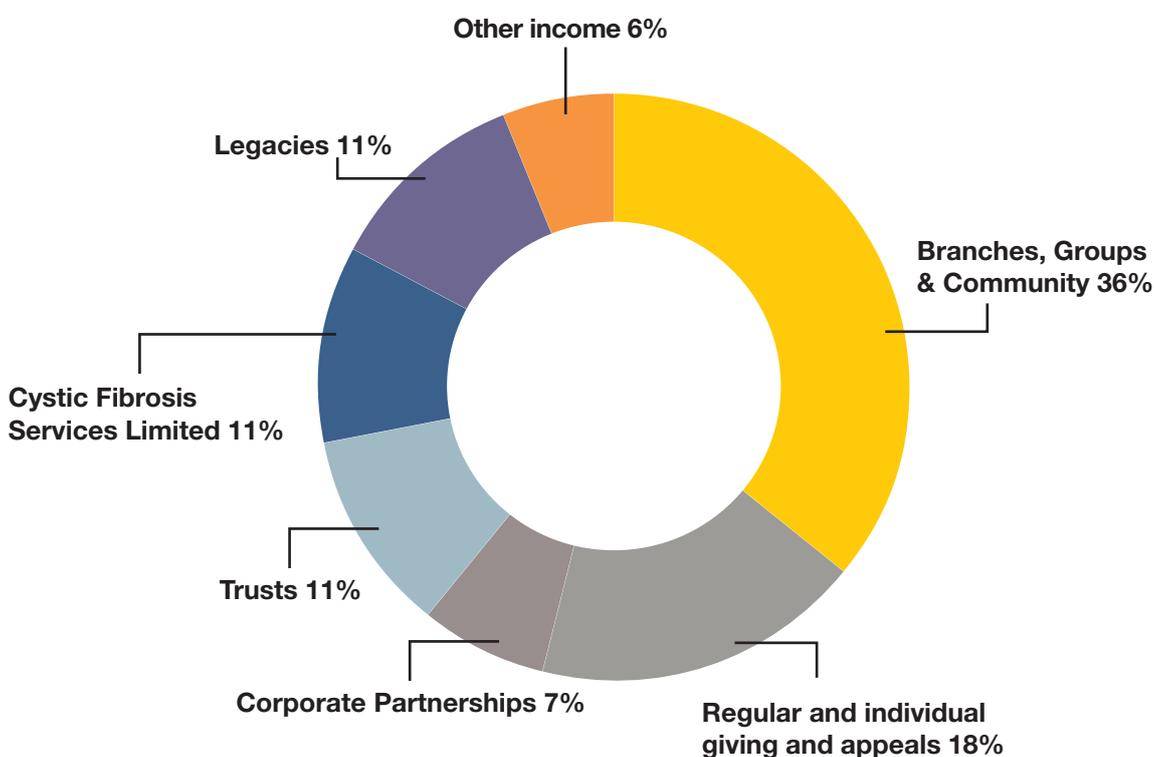
Income

The Trust's income from normal activities for the year to March 2016 was £11.4 million, an increase of 1% over the previous year. This does not include a one-off gain in the prior year of £827,000 due to the sale of the former office premises in Bromley.

84% of the Trust's income from normal activities was voluntary income, bringing in £9.6m, consistent with the prior year. Income raised by community fundraising and branches was £4.2m which represents 40% of this figure (a slight fall compared to 2014/15), confirming the continuing importance of the volunteer network to our fundraising efforts. While income from legacies and corporate partnerships was lower than in the prior year, income from Trusts and Foundations doubled – this significant growth is the result of a strategic focus on this area of fundraising.

Income raised through CFSL, the Trust's trading subsidiary, was at £1.3m (2014/15 - £1.4m). Three (2014/15 - 3) long term commercial contracts are in place for Phase IV pharmacovigilance studies based on the extraction of data from the Trust's Cystic Fibrosis Registry, and we are actively seeking further new business in this area, including shorter term contracts for specific projects.

> 2015/16 income by income stream



| Income from normal activities: | £'000 |
|--|---------------|
| Branches, Groups & Community | 4,157 |
| Regular and individual giving and appeals | 2,073 |
| Corporate Partnerships | 772 |
| Trusts | 1,274 |
| Cystic Fibrosis Services Limited | 1,264 |
| Legacies | 1,217 |
| Other income | 629 |
| Total income from normal activities | 11,386 |

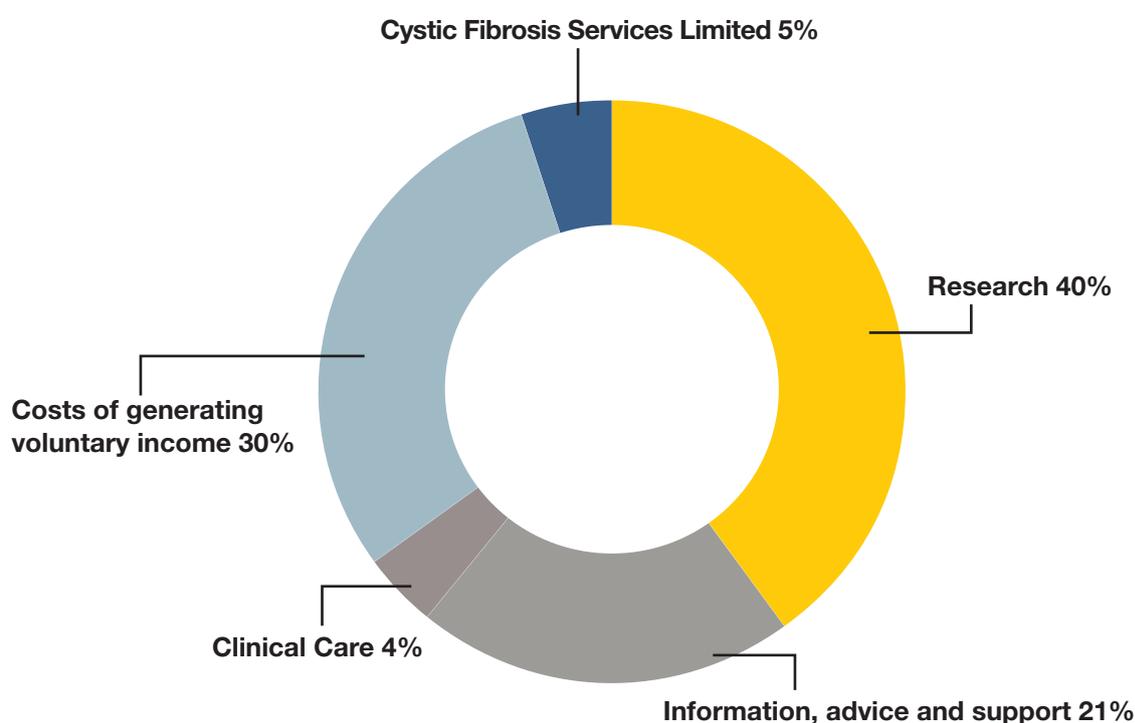
Expenditure

The Trust's total expenditure for the year was £13.6m, a 13% increase compared to the previous year. Almost all of this increase was in the area of charitable activity – £8.9m, representing 65% of total expenditure (2014/15 62%), was spent on programmes of research, information, advice and support and clinical care. The remainder was spent on fundraising and running the charity, reflecting investment in fundraising and information technology as part of setting the basis for future growth within the context of the 5 year strategic plan.

Total grant commitments in the year at £4.0m were 9% higher than in the prior year. Grants worth £3.8m (2014/15 £3.1m) were committed to a range of institutions, including £2.6m (2014/15 £1.5m) committed for four Strategic Research Centres.

Work on the Flagship Programmes of SmartcareCF, CF Registry Platform Development and Therapeutic Development have continued, with total spend on these programmes of £1.2m (2014/15 £0.5m).

> 2015/16 expenditure by cost type



| Expenditure: | £'000 |
|--------------------------------------|---------------|
| Research | 5,461 |
| Information, advice & support | 2,931 |
| Clinical Care | 496 |
| Charitable activities total | 8,888 |
| Costs of generating voluntary income | 4,029 |
| Cystic Fibrosis Services Limited | 666 |
| Total expenditure | 13,583 |

> Investment policy

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

> Review of investments in the year

The value of the investment portfolio (including endowment funds) has decreased by £0.2m (2014/15, increase of £0.4m) in the year – after the transfer out of £0.1m of income generated on the endowment funds – a 3% fall. While income generated on investments and realised gains/losses totalled £0.2m, these were offset by unrealised losses totalling £0.3m resulting from uncertain financial markets throughout the period. Management fees totalling £0.04m were charged by the investment managers in the year.

> Reserves

The Trust's reserves as at 31 March 2016 totalled £10,765,000 (2015 – £13,286,000). The Trustees maintain the following reserves:

- Designated reserves – the Trustees have opted to set aside free reserves for the following purposes:
 - A fixed asset reserve, equal to the net book value of the fixed assets (£824,000) is held to ensure these funds are not considered to be realisable
 - A strategic reserve (£2,050,000) is held to fund the budgeted deficit in the 2016/17 financial year and enable the continued progress of the flagship programme (see page 13)
- Operating reserve – held at a value (£4,542,000) 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 – (£1,767,000) to be deployed in financing the ambitions described in the Trust's 5 year Business Delivery Plan.
- Restricted income funds – (£562,000) relating to donations restricted to various specified activities. More information about the reserves can be found in note 5 to the accounts.

The Trustees keep reserves policy under regular review to ensure it is set at the appropriate levels to reflect changes in the business outlook as they materialise.

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

Principal risks and uncertainties

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

The principal risks and uncertainties that the Trustees have identified relate to remaining engaged with, and meeting the expectations of people with cystic fibrosis; 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 which 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 **13 July 2016** 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 for the year ended 31 March 2016, which comprise the Consolidated Statement of Financial Activities, the Consolidated Balance Sheet, the Charity Balance Sheet, the Consolidated Cash Flow Statement and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (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 set out on pages 20, 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 2016 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 matter prescribed by the Companies Act 2006

In our opinion the information given in the Trustees' Annual Report incorporating the Strategic Report for the financial year for which the financial statements are prepared is consistent with the financial statements.

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 Charities 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 13 July 2016

26 Red Lion Square
London
WC1R 4AG

haysmacintyre is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Cystic Fibrosis Trust

> Consolidated statement of financial activities

(Incorporating an Income and Expenditure Account)

For the year ended 31 March 2016

| | Note | Unrestricted Funds £'000 | Restricted Funds £'000 | Endowment Funds £'000 | Total Funds 2016 £'000 | Prior period total funds 2015 £'000 |
|--|----------|--------------------------------|------------------------------|-----------------------------|---------------------------------------|---|
| Income and endowments from: | | | | | | |
| Donations and legacies | 2 | 7,919 | 1,698 | - | 9,617 | 9,652 |
| Other trading activities | 12 | 1,264 | - | - | 1,264 | 1,376 |
| Investments | 2b,7 | 230 | - | 51 | 281 | 220 |
| Other income: | | | | | | |
| Fixed asset disposals gain | 6 | - | - | - | - | 827 |
| Other income | 2 | 224 | - | - | 224 | 38 |
| Total income | | 9,637 | 1,698 | 51 | 11,386 | 12,113 |
| Expenditure on: | | | | | | |
| Raising funds | 3 | 4,634 | 61 | - | 4,695 | 4,522 |
| Charitable activities | | | | | | |
| Research | 3 | 4,779 | 682 | - | 5,461 | 4,228 |
| Clinical Care | 3 | 618 | (122) | - | 496 | 619 |
| Information, advice & support | 3 | 2,748 | 183 | - | 2,931 | 2,603 |
| Total charitable activities | | 8,145 | 743 | - | 8,888 | 7,450 |
| Total resources expended | 3 | 12,779 | 804 | - | 13,583 | 12,032 |
| Net income/(expenditure) before investment gains/losses | | (3,142) | 894 | 51 | (2,197) | 81 |
| Realised investment gains/(losses) | | (4) | - | (37) | (41) | 91 |
| Unrealised investment gains/(losses) | | (214) | - | (69) | (283) | 171 |
| Net investment gains/(losses) | | (218) | - | (106) | (324) | 262 |
| Net income/(expenditure) | | (3,360) | 894 | (55) | (2,521) | 343 |
| Transfers between funds | 5 | 766 | (669) | (97) | - | - |
| Net movement in funds | | (2,594) | 225 | (152) | (2,521) | 343 |
| Reconciliation of funds: | | | | | | |
| Total Funds brought forward | | 11,777 | 337 | 1,172 | 13,286 | 12,943 |
| Total funds carried forward | 5 | 9,183 | 562 | 1,020 | 10,765 | 13,286 |

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 16)

The notes on pages 23 to 40 form part of these financial statements.

Cystic Fibrosis Trust

> Consolidated and Charity Balance Sheets

As at 31 March 2016

| | Notes | Consolidated | | Charity | |
|---|-------|------------------------|------------------------|------------------------|------------------------|
| | | Total 2016 £'000 | Total 2015 £'000 | Total 2016 £'000 | Total 2015 £'000 |
| Fixed assets | | | | | |
| Tangible assets | 6 | 824 | 289 | 824 | 289 |
| Investments | 7 | 5,181 | 5,463 | 5,181 | 5,463 |
| | | 6,005 | 5,752 | 6,005 | 5,752 |
| Current assets | | | | | |
| Debtors | 8 | 1,875 | 553 | 1,973 | 2,072 |
| Cash held as short term investment | | 12,263 | 9,704 | 12,263 | 9,704 |
| Cash at bank and in hand | | 1,154 | 5,441 | 1,060 | 3,921 |
| | | 15,292 | 15,698 | 15,296 | 15,697 |
| Liabilities | | | | | |
| Creditors: amounts falling due within one year | | | | | |
| Grants payable | 10 | (4,940) | (3,833) | (4,940) | (3,833) |
| Creditors and accrued charges | 11 | (1,565) | (1,001) | (1,569) | (1,000) |
| | | (6,505) | (4,834) | (6,509) | (4,833) |
| Net current assets | | 8,787 | 10,864 | 8,787 | 10,864 |
| Creditors: amounts falling due after one year | | | | | |
| Grants payable | 10 | (4,027) | (3,330) | (4,027) | (3,330) |
| Total net assets | | 10,765 | 13,286 | 10,765 | 13,286 |
| The funds of the charity: | | | | | |
| Endowment funds | 5 | 1,020 | 1,172 | 1,020 | 1,172 |
| Restricted Income funds | 5 | 562 | 337 | 562 | 337 |
| Unrestricted funds: | | | | | |
| Designated Reserves | 5 | 2,874 | 3,160 | 2,874 | 3,160 |
| Operating Reserves | | 4,542 | 5,435 | 4,542 | 5,435 |
| Retained Reserves | | 1,767 | 3,182 | 1,767 | 3,182 |
| Total charity funds | | 10,765 | 13,286 | 10,765 | 13,286 |

The notes on pages 23 to 40 form part of these financial statements.

Approved and authorised for issue by the Trustees on **13 July 2016** and signed on their behalf by:

George Jenkins, Chairman

| | 2016 £'000 | 2015 £'000 |
|---|----------------|---------------|
| Net cash provided by (used in) operating activities (Note A) | (1,115) | 2,102 |
| Cash flows from investing activities: | | |
| Dividends and interest from cash held as short term investments | 80 | 70 |
| Purchase of fixed assets | (816) | (243) |
| Purchase of investments | - | - |
| Transfer of income generated on endowment funds | 123 | - |
| Proceeds of sales of fixed assets | - | 1,483 |
| | (613) | 1,310 |
| (Increase) in cash held as short term investments | (2,559) | (4,031) |
| (Decrease) in cash (Note B) | (4,287) | (619) |

Notes to Cash Flow Statement

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

| | 2016 £'000 | 2015 £'000 |
|--|----------------|---------------|
| Net income/(expenditure) for the reporting period (as per the statement of financial activities) | (2,521) | 343 |
| Adjustment for: | | |
| Fixed asset disposal gain | - | (827) |
| Depreciation charges | 281 | 131 |
| Dividends and interest from investments | (281) | (220) |
| (Gains)/losses on investments | 324 | (262) |
| Investment management charge | 37 | 34 |
| (Increase)/decrease in debtors | (1,322) | 540 |
| Increase/ (decrease) in creditors | 2,368 | 2,363 |
| | (1,115) | 2,102 |

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

| | 2016 £'000 | 2015 £'000 |
|--|---------------|---------------|
| Cash and cash equivalents at the beginning of the reporting period | 15,145 | 11,733 |
| Change in cash and cash equivalents in the reporting period | (4,287) | (619) |
| Increase in short term investments | 2,559 | 4,031 |
| Cash and cash equivalents at the end of the reporting period | 13,417 | 15,145 |
| (being cash at bank and in hand and cash held as short term investments) | | |
| | 2016 | 2015 |
| Analysis of cash and cash equivalents: | | |
| | £'000 | £'000 |
| Cash on hand | 1,154 | 5,441 |
| Notice deposits (less than 3 months) | 12,263 | 9,704 |
| Total cash and cash equivalents | 13,417 | 15,145 |

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) Reconciliations with previous Generally Accepted Accounting Practice

In preparing the accounts, the Trustees have considered whether in applying the accounting policies required by FRS 102 and the Charities SORP FRS 102 the restatement of comparative items was required. The opening fund balances at the date of transition have not been restated to an immaterial amount arising from discounting on long term liabilities. No restatement of items has been required in making the transition to FRS 102. The transition date was 1 April 2014.

In accordance with FRS 102, a reconciliation of opening balances and net income /(expenditure) for the year is provided with the net income/(expenditure) under previous GAAP adjusted for the presentation of investment gains/losses as a component of reported income.

| Reconciliation of reported net income | £'000 |
|--|--------------|
| Net income/expenditure as previously stated | 81 |
| Adjustment for gains/(losses) on investment now treated as a component of net income | 262 |
| 2016 net income restated | 343 |

c) Charity status

The charity is a company limited by guarantee. The members of the company include the Trustees named on page 3. 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.

d) Consolidation

The financial statements include the results and assets and liabilities of the charity and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own statement of financial activities under section 408 of Companies Act 2006. The deficit for the parent charity was £2,521,000 (2015- surplus of £343,000).

e) 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.

f) 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.

g) 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 recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. 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.

h) 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.

i) Grants

Grants committed and awarded during the year are expensed.

j) 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.

k) 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 Trust operates a defined contribution pension scheme for the benefit of its employees. The assets of the scheme are held independently from those of the Charity in an independently administered fund. The pensions costs charged in the financial statements represent the contributions payable during the year.

l) 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.

m) 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.

n) 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.

o) 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.

2a. Income from donations and legacies

| | Unrestricted Funds £'000 | Restricted Funds £'000 | Total 2016 £'000 | Total 2015 £'000 |
|---|--------------------------------|------------------------------|---------------------------------|------------------------|
| Branches, Groups & Community | 3,807 | 56 | 3,863 | 4,219 |
| Legacies | 1,190 | 2 | 1,192 | 1,361 |
| Individual donations | 247 | 318 | 565 | 542 |
| Corporate | 522 | 145 | 667 | 797 |
| Regular giving and appeals | 1,206 | 53 | 1,259 | 1,295 |
| Trusts | 149 | 1,124 | 1,273 | 632 |
| Donations in kind | 105 | - | 105 | - |
| Gift Aid | 568 | - | 568 | 685 |
| NHS National Services England | 81 | - | 81 | 82 |
| NHS National Services Scotland | 44 | - | 44 | 39 |
| Total income from donations and legacies | 7,919 | 1,698 | 9,617 | 9,652 |

Within Other Income (shown separately on the Statement of Financial Activity) is £176,000 received from HMRC regarding partial recovery of VAT on eligible purchases. Going forward, the Trust will continue to make claims for recoverable VAT on a regular basis.

The remaining £48,000 within Other Income (2015 – £38,000) 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 2016 £'000 | Total 2015 £'000 |
|--------------------------------|--------------------------------|------------------------------|---------------------------------|------------------------|
| Income from listed investments | 165 | 53 | 219 | 115 |
| Bank interest | 65 | (3) | 62 | 105 |
| Total investment income | 230 | 50 | 281 | 220 |

3a. Expenditure

| | Grants Restricted £'000 | Grants Unrestricted £'000 | Direct costs £'000 | Support costs £'000 | Total 2016 £'000 | Total 2015 £'000 |
|-------------------------------|-------------------------------|---------------------------------|--------------------------|---------------------------|------------------------|------------------------|
| Raising funds | | | | | | |
| Fundraising | - | - | 2,473 | 1,556 | 4,029 | 4,000 |
| Trading and Merchandising | - | 593 | 73 | - | 666 | 522 |
| Charitable activities | | | | | | |
| Research | 1,199 | 2,580 | 1,434 | 248 | 5,461 | 4,288 |
| Clinical care | (133) | 152 | 310 | 167 | 496 | 619 |
| Information, advice & support | 118 | 118 | 1,718 | 977 | 2,931 | 2,603 |
| | 1,184 | 3,443 | 6,008 | 2,948 | 13,583 | 12,032 |

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

**Analysis of allocated
Support Costs**

| | Governance £'000 | Finance £'000 | IT Support £'000 | HR & OD £'000 | HQ & Facilities £'000 | Total 2016 £'000 | Total 2015 £'000 |
|-------------------------------|---------------------|------------------|---------------------|------------------|-----------------------------|------------------------|------------------------|
| Fundraising | 213 | 244 | 496 | 211 | 392 | 1,556 | 1,525 |
| Research | 34 | 39 | 79 | 34 | 62 | 248 | 245 |
| Clinical care | 23 | 26 | 53 | 22 | 43 | 167 | 198 |
| Information, advice & support | 134 | 153 | 311 | 133 | 246 | 977 | 912 |
| Total costs | 404 | 462 | 939 | 400 | 743 | 2,948 | 2,880 |

Costs are allocated on the basis of time spent on the activity by full time staff.

3a. Expenditure (continued)

Net income/ (expenditure) in the year:

| | 2016 | 2015 |
|-------------------------------------|--------------|-------|
| | £'000 | £'000 |
| Auditors remuneration excluding VAT | 17 | 16 |
| Auditors – tax advice | 32 | 9 |
| Depreciation | 281 | 131 |
| Operating leases – building | 245 | - |
| Operating leases – other | 12 | 12 |
| Trustees' travel expenses | 4 | 2 |

3b. Grants

Grants were awarded during the year as follows:

| | 2016 | 2015 |
|------------------------|--------------|-------|
| | £'000 | £'000 |
| Grants to institutions | 4,382 | 3,103 |
| Grants to individuals | 246 | 583 |
| | 4,627 | 3,686 |

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.

| | 2016 | 2015 |
|---|----------------|---------|
| | £'000 | £'000 |
| Balance at start of year | 7,163 | 5,020 |
| Adjustment to opening balance | - | (27) |
| Awarded in the year | 4,628 | 3,686 |
| Paid in year | (2,823) | (1,516) |
| Balance at end of year | 8,967 | 7,163 |
| Falling due within one year (note 9) | 4,940 | 3,833 |
| Falling due after more than one year (note 9) | 4,027 | 3,330 |

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

| | 2016 |
|---|--------------|
| | £'000 |
| University of Newcastle | 750 |
| University of Exeter | 750 |
| University College London | 768 |
| University of Leeds / Leeds Hospital | 500 |
| University of Cambridge / Papworth Hospital | 224 |
| Verona Pharma | 200 |
| University of Manchester / Wythenshawe Hospital | 151 |
| Kings College Hospital | 113 |
| Royal Brompton Hospital | 95 |
| SPARKS / UCL | 75 |
| Belfast Health & Social Care Trust | 75 |
| Action Medical Research | 50 |

3b. Grants (continued)

| | |
|---|--------------|
| Frimley Park Hospital | 28 |
| Southampton Hospital | 25 |
| University of Bristol / Bristol Hospital | 57 |
| London South Bank University | 19 |
| ECFS – European Cystic Fibrosis Society | 17 |
| University of Nottingham / Queen's Medical Centre | 15 |
| | 3,912 |
| Less: Grant commitments from previous years released in the year (see note below) | (682) |
| Add: Grant commitments made to unspecified research institutions | 559 |
| Add: Registry support grants made to various CF centres | 593 |
| Total grants made to institutions | 4,382 |

Two commitments made in previous financial years were reversed in the year:

- A commitment of £432,000 made in 2012/13 to Kings College Hospital was reversed, as the planned project will no longer go ahead. Of this commitment, £157,000 was funded from restricted funds, and remains as an outstanding fund balance at the end of the year (see note 5).
- A commitment of £250,000 made in 2014/15 to Dundee University was reversed out as this commitment was contingent on an application for matched funding from a third party, which was unsuccessful.

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:

| | 2016 £'000 | 2015 £'000 |
|---|---------------|---------------|
| Salaries | 3,593 | 3,007 |
| Redundancy and other termination payments | 122 | 90 |
| Temporary Staff | 210 | 668 |
| Social security costs | 384 | 332 |
| Other pension costs | 192 | 150 |
| | 4,501 | 4,247 |

Redundancy and other termination payments totalling £122,225 were paid to 10 (2015 – £90,000 paid to 15) staff members in the year. In May 2015 the Trust relocated to new office premises, and some staff members chose not to relocate, giving rise to redundancies. The Trust has also restructured a number of teams to ensure they are fit for purpose to deliver the new strategic direction. Whilst some postholders have been redeployed into new roles, a number have been made redundant.

Analysis of average salaried staff numbers by category:

| | 2016 No. | 2015 No. |
|--|-------------|-------------|
| Fundraising | 41 | 41 |
| Research | 7 | 5 |
| Clinical care | 5 | 6 |
| Information, advice & support | 27 | 23 |
| Management | 2 | 3 |
| Finance | 4 | 2 |
| IT and project management support | 6 | 4 |
| HR & OD | 4 | 5 |
| Facilities | 1 | 1 |
| Total average monthly headcount | 97 | 90 |

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

| | 2016 No. | 2015 No. |
|--------------------|-------------|-------------|
| £60,001 - £70,000 | 3 | 2 |
| £80,001 - £90,000 | - | 1 |
| £90,001 - £100,000 | 1 | 1 |

Pension contributions to defined contribution pension schemes for these employees totalled £27,879 (2015 – £24,004).

Remuneration of key management personnel: The total amount paid to key management personnel was £371,000 which relates to 6 individuals who served on the Senior Leadership Team during the year (2015 – £369,000 paid to 5 individuals)

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. Expenses of £3,588 (2015 – £1,918) were settled on 4 (2015 – 3) trustees.

5a. Funds

| | 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) | 229 |
| 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 |

Continued on next page

5a. Funds (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) | - | 6 |
| SmartCare CF | 38 | - | 550 | (336) | (252) | - |
| 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 | - | (59) | 507 |
| EW Joseph Endowment | 202 | (18) | 9 | - | (26) | 167 |
| Joseph Levy Endowment | 302 | (31) | 16 | - | 2 | 289 |
| Robert Couper Endowment | - | - | - | - | - | - |
| Sally Wrigley Memorial Fund | 20 | - | - | - | - | 20 |
| Other Endowment funds | 59 | (7) | (1) | - | (14) | 37 |
| Total Endowment Funds | 1,172 | (106) | 51 | - | (97) | 1,020 |
| Total Charity Funds | 13,286 | (324) | 11,386 | (13,583) | - | 10,765 |

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 2016/17 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 – A further £140k of restricted donations were received against fundraising pledges made as part of the 2011 Gene Therapy appeal. These donations reduce the deficit on the brought forward balance to £20k, underwritten by unrestricted reserves.
- 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

5a. Funds (continued)

- Strategic Research Centres:
Imperial College: Pseudomonas infection,
Cambridge: Mycobacterium abscessus infection,
Newcastle: INOVCF-Innovative non-CFTR Approaches,
Bristol: F508del0CFTR,
UCL: Personalised Engineered Cell Therapies,
- Venture Innovation Awards:
UCL: Prenatal diagnosis for autosomal recessive conditions,
Imperial College: Antibacterial activity of Glatiramer acetate
- 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.
- 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.
- **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 education about cystic fibrosis. See comments about the corresponding endowment fund below.
- Sailing Fund – funding sailing related activities for people with cystic fibrosis; the Trust is currently investigating ways to use these funds effectively while avoid infection risks.
- Leisure Fund – funding leisure activities for people with cystic fibrosis, including the holiday 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.
- 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.

Cystic Fibrosis Trust

> Notes to the Financial Statements (continued)

For the year ended 31 March 2016

5a. 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 is restricted 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.
- Transfers were made from the SmartcareCF restricted fund into the Fixed Asset Reserve, reflecting costs which were funded by restricted donations and which were capitalised as platform development assets.

Cystic Fibrosis Trust

> Notes to the Financial Statements (continued)

For the year ended 31 March 2016

5b. Analysis of funds

| | Unrestricted £'000 | Endowment funds £'000 | Gene Therapy Restricted £'000 | Other restricted £'000 | 2016 £'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 |

6. Fixed assets – Tangible assets

| | Furniture & fittings £'000 | Computer hardware £'000 | Computer software £'000 | Website development £'000 | Platform development £'000 | Total £'000 |
|--|----------------------------------|-------------------------------|-------------------------------|---------------------------------|----------------------------------|----------------|
| Cost | | | | | | |
| At 31 March 2015 | 225 | 697 | 243 | 173 | 73 | 1,411 |
| Additions | 403 | 73 | - | 230 | 110 | 816 |
| Disposals | - | - | - | - | - | - |
| At 31 March 2016 | 628 | 770 | 243 | 403 | 183 | 2,227 |
| Depreciation | | | | | | |
| At 31 March 2015 | 225 | 579 | 242 | 76 | - | 1,122 |
| Disposals | - | - | - | - | - | - |
| Charge for the year | 120 | 77 | 1 | 28 | 55 | 281 |
| At 31 March 2016 | 345 | 656 | 243 | 104 | 55 | 1,403 |
| Net book value at 31 March 2016 | 283 | 114 | - | 299 | 128 | 824 |
| Net book value at 31 March 2015 | 0 | 118 | 1 | 97 | 73 | 289 |

The balances carried forward have been restated to be consistent with the current year classification between asset classes.

7. Fixed assets – Investments

| Group and Charity | Total 2016 £'000 | Total 2015 £'000 |
|-----------------------------------|------------------------|------------------------|
| Market value as at 31 March 2015 | 5,463 | 5,086 |
| Additions at cost | 2,448 | 1,476 |
| Disposals at opening book value | (2,596) | (1,477) |
| Net gains/(losses) on investments | (353) | 263 |
| | 4,962 | 5,348 |
| Change in cash | 219 | 115 |
| Market value as at 31 March 2016 | 5,181 | 5,463 |

7. Fixed assets – Investments (continued)

| Represented by: | 2016 £'000 | 2015 £'000 |
|--------------------------------------|-----------------------------|---------------|
| Equities | 3,150 | 2,541 |
| Fixed Interest and multi-asset funds | 881 | 1,799 |
| Property | 837 | 486 |
| Cash | 313 | 637 |
| | 5,181 | 5,463 |

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 2016. These make up more than 5% of total investments:

| | Total 2016 £'000 |
|---------------------------------------|---|
| Schroder Chartity Equity Fund | 1,294 |
| The Equity Income Trust for Charities | 1,856 |
| The income trust for charities | 369 |
| Charities property fund | 410 |
| Property income trust for charities | 427 |
| Ruffer charity assets Trust | 512 |

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.

8. Current Assets

| | Group 2016 £'000 | Group 2015 £'000 | Charity 2016 £'000 | Charity 2015 £'000 |
|--|---|------------------------|---|--------------------------|
| Trade debtors | 492 | 95 | - | - |
| Amount due from subsidiary undertaking | - | - | 590 | 1,614 |
| Prepayments and accrued income | 1,383 | 458 | 1,383 | 458 |
| | 1,875 | 553 | 1,973 | 2,072 |

9. 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.

10. Grants Payable

| | 2016 £'000 | 2015 £'000 |
|--|----------------------|---------------|
| Grant creditor at 1 April | 7,163 | 5,020 |
| Prior year adjustment | - | (27) |
| Grants paid during the year | (2,823) | (1,516) |
| Grants approved before 31 March 2016 and payable within one year | 2,913 | 2,097 |
| Grants approved before 31 March 2016 and payable after one year | 1,714 | 1,589 |
| Grant creditor at 31 March | 8,967 | 7,163 |
| Represented by | | |
| Grants due within one year at 31 March | 4,940 | 3,833 |
| Grants due > 12 months | 4,027 | 3,330 |
| | 8,967 | 7,163 |

11. Creditors

| | Group 2016 £'000 | Group 2015 £'000 | Charity 2016 £'000 | Charity 2015 £'000 |
|------------------------------|--------------------------------------|------------------------|--|--------------------------|
| Trade creditors | 498 | 55 | 498 | 55 |
| Other creditors | 126 | 167 | 131 | 167 |
| Accruals and deferred income | 942 | 779 | 940 | 778 |
| | 1,566 | 1,001 | 1,569 | 1,000 |

Cystic Fibrosis Trust

> Notes to the Financial Statements (continued)

For the year ended 31 March 2016

12. Interest in subsidiary

Cystic Fibrosis Services Limited is incorporated in England 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 2016 £'000 | Total 2015 £'000 |
|---|------------------------|------------------------|
| Sales and sundry income | 1,264 | 1,376 |
| Cost of sales and administration | (666) | (523) |
| Intercompany recharges | (67) | (60) |
| Net contribution to parent charity | 531 | 793 |

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

| | Total 2016 £ | Total 2015 £ |
|---|--------------------|--------------------|
| Current Assets | | |
| Debtors | 497,205 | 92,085 |
| Cash at bank | 94,813 | 1,520,332 |
| | 592,018 | 1,612,417 |
| Creditors: amounts falling due within one year | (592,016) | (1,612,415) |
| 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.

Cystic Fibrosis Trust

> Notes to the Financial Statements (continued)

For the year ended 31 March 2016

13. Leasing commitments

At 31 March 2016, the Trust's future minimum operating leases payments relating to buildings were:

| | 2016 £'000 | 2015 £'000 |
|----------------------------|---------------|---------------|
| Within one year | 271 | - |
| Between one and five years | 1,086 | - |

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

At 31 March 2016, the Trust's future minimum operating leases payments relating to equipment were:

| | 2016 £'000 | 2015 £'000 |
|----------------------------|---------------|---------------|
| Within one year | 20 | - |
| Between one and five years | 73 | - |

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.

The Trust paid £6,000 to the Citizens Advice Bureau (2015 – £3,000) in the year, as a contribution towards a project that the Trust is working on with this organisation's Belfast office. The wife of one of the Trustees (Brian Henderson) is an employee of Citizens Advice Bureau in Northern Ireland.

The Trust awarded a Strategic Research Centre grant of £371,399 to the Leeds Institute of Rheumatic and Musculoskeletal Medicine, and a Clinical Excellence and Innovation Award of £38,740 to Wythenshaw Hospital. One of the Trustees (Professor Andrew Jones) was co-applicant and lead applicant respectively for these projects. The Trustees ensured that all grant making decisions involving this Trustee were carried out on an arms length basis, in accordance with the policy on conflicts of interest, and Professor Jones took no part in the decisions to make either of these awards.

Total donation income from the Trustees in the year was £30,504 (2015 – £20,180). In addition, three of the trustees (2015 – 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. Capital commitments

As at the balance sheet date, the Trust did not have any capital commitments (2015 – £336,000 relating to the fitting out of the new office space).

Cystic Fibrosis Trust

> Notes to the Financial Statements (continued)

For the year ended 31 March 2016

16. Prior year Consolidated Statement of Financial Activities

| | Note | Unrestricted Funds £'000 | Restricted Funds £'000 | Endowment Funds £'000 | Total Funds 2015 £'000 |
|--|----------|--------------------------------|------------------------------|-----------------------------|------------------------------|
| Income and endowments from: | | | | | |
| Donations and legacies | 2 | 8,409 | 1,243 | - | 9,652 |
| Other trading activities | 11 | 1,376 | - | - | 1,376 |
| Investments | | 185 | 32 | 3 | 220 |
| Other income: | | | | | |
| Fixed asset disposals gain | 6 | 827 | - | - | 827 |
| Other income | | 38 | - | - | 38 |
| Total Income | | 10,835 | 1,275 | 3 | 12,113 |
| Expenditure on: | | | | | |
| Raising funds | 3 | 4,522 | - | - | 4,522 |
| Charitable activities | | | | | |
| Research | | 3,324 | 963 | 1 | 4,288 |
| Clinical Care | | 619 | - | - | 619 |
| Information, advice & support | | 2,511 | 92 | - | 2,603 |
| Total charitable activities | | 6,454 | 1,055 | 1 | 7,510 |
| Total resources expended | 3 | 10,976 | 1,055 | 1 | 12,032 |
| Net income/(expenditure) before investment gains/losses | | (141) | 220 | 2 | 81 |
| Realised investment gains/(losses) | | 100 | - | (9) | 91 |
| Unrealised investment gains/(losses) | | 116 | - | 55 | 171 |
| Net investment gains/(losses) | | 216 | - | 46 | 262 |
| Net income/(expenditure) | | 75 | 220 | 48 | 343 |
| Transfers between funds | 5 | 33 | (33) | - | - |
| Net movement in funds | | 108 | 187 | 48 | 343 |
| Reconciliation of funds: | | | | | |
| Funds brought forward | | 11,669 | 150 | 1,124 | 12,943 |
| Total funds carried forward | 5 | 11,777 | 337 | 1,172 | 13,286 |

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

- Allan Gormly CMG CBE¹ (retired March 2016)
 - Brian Henderson¹ (retired March 2016)
 - Professor John Price MD FRCP FRCPCH
 - Caroline Cartellieri Karlsen¹
 - Peter Norris
 - David Turner QC¹
 - Professor Andrew Jones
 - Michael Winehouse¹
 - Louise King¹
 - Hannah Begbie¹
-

> Finance and Audit Committee

Chairman

- Peter Norris
 - Allan Gormly CMG CBE
 - Brian Henderson
 - David Turner QC
 - Stephen Mullen (Independent Member)
 - Guy Harington (Investments Committee)
 - Alistair Peel (Investments Committee)
-

> Nomination & Development Committee

Chairman

- Allan Gormly CMG GBE (Chairman)
- Brian Henderson
- George Jenkins OBE
- Professor John Price MD FRCP FRCPCH

> Charity Management

- Ed Owen - Chief Executive¹
 - Elizabeth Bishop FCA – Director of Finance and Resources
 - Dr Janet Allen MD FRSE – Director of Strategic Innovation
 - Dr Keith Brownlee – Director of Impact
-

> Principal and Registered Office

One Aldgate
London
EC3N 1RE

T 020 3795 1555

E enquiries@cysticfibrosis.org.uk

W cysticfibrosis.org.uk

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

> Auditors

haysmacintyre
26 Red Lion Square London WC1R 4AG

> Bankers

Royal Bank of Scotland plc
15 Bishopsgate London EC2N 3NW

> Investment Managers

Cazenove Capital Management
12 Moorgate London EC2R 6DA

Allan Gormly and Brian Henderson's term as Trustees concluded on 31st March 2016. During the year invitations to join the Board were extended to Ffyoona Dawber and Ryan Tohill. These invitations were accepted and their tenures officially commenced in April 2016.

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. An open recruitment process was held in the last quarter of 2015 to select new Trustees.

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, Ed Owen and his Senior Leadership Team.

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. During the year, four Trustees retired and four new Trustees were appointed.

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 Senior Leadership Team (SLT) and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Cystic Fibrosis Trust

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2016. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 2nd Floor, One Aldgate, London EC3N 1RE.