

**Company Registration No. 3880213**  
**Charity No. 1079049**  
**OSCR No. SC040196**

**CYSTIC FIBROSIS TRUST**  
**ANNUAL REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2013**

**CYSTIC FIBROSIS TRUST**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2013**

**Patron**

HRH Princess Alexandra KG GCVO

**Honorary President**

Dr James Littlewood OBE MD FRCP FRCPE  
DCH

**TRUSTEES**

**Chairman**

George Jenkins OBE #  
(Appointed July 2012)

**Vice Chairman**

Allan Gormly CMG CBE #

**Honorary Treasurer**

Rupert Pearce Gould FCA

Jenny Agutter #

Georgia Arnold #  
(until March 2013)

Sir Peter Cresswell #  
(retired July 2013)

Katrina Dujardin #

Professor Stuart Elborn CBE MD FRCP

Brian Henderson #

Archie Norman  
(until January 2013)

Professor John Price MD FRCP FRCPCH

Martyn Rose #

Peter Sharp #

*# indicates either CF patient, carrier or close relative of a carrier of the defective gene*

**Finance and Audit Committee**

Rupert Pearce Gould (*Chair*)

Allan Gormly

Guy Harington

Peter Norris

Alistair Peel

Peter Sharp

**Nomination & Development Committee**

Allan Gormly (*Chair*)

Katrina Dujardin

Brian Henderson

George Jenkins OBE

Professor John Price MD FRCP FRCPCH

**Charity Management** Ed Owen - Chief

Executive # (*from May 2012*)

Phil Smith - Director of Finance &

Business Services

(*until Feb 2013*)

Stephen Williams - Director of Finance &

Business Services

(*from Feb 2013*)

Jo Osmond – Director of Clinical Care and  
Commissioning

(*until Oct 2013*)

Tamsyn Clark – Director of Marketing  
(*maternity leave from May 2013*)

Iain McAndrew – Interim Director of  
Marketing

(*from May 2013*)

Dr Janet Allen MD FRSE - Director of  
Research

(*from September 2012*)

Dr Matthew Sowemimo – Director of Policy &  
Communications

(*from April 2013*)

**Principal and Registered Office**

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Company Limited by Guarantee

Company registration number: 3880213

Charity registration number:

England & Wales – 1079049

Scotland – SC040196

**Auditors**

Crowe Clark Whitehill LLP

St Bride's House

10 Salisbury Square

London EC4Y 8EH

**Bankers**

The Royal Bank of Scotland plc

15 Bishopsgate

London EC2N 3NW

**Investment Managers**

Schroder & Co. Ltd

100 Wood Street

London EC2V 7ER

**CYSTIC FIBROSIS TRUST**  
**TRUSTEES' REPORT (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2013**

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The trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2013. 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.

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.

#### **About cystic fibrosis**

Cystic fibrosis is a life-shortening genetic condition that slowly destroys the lungs and digestive system that affects almost 10,000 people in the UK. When the Cystic Fibrosis Trust began its work almost 50 years ago, a child born with the condition was unlikely to live beyond the age of 10. Today average life expectancy is more than 40 years old. Yet only half of those with the condition live to celebrate their 40<sup>th</sup> birthday. So, while there has been significant progress over recent decades, there is still a huge amount to be done.

#### **About us**

Founded in 1964, the Cystic Fibrosis Trust is the only UK-wide charity making a daily difference to the lives of people with cystic fibrosis, and those who care for them. Fighting it is a battle we must win. That's why we must keep working for and fundraising for change; why we must develop better treatments and, ultimately, a cure. Because cystic fibrosis *is* beatable.

#### **What we do:**

- **Investing in cutting-edge research**
- **Driving up standards of clinical care**
- **Providing support for all**
- **Campaigning hard**
- **Being heard**

In January 2012, we published a four-year strategy – “Living Longer, Living Better”. This sets at its heart the needs of the cystic fibrosis community, and how research, care, support and communications can be better developed and linked to deliver real benefits to those with cystic fibrosis.

To strengthen our ability to deliver this strategy, a number of important appointments were made in 2012/13, including George Jenkins OBE as Chairman, Ed Owen as Chief Executive and Dr Janet Allen as Director of Research.

#### **Delivering the future**

**During 2012/13 the Trust continued its strategy of building a financially stable organisation. This strategy focuses on building sufficient reserves and cash balances to provide substantial investment opportunities in the research and clinical care programmes over coming years and this is reflected in the current year's performance.**

The 2013/14 financial year sees the introduction of a series of initiatives that are crucial to the future growth and success of the Cystic Fibrosis Trust. This includes an ambitious new research strategy, the continued roll-out of our inspirational new brand and website, and the implementation of a more streamlined peer review process of clinical care centres. The last quarter will see the beginning of the Trust's 50<sup>th</sup> anniversary year, which will provide further opportunities to motivate our supporters, increase awareness about cystic fibrosis, and raise new funds to support our work.

The Trust has drawn up an operational plan for 2013/14 that links the strategic plan to the programmes of work for the year ahead. The OP translates the strategic plan and overall vision into actual steps, complete with mechanisms for measuring and reporting progress.

**CYSTIC FIBROSIS TRUST**  
**TRUSTEES' REPORT (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2013**

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This will help the Trust in its commitment towards becoming a more professional, impact-driven organisation.

**Investing in cutting-edge research**

Since the Trust was founded, we have been a major funder of research into the causes and treatment of cystic fibrosis.

**How our research grant programmes deliver public benefit**

Funds spent on research can lead to the development of new therapies, and a greater understanding of the mechanisms of disease and the basic CF defect. We also contribute to improving the length and quality of life for people with cystic fibrosis through the dissemination of research findings nurturing new CF scientists.

Research currently funded by the Cystic Fibrosis Trust includes:

- **Gene therapy**

The Trust established the UK CF Gene Therapy Consortium (GTC) (University of Edinburgh, Oxford University and Imperial College), in 2001 aims to deliver the normal CFTR gene to the airways by nebulising the gene either in liposomes (Wave 1) or in a viral vector (Wave 2).

This pioneering work has advanced to the stage where the Wave 1 product is currently in a Phase 2b clinical trial. This is the largest gene therapy trial worldwide. The GTC was successful in securing additional funds from the government-funded Efficacy and Mechanism Evaluation to complement funding provided by the Trust. The results of this trial are expected in 2014.

In February 2013 the Trust awarded a grant of £308,000 to the GTC for its work to develop a viral vector as a delivery mechanism for gene therapy (Wave 2). This 14-month grant complements funding for Wave 2 work announced in 2012 from the MRC through its Developmental Pathway Funding Scheme.

- **Lung-reconditioning research**

We also funded a project at Newcastle University aimed at transforming currently unusable donated lungs into viable lungs for transplantation, and supported the roll-out of the study to all five UK transplant centres.

- **Lung-function testing and early detection of lung damage**

We are continuing the unique and successful London CF Collaborative study (LCFC) of clinical status, lung function and structure in children, which we have funded since 1999.

We are also funding research into two cutting-edge technologies developed to measure changes in gas distribution in the airways, one of the earliest consequences of CF lung disease.

- **Immunology**

The Trust has funded a study at the University of Liverpool looking at the ways in which drugs inadvertently activate the patient's immune system.

- **Microbiology**

We are funding a study running until the end of July 2013 that will reveal the direct impact that diabetes has on *Burkholderia* infections of the CF lung, and help guide the most effective management of CF-related diabetes.

- **Basic science**

We are funding a study to help understand the structure of the CFTR protein and the effect of mutations on CFTR structure. We are also supporting research that aims to promote the development of new drugs to treat defects at the root of cystic fibrosis.

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**TRUSTEES' REPORT (CONTINUED)**  
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**Research strategy 2013/14**

The Trust's new five-year research strategy was published in April 2013 at an international scientific conference organised jointly by the Trust and the Wellcome Trust. The focus of the new strategy is to increase impact, leverage greater resources into cystic fibrosis research and to enhance the role of patients in shaping and developing future priorities.

This new strategy ([cysticfibrosis.org.uk/researchstrategy](http://cysticfibrosis.org.uk/researchstrategy)) aims to build on past achievements and positions the Trust to play a leading role in supporting research to benefit people with cystic fibrosis. This five-year strategy refines the way the Trust manages its research portfolio by becoming more outward-looking and building vital partnerships with government agencies such as NIHR, funding councils, industry and other bodies, including overseas CF organisations. This will maximise investment in work that has a real potential impact on the lives of people with cystic fibrosis.

The strategy establishes four funding streams for research:

- Strategic research centres
- Venture and innovation awards
- Research sandpits
- Research coordinators

In contrast to previous years, bespoke calls for applications will be published. The first of these, calling for applications to form up to two strategic research centres, was announced in May 2013.

As part of the new strategy, the governance of research will be restructured to include a Research Strategy Advisory Board and Research Strategy Implementation Board.

**Driving up standards of clinical care**

All people with cystic fibrosis should receive the best possible care wherever they live, and multi-disciplinary teams in more than 50 specialist cystic fibrosis centres provide expert care within the NHS.

Newborn screening throughout the UK is ensuring early diagnosis, improving the quality and length of life for people with cystic fibrosis.

**Implementation of a national tariff for cystic fibrosis – Payment by Results (PbR)**

Following a four-year project, funded and facilitated by the Trust, to develop an annual banded national tariff for cystic fibrosis care in England, the Department of Health (DoH) agreed the phased implementation of a mandatory tariff for cystic fibrosis in England from 1 April 2013. We also continue to work closely with the NHS in Scotland, Wales and Northern Ireland.

**Quality Improvement Programme (QIP) and peer review**

The Quality Improvement Programme (QIP) includes a new, improved, evidence-based peer review process to ensure we drive up standards across all cystic fibrosis centres in the UK. Peer reviews help identify and communicate best practice, improving standards across the NHS.

During 2011/12 a full review of the peer review process was undertaken with a revised procedure developed to make best use of resources and be less burdensome for centres being reviewed. The new process was launched in January 2013.

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**TRUSTEES' REPORT (CONTINUED)**  
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A programme of 10 reviews is taking place in 2013 and 13 more are scheduled for 2014. A full annual report will be provided in January 2014 with individual peer review reports being published on our website.

**UK CF Registry**

The Trust hosts a high-quality patient registry/database containing information about the location and health outcomes of people with cystic fibrosis. The Registry helps us monitor patient care and treatment and is an important tool in helping to raise the standard of care.

The CF Registry is becoming increasingly valuable as a research tool, with 99% coverage of the UK CF population and over 89% complete data for all patients. It is now possible to compare data with that collected by CF registries in the US and Europe.

During 2012/13 the CF Trust initiated a model of analysing the data for Phase IV pharmacovigilance studies for patient safety of newly licenced therapies. The European Medicine Agency has noted how important registry data is and has insisted these studies are done via Registry data.

In January 2013 we published the UK CF Registry Annual Data Report 2011 - the fifth from the Port CF database.

To build on the Registry's success we have established an external and independent review, to be undertaken in 2013, to consider the direction of the Registry over the next three to five years.

**Clinical conferences**

In May 2012 we hosted our annual meeting for the directors of the specialist CF centres in the UK in Birmingham. The meeting aimed to have an effective dialogue with clinicians who are responsible for the delivery of care to people with cystic fibrosis, to update them and get feedback on the charity's activities, and to inform our plans and activities by understanding their concerns.

**Innovation in 2013**

In September 2013 we launched a flagship two-day event, combining a medical conference with the meeting for centre directors. The new event will cater for everyone involved in the provision of clinical care at specialist CF centres and clinics in the UK.

**Providing support for all**

It is our job to provide high-quality, trusted information and advice, ensuring we assist those who need us the most.

Cystic fibrosis is a complex multi-system condition that is progressive and requires lifelong care that increases with age. Much of the daily burden of care is delivered by the parents or carers of a child with cystic fibrosis and later by the patient. We aim to ensure that patients, parents and carers have access to the information they need to understand the condition and its complications, as well as the level of care they should expect to receive.

**Publications, factsheets and consensus documents**

We provide information, advice and support through an extensive range of publications, which are produced with the assistance of experts in the relevant area.

**CYSTIC FIBROSIS TRUST**  
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We are committed to improving the quality of all the information we disseminate to ensure it covers all areas of concern and is delivered in as user-friendly a way as possible. This includes the ongoing review of all Trust publications.

CF Today, our flagship magazine, was produced three times a year containing articles on research, care, social issues and news, with a circulation of around 18,000. In 2013 the magazine is being replaced with a brand new publication, 'is'. The first issue was published for CF Week at the end of June 2013.

#### **Helpline**

The Trust continues to provide a national telephone helpline, a vital part of our commitment to providing support for everyone affected by cystic fibrosis. The helpline receives over 3,000 calls a year, and provides a confidential service that enables anyone to obtain advice, support and information on any aspect of cystic fibrosis, including help with financial support.

#### **Welfare grants**

We provide financial assistance for specific purposes to those experiencing particular difficulty at a time of stress or crisis relating to cystic fibrosis, including help with funeral costs, home start-up grants and help covering the cost of travel to transplant assessments. During the year we made 281 welfare grants at a total value of £166,911 (2011/12: 266 grants totalling £184,521).

#### **Our website**

The first phase of the new web project was completed in spring 2013, with the launch of the website. The new-look website is more dynamic, and all the content was reviewed, updated or newly created prior to launch.

The website provides several very popular community forums aimed at groups such as adults or teenagers with cystic fibrosis, parents and carers, fundraisers and researchers. This is particularly important for people with cystic fibrosis, who are unable to meet each other face to face because of the increased risk of cross-infection. By posting messages users can talk to others in a similar situation and get advice and support from their peers, who have had similar experiences.

#### **2013/14: phase II begins**

In phase II of the website's development, we will be working with stakeholders and end users to find innovative ways of engaging audiences and providing accessible information and support. These developments will further position us as the trusted authority on cystic fibrosis issues, providing hope and support for people with cystic fibrosis, their families and carers.

We will also be recruiting a dedicated Social Media officer, to help make the most of the online opportunities available and engage the online community directly.

#### **Getting in shape for the future**

In 2013 we are launching a support service survey to establish what the current CF population's information and support needs are. This will help us develop our support service to make sure that we can fully meet the needs of people affected by cystic fibrosis.

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**TRUSTEES' REPORT (CONTINUED)**  
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**Campaigning hard**

We lobby decision makers hard in the interests of our community.

In 2012/13 we spearheaded a successful eight-month campaign to ensure that a new transformational drug, Kalydeco, was made accessible free to everyone in the UK who would benefit. Kalydeco is the first licensed drug that treats the fundamental defect in people with the G551D mutation of cystic fibrosis – about 4% of patients across the UK.

Trials are now underway for people with two copies of F508del, which represents about 50% of patients with cystic fibrosis in the UK. These trials combine the use of Kalydeco with other drugs.

Other campaigns included encouraging participation in the review of children's cardiac surgery at the Royal Brompton Hospital, which threatened cystic fibrosis services, and championing other treatments being evaluated by NICE.

**Moving forward**

We are undertaking preparatory work to recruit and deploy 10 supporters in each UK region as grassroots campaigners for cystic fibrosis. This programme will help ensure the voice of people with cystic fibrosis is heard with the health service and elsewhere.

In June 2013 we launched a consultation on improving the care for those with cystic fibrosis awaiting a lung transplant. The report was launched at a Parliamentary event in London during CF Week.

**Being heard**

The general public's awareness of cystic fibrosis is low, and we are determined to increase understanding, turn the volume up on the issues, and raise more funds for our work.

**Rebrand**

Throughout 2012 we worked on a project to rebrand the Trust, to help us re-evaluate what we stand for and how we talk about cystic fibrosis and our work. This project culminated in March 2013 with the official launch of the new brand, along with a new website, a new tone of voice and a clearly defined set of values and beliefs.

The new brand will help wider plans to raise more funds for research and clinical care, and help enhance our influence where it matters.

With our new website and brand we are able to communicate more directly with a wide range of audiences, helping them to find the information they need as efficiently as possible.

**How we funded our activities, and the funds that we raised**

**Income**

We are extremely grateful to our fundraisers and supporters across the UK without whom we would be unable to carry out our vital work.

Our income for the year was £9,726,000 a fall of 6.7% (2011/12: £10,429,000). Income from individuals, branches, groups and community showed the biggest decrease of £502,000, legacy income fell by £82,000 and individual donations fell by £320,000. The flagging of income reflects the uncertainty of the current economic climate. However, these decreases were in part mitigated by an increase in trading activities by £385,000. (See note 11 to the accounts).

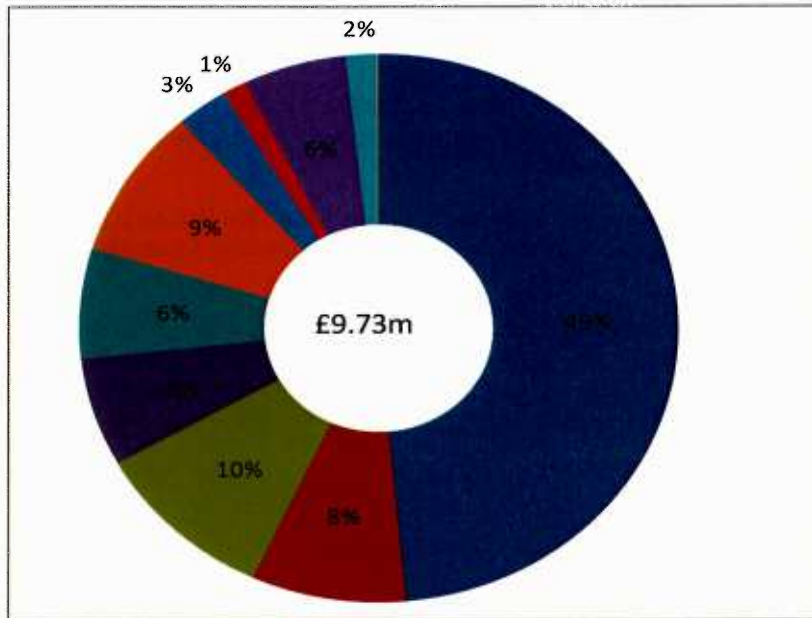
93% of our total incoming resources arises from voluntary income. Income from community fundraising and branches and groups represents about 50% of this, reflecting the commitment and enthusiasm shown by our volunteers and supporters and underlining the importance of the branch and regional fundraising network to the work of the Cystic Fibrosis Trust.



**CYSTIC FIBROSIS TRUST  
TRUSTEES' REPORT (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2013**

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**Income this year £9.73m (2011/12: £10.43m)**



**Income**

● Branches, Groups & Community	£4,723,564
● Legacies	£805,042
● Individual donations	£971,030
● Corporate	£623,931
● Gift Aid	£629,496
● Regular giving and appeals	£860,879
● Trusts	£275,285
● Department of Health	£126,110
● Trading and merchandising	£539,000
● Investment & interest income	£169,000
Other incoming resources: Fixed	£3,050

Total Voluntary income £9,726,387

Our annual CF Week is an opportunity for us to unite and focus the CF community in a week of fundraising and awareness. In 2012 over £270,000 was raised during CF Week (a 17% increase on 2011). This year's CF Week was held at the end of June 2013.

The Trust's 50<sup>th</sup> anniversary in 2014 will provide further opportunities to engage and enlarge our supporter base.

Companies are also vital to our work and our corporate team builds and nurtures relationships with businesses across the UK. We also receive funding from charitable trusts, major gifts from individual donors, and legacies, which enable us to better plan our work and fund world-leading research projects such as gene therapy and improving the availability of lungs for transplant.

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Fundraising for a genetic condition that affects a relatively small but growing number of people in the UK continues to be a challenge and requires a relatively large fundraising department. This is demonstrated by the range of sources of income (see note 2) and the large proportion of income that is generated by community fundraising and branches and groups. These fundraising areas require much organisation and nurturing.

**Future income**

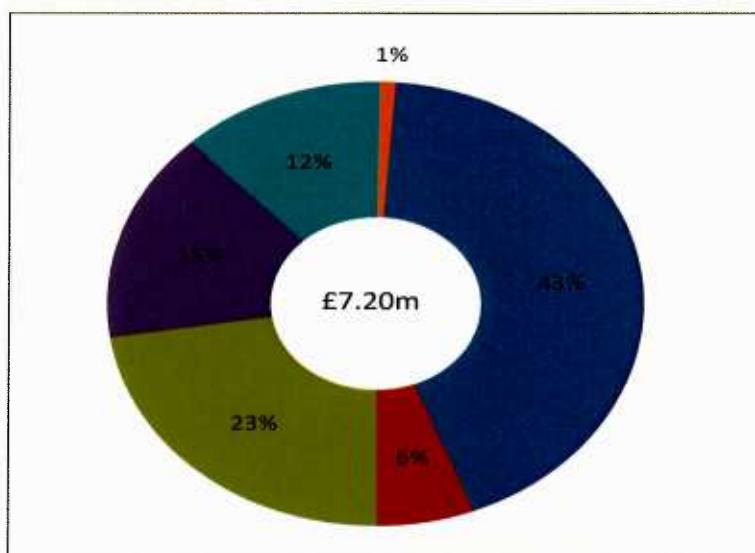
To achieve a more balanced income, we are developing plans to maximise our income from High Value Donors and corporate partners, with a particular focus on establishing partnerships with the pharmaceutical industry.

We are also launching a campaign to boost membership of the Sixty Five Roses Club, which is designed for private donors who give between £1,000 and £5,000 to the Trust each year.

**Expenditure**

The cost of generating the funds rose from £2.8m to £3.1m whereas overall expenditure in the year increased from £6m to £7.2m. The vast majority (£577,000) of this overall expenditure increase was made in charitable expenditure. These costs include the trading and merchandising operations. The core Governance costs for the year were £63,000 (£95,000 in 2011/12).

**Total spend this year was £7.2m (2011/12: £6m)**



**Expenditure**

● Fundraising	£3,094,906
● Trading-Merchandising	£421,000
● Research	£1,627,724
● Clinical care	£1,110,000
● Information, advice & support	£884,320
● Governance	£63,364
	<b>£7,201,314</b>