# Cystic Fibrosis why we're here

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

For the year ended 31 March 2015

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

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#### > Patron

HRH The Prince of Wales KG KT GCB OM

#### > Honorary President

 Dr James Littlewood OBE MO FRCP FRCPE DCH TRUSTEES

## > Trustees

Chairman
George Jenkins OBE¹

## Vice Chairman

- Allan Gormly CMG CBE¹
- Rupert Pearce Gould FCA (retired October 2014)¹
- Katrina Dujardin¹ (retired September 2015)
- Professor Stuart Elborn CBE MD FRCP (retired June 2014)
- Brian Henderson¹
- Professor John Price MD FRCP FRCPCH
- Martyn Rose (retired December 2014)1
- Peter Sharp (retired December 2014)1
- Caroline Cartellieri Karlsen¹
- Peter Norris
- David Turner QC¹
- Dr Andrew Jones (from October 2014)
- Michael Winehouse (from March 2015)¹
- Louise King (from March 2015)1
- Hannah Begbie (from March 2015)1

#### > Finance and Audit Committee

- Rupert Pearce Gould (Chairman – to November 2014)
- Peter Norris (Chairman from November 2014)
- Allan Gormly
- Peter Sharp (retired December 2014)
- David Turner QC (from February 2015)
- Stephen Mullen (Independent Member from February 2015)
- Guy Harington (Investments Committee)
- Alistair Peel (Investments Committee)

#### > Nomination & Development Committee

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

#### > Charity Management

- Ed Owen Chief Executive<sup>1</sup>
- Joanna Knowles —Interim Director of Operations
- lain McAndrew Director of Engagement & Income Generation
- Dr Janet Allen MD FRSE Director of Research & Care
- Lucy Semmens Director of Strategy & Performance

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Company Limited by Guarantee

Company registration number: 3880213

Charity registration number:

England & Wales -1079049

Scotland -SC040196

#### > Auditors

haysmacintyre 26 Red Lion Square London WC1R 4AG

#### > Bankers

Royal Bank of Scotland plc 15 Bishopsgate London EC2N 3NW

#### >Investment Managers

Cazenove Capital Management 12 Moorgate London EC2R 6DA

<sup>&</sup>lt;sup>1</sup> Indicates either person with cystic fibrosis, carer or close relative of someone with cystic fibrosis.

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2015. 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.

# Structure, governance and management

#### >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.

A review of financial governance was undertaken in the summer of 2014 by the Trust's auditors, haysmacintyre. Key recommendations were accepted by Trustees and new arrangements have now been proposed. Trustees discussed future governance arrangements at a special development meeting in November 2014, and work is underway to develop consistent and appropriate governance arrangements going forward.

#### > 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 2014 to select three new Trustees. A fourth Trustee was invited to join the Board (following interview) due to the specific clinical research skills required.

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, including:

- copies of board minutes;
- the most recent annual audited accounts;
- Finance Committee reports;
- the Trust's objectives and strategic plan; and
- a copy of the Charity Commission's briefing document, 'The Essential Trustee'.

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

Members of the SLT during 2014/15 have been the Chief Executive and the Directors of Operations, Engagement and Income Generation, Strategy and Performance, and Research and Clinical Care.

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.

#### > 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.



## 📂 About cystic fibrosis

Cystic fibrosis is a life-shortening genetic condition affecting more than 10,000 people in the UK today. It slowly destroys the lungs and digestive system, and imposes a heavy treatment burden of drugs, physiotherapy and hospital care on those with the condition. According to the 2013 report of the UK Cystic Fibrosis Registry, the average survival rate for cystic fibrosis in the UK is now 36.6 years.



#### 📂 About us

The Cystic Fibrosis Trust is the only UK-wide charity working to improve and transform the lives of people with cystic fibrosis.

#### We do this by:

- investing in cutting-edge research and its application to patients;
- driving up standards of clinical care;
- providing information, advice and support for people with cystic fibrosis and their families;
- campaigning and influencing policy affecting people with cystic fibrosis; and
- raising awareness of cystic fibrosis in the media and among the general public.

# Delivering for people with cystic fibrosis – achievements and performance

The Cystic Fibrosis Trust is committed to improving and transforming the lives of people with cystic fibrosis.

2014 was the Trust's 50th anniversary, which provided a platform to grow support, improve services and enhance impact. Major activities relating to the Trust's 50th anniversary included a Gala Dinner in May, and a reception held at Clarence House in December where we said a fond farewell to HRH Princess Alexandra and thanked her for her patronage over the last 47 years, and welcomed our new Patron, HRH The Prince of Wales.

2014/15 has been a vital and productive year in the development of a more ambitious, dynamic organisation focused on improving and transforming the lives of people with cystic fibrosis, as set out in the 2020 vision document adopted by the Cystic Fibrosis Trust in March 2014.

The Trust's work relies on the extraordinary efforts of thousands of supporters across the UK. They raise millions of pounds every year and play a vital part in the fight to beat cystic fibrosis. We thank each and every one of them.

Delivery across all core charitable activities in 2014/15 has been good in support of the longer-term growth of the Trust's impact. Significant organisational changes designed to facilitate effective future delivery, including the accommodation project, have progressed well.

#### Research

2014/15 reflected the second year of the roll-out of the Trust's five year research strategy.

#### > Strategic Research Centres (SRCs)

Following an open call in 2014, the Trust provided funding for two £750,000 SRCs, virtual centres of excellence bringing together scientific experts from across the world to tackle specific issues in cystic fibrosis, and to recruit the brightest and best young researchers into cystic fibrosis research.

#### These were:

- F508del-CFTR SRC led by Dr David Sheppard at the University of Bristol, this project aims to promote the development of new drugs to treat the most common cause of cystic fibrosis, a genetic mutation carried by around 90% of people living with cystic fibrosis in the UK, called F508del.
- The Cystic Fibrosis Epidemiological Network (CF-EpiNet) – led by Prof Di Bilton and her colleagues at the Royal Brompton Hospital, this SRC will explore harnessing data to improve the lives of people with cystic fibrosis.

On advice from the Strategy Implementation Board, which met in January 2015, a commitment was made to commit to two Strategic Research Centres in 2014/15 rather than three because of our clear policy to support only what is judged to be excellent science.

A new call for SRCs was issued in February 2015.

#### > Venture and innovation Awards (VIAs)

In November 2014 the Trust announced a Venture and Innovation Award for a specific company, a £65,000 grant to support research by Verona Pharma into its leading pipeline drug RPL554, a new inhaled treatment for cystic fibrosis.

We contributed £49,687 towards a project jointfunded with Action Medical Research developing a new type of gene therapy which will switch a gene called ENaC off, to protect the lung from the dehydration process and in turn protect the lungs from bacterial infections.

In 2015 we announced an award of £46,000 for a project led by Dr Patrick Harrison at University College, Cork, exploring the use of 'CRISPR' genetic editing to restore CFTR function. In this project external funding came from CFF.

#### > Research Sandpits

Two research 'sandpits' were held in 2014/15, one on identifying hurdles to running clinical trials in the UK and another on adolescence.

#### > Gene Therapy Consortium

The Gene Therapy Consortium was due to publish the results of its Phase 2b study of its Wave 1 product in October 2014 at the North American Cystic Fibrosis Conference in Atlanta. This was, however, postponed and the results were presented in a private presentation for the CF community in May 2015, before being published later in the summer.

The Cystic Fibrosis Trust-GTC liaison group met on three occasions during 2014/15 to discuss arrangements regarding the communication of the study results, potential commercial partnerships and relevant funding arrangements involving the Trust.

#### > Research Partnerships

The Trust continues to develop new relationships to further CF research, including in industry, academia and government. Work is underway to identify collaborations with our American counterpart the Cystic Fibrosis Foundation (CFF) on particular research programmes.

### >Summer Studentships

In 2014 the Trust's first Sir John Batten summer studentships took place, designed to encourage young medical trainees to focus work in cystic fibrosis. In 2015 the scheme has been expanded as the Trust joins forces with the British Lung Foundation to fund up to 10 summer placements.

#### **Clinical Care**

Following a review into the Trust Clinical Care strategy, the Trust has implemented a series of recommendations including:

- The appointment of a Clinical Lead.
- The establishment of a Clinical Advisory Group representing all clinical and Allied Health Professional groups. This is chaired by Prof John Price and its first meeting was in November 2014.
- The reintroduction of the Clinical Fellows Programme to help invest in future quality cystic fibrosis clinicians. Two fellowships were funded in 2014/15.

12 peer reviews of Cystic Fibrosis Centres were completed in 2014/15. In December, a joint meeting of the Trust, the British Thoracic Society and the British Paediatric Respiratory Society, agreed to make interim changes to streamline the existing peer review process for 2015/16 and develop more fundamental changes for 2016/17. The Trust has brought in Dr Keith Brownlee, a former CF paediatric consultant in Leeds, to lead this work.

Following a successful pilot project in 2013/14, the Trust launched 'Genotype Matters' in January 2015, a campaign to raise awareness of the importance for people with CF of knowing their genotype, and to ensure accurate genotype information was held by CF Centres on all people with cystic fibrosis in the UK. The project provides grants to those Centres to retest those with incomplete data, and it has proved very popular with both the clinical and patient communities.

The Trust has worked closely with the Clinical Reference Group for Cystic Fibrosis and commissioners on key issues relating to funding and NHS England proposals to move specialised services to new co-commissioning arrangements.

#### > Clinical fellowships

The clinical fellowships programme was restarted in 2014. These fellowships are aimed at supporting specialist training in cystic fibrosis for physicians who have completed their specialist respiratory training. The purpose of these is effectively to train the next generation of CF centre directors. Two were awarded, one to the Royal Brompton Hospital and one to Wythenshawe Hospital, Manchester.

#### **CF Registry**

Following a review completed in early 2014, the Trust has embarked on a strategic development programme to enhance the impact of the CF Registry. This has included:

- the appointment of a Registry Lead to oversee all strategic and operational activities;
- the appointment of Jem Rashbass, the National Director for Disease Registration in Public Health England, as chair of the CF Registry Development Committee; and
- the establishment of the procurement process for a new, fit-for-purpose platform.

In the summer of 2014, the Trust signed the third Phase IV pharmacological study contract with Forest Pharmaceuticals.

## **SmartCareCF**

Following the Trustee's decision in the summer of 2014 to fund the study led by Prof Andreas Floto to test the feasibility of remote monitoring in cystic fibrosis in the summer of 2014, the Trust has worked closely with the Papworth team and other CF centres to design and shape the work. This included procuring a supplier, Fat Fractal, to design and deliver a bespoke IT platform. Recruitment of patients for the six-month non-interventional study began in summer 2015.

The Trust will continue to work in close collaboration with key academic and industry partners.

The programme's aims were announced to coincide with the visit to the Royal Brompton Hospital by the Trust's new Patron, HRH The Prince of Wales, in December 2014.

## Information and support

In December 2014, Trustees agreed a new support services strategy designed to provide the best information and support to people with cystic fibrosis and their carers at all stages of life. This will transform the work of the Trust in this area of activity and provide demonstrable impact.

Additional resource has been recruited to ensure effective operation of the helpline, and a pilot project was launched in January to provide a network of peer-to-peer support for new CF parents.

A new process for the application and approval of support grants for people with cystic fibrosis has been established with new, fairer criteria. A new grants panel, established under the chairmanship of Peter Sharp, met for the first time in February.

This team now has a solid bedrock to be able to grow from and transform the direct support and advice to our community that can be so valuable in times of need.

## **Engagement and Communications**

Engagement with the cystic fibrosis community and the wider public has been significantly enhanced during 2014/15, to mobilise support and increase awareness. This has included the appointment of a new Engagement Director and over 30 new regional media volunteers to assist the in-house team.



## Key achievements include:

- A 10-point increase in public perception and awareness of the Trust in the annual Charity Brand Index published in the summer of 2014. The Trust moved from 85th in the ranking to 75th after five successive years of decline.
- 649 print media pieces with an equivalent advertising value of £1.2m by end of Q3 2014/15.
- More than 31,000 views of the Breath Before film produced for the Trust's partnership with the British Comedy Awards in December 2014. The film has recently been awarded You Tube's doGooder 'Best Non-Profit Video Award' for 2015 after receiving more than 3,600 votes worldwide.

# Engagement with key stakeholders has also been boosted through 2014/15 including:

- The national CF conference in Manchester in September with record number of clinical and research attendees and key speakers Preston Campbell, of the CFF, and Tim Kelsey, NHS England Director.
- The launch of an all-party Parliamentary Group on Cystic Fibrosis in the House of Commons December with more than 60 Parliamentary 'champions' alongside arranging more than 20 MP visits to CF centres across the UK.
- Campaigns resulting in 15,000 actions, such as the one focused on improving facilities at the adult CF centre at Kings College Hospital.
- Targeted action to seek reimbursement of Kalydeco for the 44 people in England and Wales with non-G551D gating mutations, and a seminar in December with industry and clinicians on issue of access to high-cost medicines.

The work to promote the recommendations of the Trust's 'Hope for More' transplant campaign continues, and the Trust was represented at the European Cystic Fibrosis Conference in Gothenburg in June and the NACFC in Atlanta in October. A delegation visited the CFF in Bethesda in February 2015 to discuss future collaboration.

## Involving people with CF

Putting people with CF at the heart of everything we do is a core part of the Trust's vision and future strategy. A new Head of Principal Involvement was recruited and has been developing an involvement strategy to be discussed by Trustees in March 2015. New IT arrangements and accommodation will enable the Trust to overcome cross-infection barriers to interact more effectively with people with cystic fibrosis. Two new Trustees appointed in early 2015 are people with cystic fibrosis.

#### **Income generation**

# The main focus this year has been putting in place key building blocks for future growth.

- Restructure of the Community Events Team, now completed with all posts filled and a refocused strategy implemented to better engage and build long term relationships with key supporters (eg Team CF cycling).
- Over-performance in Individual Giving through a series of above-target campaigns, raffles and an extended telephone fundraising campaign contributing sustainable long term income; combined with another buoyant year for legacies with good growth in our new 'In memory' and tribute fund programme.
- In Philanthropy & Strategic Partnerships, the focus has been on building capacity with the adoption of a high value, philanthrophy and corporate partnerships strategy, a relaunch of the 65 Roses Club for regular donors, the implementation of relationship and stewardship management and funding pipeline opportunities (including more than 280 Trust applications), and the appointment of a statutory fundraising expert.
- A £250k grant for SmartCareCF from the Grand Charity of Freemasons provided a breakthrough moment in the Trust's ability to access major grants.
- Cultivation to win back key influential donors and stakeholders through a series of 1:1 and select events (eg Clarence House).
- "Wood for Trees" data audit and donor segmentation analysis with the appointment of a Business Intelligence Manager to ensure fundraising and engagement opportunities are evidence-led decisions.
- We received a £450k grant from the Robert Luff Foundation as support for the Strategic Research Centre led by Professor Floto and established in 2013/14.

## **Organisational Development**

2014/15 represented the first year of the Trust's People Strategy aimed at developing workforce planning and embedding new practices and culture within the organisation.



## **Achievements include:**

- An increase in employee satisfaction based on a benchmark annual survey. The Trust also participated in the Best Company Survey and received a 'One to Watch' score. Given the amount of change that has occurred this is an excellent result.
- An increase in the number of managed volunteers, from 165 to 505, and receiving the Investors in Volunteering award in August 2014.
- Increased impactful learning and development, supporting the organisation to understand more about what it does and the skills needed to drive success.

There have also been a number of significant restructures across the organisation to align the roles to deliver the strategy. In particular this included the regional fundraising team which was carried out in Q3 of 2014/15. Recruitment to all new posts has now been completed.

Overall there has been a notable change in the ways of working within the Trust. A number of experienced and committed people have been recruited who are demonstrating added value. There is a genuine excitement about what the Trust is trying to achieve and the majority of people are aligned to delivering this through a high standard of work.

2014/15 was also the first year of the roll-out of the Trust's IT strategy, designed to ensure the organisation is at the forefront of using technology.

The relocation of the Trust's head office from Bromley to a more central London location is a key part of the work to get the organisation in the best possible shape to deliver the ambitious plans of the future.

## **Financial review**

#### Income

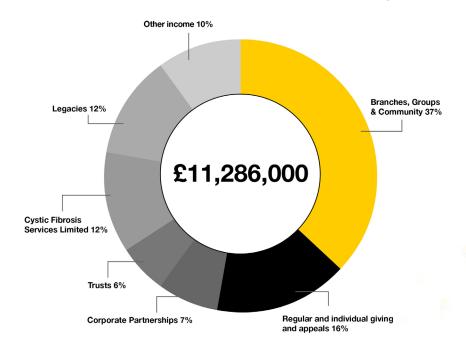
The Trust's income from normal activities for the year to March 2015 was £11.3 million, an increase of 4% over the previous year. This represents a significant achievement by the Trust's supporters, and offers a firm base for the Trust's ambitious plan to reach £20 million of annual income by 2020.

In March 2015, the Trust sold its offices in Bromley which were in need of very significant repair and refurbishment to a residential developer, generating a one-off profit on disposal of £828,000, and has moved to smaller, modern, flexible rented accommodation in Aldgate in central London.

86% of the Trust's income from normal activities was voluntary income, bringing in £9.7m. Income raised by community fundraising and branches represented 44% of this figure, confirming the continuing importance of the volunteer network to our fundraising efforts. Giving from legacies, individuals, corporates and trusts also increased.

Of particular note this year is the income raised through CFSL, the **T**rust's trading subsidiary, which increased by 73% to £1.4m. A number of 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.

## >2014/5 income from normal activities by income stream



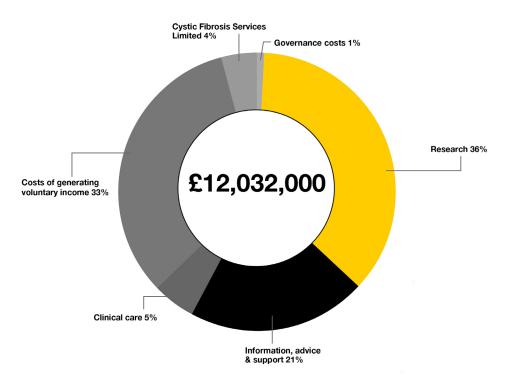
Income from normal activities:	£'000
Branches, Groups & Community	4,219
Regular and individual giving and appeals	1,837
Corporate Partnerships	797
Trusts	632
Cystic Fibrosis Services Limited	1,376
Legacies	1,361
Other income	1,064
Total income from normal activities	11,286
Fixed asset disposal gain	827
Total income	12,113

## **Expenditure**

The Trust's total expenditure for the year including charitable activities was £12.0m, a 19% increase compared to the previous year. £7.4m, representing 62% of total expenditure, was incurred on charitable activities, with spending 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.

Research grant commitments in the year at £4.3m were broadly consistent with the prior year. Outstanding grant balances not yet paid to grantees are held on the balance sheet as cash held as short term investments. Grants worth £3.0m were committed to a range of institutions, including £1.5m committed for two Strategic Research Centres at the Royal Brompton and the University of Bristol.

## >2014/5 expenditure by cost type



Expenditure:	£'000
Research	4,281
Information, advice & support	2,580
Clinical Care	614
Charitable activities total	7,475
Costs of generating voluntary income	3,962
Cystic Fibrosis Services Limited	523
Governance costs	72
Total expenditure	12,032

#### > Investment policy

The Finance Committee sets the investment policy. Our 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. General funds are invested in a balanced portfolio that includes some exposure to less liquid assets such as property and employing 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 against commitments for grants. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance Committee.

#### > Reserves

The Trustees' reserves policy is to hold designated reserves to cover specific commitments as set out in Note 5 to the accounts. In addition to the designated reserves, the Trustees are holding an operating reserve sufficient, as a minimum, to cover six months' operating costs, major fluctuations in income from budget and contingencies for long-term commitments and any deficit on restricted reserves due to over commitment or payment on those projects – the total of which amounts to £5.4m. This leaves retained reserves of £3.2m which are held for future initiatives. The Trustees keep the Trust's reserves policy under regular review in the light of long-term business planning and remain confident that such initiatives will come forward as defined in the ambitious plans for the future.

## Plans for the future

Building on the planning completed in 2014, the Trust has developed a business delivery plan (BDP) that sets out a framework for the delivery of its ambitious 2020 strategy and its mission to beat cystic fibrosis for good.

The BDP has been developed in the context of the establishment of a £50m major appeal to underpin the delivery of new, flagship projects and with input from key employees drawn from across the Trust to understand the opportunities that are presented by the Trust doubling its annual core income to around £20m by 2020.

Five emotive themes have been developed from the detailed needs analysis completed in 2014, relating to the areas where the Trust is considered to be able to make the most change and impact for people with CF and its wider community. The five themes, each of which have three impact measures, are:

- 1. **Supporting breaths for life** we will promote healthy lungs by preventing and significantly slowing decline, and we will improve access to successful lung transplants. The three key areas of activity driving impact here will be promoting activity, fighting irreversible lung damage, and increasing access to transplantation.
- 2. **Empowering young lives** we will ensure that adolescence is a time of growth and opportunity for all people with cystic fibrosis by engaging and supporting young people to make positive choices. In this area our work will be directed to engaging and understanding, empowering and enabling, and support through transition (one of the pivotal periods in the life of a young person with cystic fibrosis).
- 3. **Making ambitions possible** we will provide the appropriate tools for people with cystic fibrosis to live life to the full, by championing personal ambitions, lifting barriers and providing support whenever needed. In this area we will enable our community to achieve their ambitions, we will reduce the treatment burden and improve care, and improve health and wellbeing.

## 4. Changing lives through

transformational therapies - we will enable increased access to transformational therapies for people with cystic fibrosis and identify the pathways to cure cystic fibrosis in the longer-term. Key areas of activity here will be accelerating clinical trials, receiving precision therapies, and beating cystic fibrosis.

#### 5. Harnessing the power of knowledge

- we will offer an unrivalled source of expertise and information to drive change and deliver maximum impact for people with cystic fibrosis. Our work here will centre around information (delivering an expert knowledge base), interaction (interacting with our community), and innovation (influencing change).

## 🣂 Flagship programmes

Three 'flagship' programmes will elevate the impact of the Trust to a higher level that would not be possible without major investment:

- SmartCareCF
- Therapeutic Drug Discovery Pipeline
- Hubs of Innovation

These flagship programmes will scale up ambition in order to deliver in excess of daily core activity and quicken the pace of advancement in terms of access to new therapies, reducing the burden of care and developing new ideas.

## **Principal risks and uncertainties**

Systems of internal control embedded within the culture of the Trust and which are designed to provide reasonable assurance against material misstatement or loss include:

- strategic and operational plans and an annual budget;
- consideration of financial and non-financial results on a regular basis;
- assessment of major projects against core objectives; and
- identification and management of risks.

#### > Risk management

The Board has overall responsibility for ensuring that risk is managed in a constructive and considered manner and mitigated (where possible). Risks in relation to delivery of the Trust's ambitious five-year strategy and business development plan have been identified, the key financial ones being:

- projects starting in advance of full-life funding being in place to deliver all required activity;
- income falling short of expectations; and
- a loss of financial flexibility arising from a greater proportion of restricted funding.

These risks are being mitigated through regular scrutiny of financial performance by both the Finance Committee and the Board through monthly management accounts and forecasting, particularly in relation to income. A series of Golden Rules have also been agreed to guide long-term financial decisionmaking. The Trustees will continue to assess risk in a constructive manner to safeguard the efficacy of the Trust.

## 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' Annual Report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Practice (United Kingdom Accounting Standards).

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 account of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period.

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

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable 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 charity will continue in business.

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

Insofar as each of the Trustees of the charitable company at the date of approval of this report is aware there is no relevant audit information (information needed by the charitable company's auditor in connection with preparing the audit report) of which the charitable company's auditor is unaware. Each Trustee has taken all of the steps that he/she should have taken as a Trustee in order to make himself/herself aware of any relevant audit information and to establish that the charitable company's auditor is aware of that information.

In approving this Trustees' Report, the Board members are also approving the Strategic Review, in their capacity as company directors.

This report was approved by the Trustees on 18 November 2015 and signed on their behalf by: Mr George R Jenkins OBE Chairman

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

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2015 which comprise the Group Statement of Financial Activities, the Group Summary Income and Expenditure Account, the Group and Parent Charitable Company Balance Sheets, the Group 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 page 15, 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 2015 and of the group's and the parent charitable company's incoming resources and application of resources, 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 Charity Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- the charitable company (and group) has (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 18 November 2015

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.

## > Consolidated statement of financial activities

(Incorporating an Income and Expenditure Account) For the year ended 31 March 2015

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total 2015 £'000	Total 2014 £'000
Incoming resources						
Incoming resources from generated funds						
Voluntary income	2	8,409	1,243	-	9,652	9,812
Activities for generating funds						
Registry, trading and merchandising	12	1,376	-	-	1,376	797
Investment & interest income		185	32	3	220	166
Fixed asset disposals gain	6	827	-	-	827	31
Other incoming resources		38	-	-	38	-
Total incoming resources		10,835	1,275	3	12,113	10,806
Resources expended						
Cost of generating funds						
Costs of generating voluntary Income	3	3,962	-	-	3,962	3,293
Costs of registry, trading and merchandising	12	523	-	-	523	318
Cost of generating funds		4,485	-	-	4,485	3,611
Charitable activities						
Research		3,322	958	1	4,281	4,118
Clinical Care		614	-	-	614	726
Information, advice & support		2,483	97	-	2,580	1,609
Cost of charitable activities		6,419	1,055	1	7,475	6,453
Governance costs		72	-	-	72	59
Total resources expended	3	10,976	1,055	1	12,032	10,123
Net incoming/(outgoing) resources before investment gains/(losses)		(141)	220	2	81	683
Transfers between funds	5	33	(33)	-	-	-
Realised investment gain/(loss)		100	-	(9)	91	61
Surplus/(deficit) for the year		(8)	187	(7)	172	744
Unrealised investment gains/(losses)		116	-	55	171	304
Net movement in funds		108	187	48	343	1,048
Funds brought forward		11,669	150	1,124	12,943	11,895
Funds carried forward	5	11,777	337	1,172	13,286	12,943

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

The notes on pages 20 to 31 form part of these financial statements.

## > Consolidated and Charity Balance Sheets

As at 31 March 2015

		Consolidated		Charity	
	Notes	Total 2015 £'000	Total 2014 £'000	Total 2015 £'000	Total 2014 £'000
Fixed assets					
Tangible assets	6	289	832	289	832
Investments	7	5,463	5,086	5,463	5,086
		5,752	5,918	5,752	5,918
Current assets					
Debtors	8	553	1,093	2,072	2,078
Cash held as short term investment	9	9,704	5,673	9,704	5,673
Cash at bank & in hand		5,441	6,060	3,921	4,851
		15,698	12,826	15,697	12,602
Creditors: amounts due within one year					
Grants payable	10	(3,833)	(3,243)	(3,833)	(3,243)
Creditors and accrued charges	11	(1,001)	(781)	(1,000)	(557)
		(4,834)	(4,024)	(4,833)	(3,800)
Net current assets		10,864	8,803	10,864	8,803
Creditors: amounts due within one year					
Grants payable	10	(3,330)	(1,777)	(3,330)	(1,777)
Net assets		13,286	12,943	13,286	12,943
Represented by:					
Endowment funds	5	1,172	1,124	1,172	1,124
Restricted Reserves	5	337	150	337	150
Unrestricted funds					
Designated Reserves	5	3,160	3,703	3,160	3,703
Operating Reserves	5	5,435	4,664	5,435	4,664
Retained Reserves	5	3,182	3,302	3,182	3,302
Total funds		13,286	12,943	13,286	12,943

The notes on pages 20 to 31 form part of these financial statements.

Approved and authorised for issue by the Trustees on and signed on their behalf by:

Mr George R Jenkins OBE Chairman

#### **18 November 2015**

Company number: 3880213

## Consolidated Cash Flow Statement

As at 31 March 2015

	2015 £'000	2014 £'000
Net cash Inflow from operating activities (Note A)	2,102	2,345
Returns on investments and servicing of finance		
Investment income from cash held as short term investments	70	166
Capital expenditure and financial investment		
Purchase of fixed assets	(243)	(44)
Purchase of investments	-	14
Proceeds of sales of fixed assets	1,483	31
	1,240	1
Management of liquid resources		
(Increase) in cash held as short term investments	(4,031)	(4,026)
Increase/(Decrease) in cash (Note B)	(619)	(1,514)

#### **Notes to Cash Flow Statement**

A. Reconciliation of net incoming resources to net cash inflow/(outflow) from operating activities

	2015 £'000	2014 £'000
Net incoming resources	81	683
Fixed asset disposal gain	(827)	0
Depreciation	131	140
Investment income	(220)	(191)
Investment management charge	34	25
(Increase)/decrease in debtors	540	(749)
Increase/ (decrease) in creditors	2,363	2,437
	2,102	2,345

#### B. Analysis of changes in net cash resources during the year

	2015 £'000	2014 £'000
Net cash resources at 1 April	11,733	9,221
Net increase/(Decrease) in cash at bank & in hand	(619)	(1,514)
Increase in short term investments	4,031	4,026
Net cash resources at 31 March	15,145	11,733

(being cash at bank & in hand and cash held as short term investments)

#### Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 1. Accounting policies

#### a) Basis of preparation

The financial statements are prepared under the historical cost convention as modified by the revaluation of investments and in accordance with applicable accounting standards, the Statement of Recommended Practice, "Accounting and Reporting by Charities" issued in March 2005 and the Companies Act 2006.

Having reviewed the expected cash flows over the next twelve months the Trustees are satisfied that sufficient reserves will be available for the charity to meet all its commitments as they fall due. Further details of the charity's reserves policy can be found in the Trustees' Report.

#### b) Consolidation

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

#### c) 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:

Computer equipment 331/3% Software 331/3% Furniture and fittings 25% Cars 20% Freehold buildings 2%

Software 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.

Freehold land is not depreciated.

#### d) Income

Income from voluntary fundraising branches and groups is taken to the Statement of Financial Activities on the basis of the accounting returns received. Donations, legacies and other income are brought into the statement of financial activities on an accruals basis, when the Trust knows with certainty that the income will be received.

#### e) Resources expended

All expenditure is accounted for on an accruals basis and includes irrecoverable VAT where applicable.

Expenditure is allocated to relevant activity categories on a basis that is consistent with the use of the resource.

- Costs of generating funds includes all costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs.
- Charitable activities includes all costs relating to activities where the primary aim is part of the objects of the charity, along with an apportionment of support costs.
- Governance costs includes the cost of trustee expenses, audit fees, and an apportionment of support costs.

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.

#### Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### f) Investments

Investments are included in the balance sheet at market value at the balance sheet date and the surplus or deficit on revaluation is shown as unrealised gains or losses on the face of the Statement of Financial Activities.

Realised gains and losses represent the difference between the sale proceeds and the opening market value of an investment or cost if purchased during the year.

Liquid resources are regarded as cash deposits held overnight or at very short call (normally seven days).

#### g) Grants

Grants committed and awarded during the year are expensed.

#### h) 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.

#### i) Pension scheme

The charity operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the charity. Charges to the Statement of Financial Activities in the period are on an accruals basis.

#### j) 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.

#### k) Funds

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

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

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

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

#### I) 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.

## > Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 2. Voluntary income

	Unrestricted Funds £'000	Restricted Funds £'000	Total 2015 £'000	Total 2014 £'000
Branches, Groups & Community	4104	115	4,219	4,309
Legacies	1,358	3	1,361	1,777
Individual donations	344	198	542	751
Corporate	412	385	797	549
Gift Aid	685	-	685	633
Regular giving and appeals	1,242	53	1,295	1,216
Trusts	143	489	632	405
NHS National Services England	82	-	82	92
NHS National Services Scotland	39	-	39	80
Total Voluntary income	8,409	1,243	9,652	9,812

The voluntary income totals as at 31 March 2014 have been reclassified in order to be consistent with the 2015 disclosure, with no change to the overall total.

#### 3. Resources expended

	Grants Restricted £'000	Grants Unrestrict- ed £'000	Direct costs £'000	Support costs £'000	Total 2015 £'000	Total 2014 £'000
Cost of generating funds						
Fundraising	-	-	2,475	1,487	3,962	3,293
Trading and Merchandising	-	439	84	-	523	318
Charitable activities						
Research	512	2,592	938	239	4,281	4,118
Clinical care	-	-	421	193	614	726
Information, advice & support	17	127	1,546	890	2,580	1,609
Governance	-	-	5	67	72	59
	529	3,158	5,469	2,876	12,032	10,123

#### Analysis of allocated Support Costs

	Manage- ment £'000	Finance £'000	IT Support £'000	HR & OD £'000	HQ & Facilities £'000	Total 2015 £'000	Total 2014 £'000
Fundraising	148	262	586	199	292	1,487	749
Research	24	42	94	32	47	239	122
Clinical care	19	34	76	26	38	193	213
Information, advice & support	89	157	350	119	175	890	682
Governance	31	26	-	4	6	67	47
Total costs	311	521	1,106	380	558	2,876	1,813

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

## Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 3. Resources expended (continued)

#### **Analysis of Governance Costs**

	2015 £'000	2014 £'000
External audit fee	18	18
Auditors - tax advice	9	12
Trustees' travel expenses	2	3
Managing strategy & compliance	43	26
Total Governance costs	72	59

#### 3b. Grants

Grants were awarded during the year as follows:

	2015 £'000	2014 £'000
Grants to institutions	3,103	3,501
Grants to individuals	583	456
	3,686	3,957

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.

	2015 £'000	2014 £'000
Balance at start of year	5,020	2,740
Adjustment to opening balance	(27)	-
Awarded in the year	3,686	3,957
Paid in year	(1,516)	(1,677)
Balance at end of year	7,163	5,020
Falling due within one year (note 9)	3,833	3,243
Falling due after more than one year (note 9)	3,330	1,777

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

	2015 £'000
Royal Brompton Hospital	825
University of Bristol	751
University of Dundee	250
University of Cambridge	220
Imperial College London	211
University of Oxford	198
Centre for Genomic & Experimental Medicine	166
Manchester University	100
Northern General Hospital	90
University Hospital South Manchester	75
Verona Pharma Plc	65
Alder Hey Hospital	50
University of Cork	46
Edinburgh University	34
ECFS - European Cystic Fibrosis Society	16
Queens University Belfast	2
Ulster University	2
University College London	2
	3,103

#### Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 4. Staff costs

Staff costs comprise the following:

	2015 £'000	2014 £'000
Salaries	3,097	2,759
Temporary Staff	668	126
Social security costs	332	295
Other pension costs	150	73
	4,247	3,253

Analysis of average salaried staff numbers by category:

	2015 No.	2014 No.
Fundraising	40	44
Research	6	4
Clinical care	5	6
Information, advice & support	24	14
Management	3	2
Finance	2	5
IT support	4	2
HR & OD	4	3
Facilities	1	2

Average number of employees during the year	89	82
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The number of employees whose pay exceeded £60,000 in the year was:

	2015 No.	2014 No.
£60,001 - £70,000	2	1
£80,001 - £90,000	1	2
£90,001 - £100,000	1	1

Pension contributions to defined contribution pension schemes for these employees totalled

£24,004 (2014 - £5,250).

No remuneration was paid to the trustees. Expenses of £1,918 (2014 - £705) were settled on 3 (2014-2) trustees.

Included within the staff costs above, redundancy payments totalling £90,000 were paid to 15 staff members in the year. The Trust has restructured a number of teams over the last 18 months 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.

After the balance sheet date, the Trust undertook a relocation process, thus giving rise to potential further redundancy costs for staff choosing not to relocate. As no final decision had been made, and these had not been announced at the balance sheet date, no provision has been made for these costs.

# > Notes to the Financial Statements (continued) For the year ended 31 March 2015

5a. Funds

5a. Funds	Balance					Balance
	31 March 2014 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	31 March 2015 £'000
Fixed Asset Reserve	832	-	-	-	(543)	289
Strategic Reserve	2,871	-	-	-	-	2,871
Total Designated Reserves	3,703	-	-	-	(543)	3,160
Operating Reserve	4,664	-	-	-	771	5,435
Retained Reserves	3,302	216	10,835	(10,976)	(195)	3,182
Total General Reserves	7,966	216	10,835	(10,976)	576	8,617
Total Unrestricted Reserves	11,669	216	10,835	(10,976)	33	11,777
Restricted Funds deficit:						
Gene Therapy Consortium	(244)	-	84	-	-	(160)
Other Restricted reserves						
Craig Legacy	25	-	-	-	-	25
E W Joseph fund	52	-	7	(21)	-	38
Fellowship Programme	-	-	75	(75)	-	-
Gene Therapy Research	193	-	328	(521)	-	-
'Mycobacterium abscessus' research	-	-	8	-	(8)	-
Genetics Repair and editing	-	-	20	(20)	-	_
Innovative approaches to CF therapy	-	-	2	-	(2)	-
Joseph Levy Memorial Fund	8	-	33	(41)	_	-
Leisure fund	31	-	-	(2)	-	29
Medical Research	-	-	8	(8)	_	-
Paediatrics	8	-	-	_	_	8
Peer Review	-	_	1	(1)	_	-
Sailing fund	27	-	-	_	_	27
Summer Student Research Placements	-	-	-	(8)	10	2
Support Services	-	-	1	(1)	-	_
Transformational Research	50	-	-	-	(50)	-
Transplant Research	-	-	100	(100)	_	-
Vertex Travel Grants	-	-	-	(11)	17	6
Genotyping - 600 Study	-	-	300	_	_	300
SmartCare CF	-	-	274	(238)	_	36
Young Entrepreneurs	-	-	10	(5)	_	5
Welfare Grants	-	_	3	(3)	_	-
CF Connect – Youth	-	-	3	_	_	3
CF Connect – Parents	-	-	18	-	-	18
Total Other Restricted Reserves	394	-	1,191	(1,055)	(33)	497
Endowment Funds:						
Ena Bennie Endowment	565	24	-	-	-	589
EW Joseph Endowment	191	11	-	-	-	202
Joseph Levy Endowment	293	9	-	-	-	302
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other Endowment funds	55	2	3	(1)	-	59
Total Endowment funds	1,124	46	3	(1)	-	1,172
Total funds	12,943	262	12,113	(12,032)		13,286
				. , ,		

#### Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 5a. Funds (Continued)

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 has been set aside for the specific purpose of funding investment in a significant modernisation programme over the next three years in support of the long-term strategy approved by trustees during the year.

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.

Gene Therapy consortium - A further £84k 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 £160k, underwritten by unrestricted reserves.

# The following restricted funds were set up in previous years and have carried forward balances at the start of the year:

- Craig Legacy funding restricted to cystic fibrosis related work at the Royal Brompton and Wythenshawe Hospitals
- EW Joseph Fund 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
- Gene Therapy Research funding research into gene therapies. The majority of expenditure in the year relates to a commitment of £109k in January 2015, followed by a further commitment of £250k a year for two years (funded by a mix of restricted and unrestricted funds) in March 2015 to support the ongoing work of the Gene Therapy Consortium.
- Joseph Levy Memorial Fund funding education about cystic fibrosis. See comments about the corresponding endowment fund below.
- Leisure Fund funding leisure activities for people with cystic fibrosis. See comments below.
- Paediatrics funding work in the paediatrics department at the Royal Brompton Hospital, including peer reviews
- Sailing Fund funding sailing related activities for people with cystic fibrosis. See comments below.
- Transformational research funding for research into transformational therapies related to cystic fibrosis

## In 2013/14, a review of restricted funds was completed. As a result:

- £27k of donations restricted to sailing activities can no longer be spent on the restricted purpose for which they were given due to crossinfection issues so permission will be sought during the year to release these restriction.
- £29k of donations restricted to leisure activities will be repurposed for funding holiday grants, as these are deemed to be in line with the terms of the original restriction

# The following new restricted funds were set up in the year:

- Fellowship programme- funding for the Trust's Clinical Fellowships Programme, funding fellowships with the aim of improving clinical care for people with cystic fibrosis
- "'Mycobacterium abscessus' research- funding work by Dr Andres Floto who is researching the mycobacterium 'Mycobacterium abscessus'
- Genetics Repair and editing- funding work by Dr Ludovic Vallier and Prof Andres Floto who are researching genetic repair and editing on W1282X and G542X mutations
- Innovative approaches to CF therapy- funding work by Michael Gray (INOVCF / Newcastle) who is researching innovative non-CFTR approaches to cystic fibrosis therapy
- Medical Research- funding non-specific medical research grants
- Peer Review- supporting the costs of running the clinical peer review programme
- Support Services- funding non-specific support service projects/services provided by the Trust to people with cystic fibrosis
- Transplant Research- funding non-specific research into cystic fibrosis associated transplants
- 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
- SmartCareCF- funding for the pilot project as part of the development of the Smartcare CF system
- Young Entrepreneurs- supporting people with CF between 18 and 32 to either set up their own business or develop an existing one with one-off grants
- Welfare Grants- funding for making welfare grants to people with cystic fibrosis (Emergency Grants and Health & Wellbeing Grants)
- CF Connect Youth funding for a project to provide peer support for teenagers with cystic fibrosis

#### Notes to the Financial Statements (continued)

For the year ended 31 March 2015

■ CF Connect – Parents- funding for a project to provide peer to peer telephone support service for parents of children newly diagnosed with cystic fibrosis.

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 and education and funds the Trust's welfare grants programme, with any unspent balance carried forward;
- The Joseph Levy Memorial Fund was established in 1999 following its merger with the Lawrence Levy Foundation. Income arising is restricted to funding education and funds the Trust's education grants during the year, with any unspent balance carried forward; and
- 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 reserves (as shown above) to reflect commitments made in the previous year that were funded from restricted reserves but which were incorrectly classified as being funded by unrestricted reserves.
- Transfers were made from the endowment funds into the corresponding restricted reserves (EW Joseph Fund, Joseph Levy Memorial Fund and Ena Bennie Memorial Fund). These relate to the net income arising from these endowment funds in the year.

## > Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 5b. Analysis of funds

	Unrestricted £'000	Endowment funds £'000	Gene Therapy Restricted £'000	Other Restricted £'000	Total 2015 £'000
Tangible fixed assets	289	=	-	-	289
Investments	4,264	1,172	-	27	5,463
Current assets	15,228	-	-	470	15,698
Internal Obligations	160	-	(160)	-	-
Current liabilities	(4,834)	-	-	-	(4,834)
Liabilities due in more than one year	(3,330)	-	-	_	(3,330)
	11,777	1,172	(160)	497	13,286

#### 6. Fixed Assets

Group and charity	Freehold property £'000	Furniture & fittings £'000	Computer equipment £'000	Cars £'000	Software £'000	Total £'000
Cost						
At 31 March 2014	948	176	897	29	95	2,145
Additions	-	-	92	-	151	243
Disposals	(948)	-	-	(29)	-	(977)
At 31 March 2015	-	176	989	-	246	1,411
Depreciation						
At 31 March 2014	280	176	788	24	44	1,312
Disposals	(297)	-	-	(24)	-	(321)
Charge for the year	17	-	78	-	36	131
At 31 March 2015	-	176	866	-	80	1,122
Net book value at 31 March 2015	-	-	123	-	166	289
Net book value at 31 March 2014	668	-	108	5	51	832

The Trust's freehold property at 11 Bromley Road was sold on 31 March 2015 and as such has been treated as a disposal in the year.

#### 7. Investments

Group and Charity	Total 2015 £'000	Total 2014 £'000
Market value as at 31 March 2014	5,086	4,749
Adjustment to brought forward balance	-	
Additions at cost	1,476	2,788
Disposals at opening book value	(1,477)	(2,922)
Net gains/(losses) on investments	263	365
	5,348	4,980
Change in cash	115	106
Market value as at 31 March 2015	5,463	5,086

## Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 7. Investments (Continued)

Represented by: Investments held in Unit Trusts	2015 £'000	2014 £'000
Equities	2,741	2,849
Fixed Interest	2,085	1,707
Cash	637	530
	5,463	5,086

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 2015. These make up more than 5% of total investments:

	Total 2015 £'000
The Equity Income Trust for Charities	1,189
Schroder charity equity fund	893
Trojan income fund	393
The income trust for charities	384
Henderson UK Property Unit Trust	275
Majedie UK Equity Fund	264

During the year, the Trustees decided to exclude tobacco related stocks from investments.

The investment manager is in the process of implementing this decision

#### 8. Debtors

	Group 2015 £'000	Group 2014 £'000	Charity 2015 £'000	Charity 2014 £'000
Trade debtors	95	153	-	-
Amount due from subsidiary undertaking	-	-	1,614	1,139
Prepayments and accrued income	458	940	458	939
	553	1,093	2,072	2,078

#### 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 investment are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.

## > Notes to the Financial Statements (continued)

For the year ended 31 March 2015

## 10. Grants Payable

	2015 £'000	2014 £'000
Grant creditor at 1 April	5,020	2,740
Prior year adjustment	(27)	-
Grants paid during the year	(1,516)	(1,677)
Grants approved before 31 March 2015 and payable within one year	2,097	2,180
Grants approved before 31 March 2015 and payable after one year	1,589	1,777
Grant creditor at 31 March	7,163	5,020
Represented by		
Grants committed and awaiting claim at 31 March	966	1,263
Grants due within one year at 31 March	2,867	1,980
Grants due > 12 months	3,330	1,777
	7,163	5,020

In May 2015 the Trustees agreed to release £432,000 previously committed to Kings College Hospital, due to lack of progress in getting the commitment to a new adult facility delivered by hospital management.

#### 11. Creditors

	Group 2015 £'000	Group 2014 £'000	Charity 2015 £'000	Charity 2014 £'000
Trade creditors	55	219	55	217
Other creditors	167	97	167	97
Accruals and deferred income	779	465	778	243
	1,001	781	1,000	557

## Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 12. Interest in subsidary

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 2015 £'000	Total 2014 £'000
Sales and sundry income	1,376	797
Cost of sales and administration	(523)	(318)
Intercompany recharges	(60)	(7)
Net contribution to parent charity	793	472

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

	Total 2015 £	Total 2014 £
Current Assets		
Debtors	92,085	153,707
Cash at bank	1,520,332	1,208,690
	1,612,417	1,362,397
Creditors: amounts falling due within one year	(1,612,415)	(1,362,395)
Net Current Assets	2	2
Net Assets	2	2
Capital and Reserves		
Called up share capital	2	2
Profit and loss account	0	0
Shareholder's funds	2	2

The charity owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd, which comprises 100 ordinary shares of £1 each. 2 shares have been allotted, which are called up and fully paid.

#### Notes to the Financial Statements (continued)

For the year ended 31 March 2015

#### 13. Operating leases

At 31 March 2015, annual commitments under non-cancellable operating leases relating to equipment which will expire within the following periods were:

	2015	2014
	£'000	£'000
Within 1 year	-	23
Within 2-5 years	-	23

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

#### 14. Related party transactions

The group has taken advantage of the exception which is conferred by Financial Reporting Standard No. 8 'Related Party Disclosures' that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

The Trust paid £3,000 to the Citizens Advice Bureau in the year, as a contribution torwards 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.

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 had entered into capital commitments relating to the fitting out of the new office space. The total value of these commitments was £336,000.



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