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

CYSTIC FIBROSIS TRUST

ANNUAL REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2012

CYSTIC FIBROSIS TRUST
TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2012

Royal Patron
HRH Princess Alexandra KG GCVO

Honorary President
Dr James Littlewood OBE MD FRCP FRCPE DCH
(from 14 November 2011)

TRUSTEES

Chair
George Jenkins OBE #
(Appointed 12 July 2012)
Dr James Littlewood OBE MD FRCP FRCPE DCH
(until 31 August 2011)

Vice Chair
Allan Gormly CMG CBE #
(Acting Chair from 1 September 2011 to 12 July 2012)

Honorary Treasurer
Rupert Pearce Gould FCA FCMA #

Jenny Agutter #
Giorgia Arnold #
Sir Peter Cresswell #
Katrina Dujardin #
Professor Stuart Elborn MD FRCP
Brian Henderson #
Archie Norman
Ed Owen # *(until 2 April 2012)*
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 Investment Committee
Rupert Pearce Gould *(Chair)*
George Jenkins OBE
Allan Gormly
Guy Harington
Dr James Littlewood *(until 31 August 2011)*
Peter Norris *(appointed 1 March 2011)*
Alistair Peel
Martyn Rose
Peter Sharp

Company Secretary
Phil Smith FCCA FMAAT

Nomination & Development Committee
Allan Gormly *(Chair)*
Giorgia Arnold
Brian Henderson
Dr Jim Littlewood *(until 31 August 2011)*
Martyn Rose

Charity Management
Ed Owen - Chief Executive #
(from 8 May 2012)
Matthew Reed - Chief Executive
(until 11 May 2012)
Phil Smith FCCA FMAAT - Director of Finance & Business Services
Malcolm Moore - Director of Operations
(until 29 February 2012)
Jo Osmond – Director of Clinical Care and Commissioning
Tamsyn Clark - Director of Marketing
(from 12 September 2011)
Dr Janet Allen MD FRSE - Director of Research *(from 3 September 2012)*

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

Principal Advisers

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

The trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2012. 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 4 of the Charities Act 2006 to have due regard to public benefit guidance published by the Charity Commission.

OUR MISSION STATEMENT

Founded in 1964, the Cystic Fibrosis Trust is the only UK registered charity solely concerned with the well-being of people with Cystic Fibrosis. It funds medical and scientific research aimed at understanding, treating and curing Cystic Fibrosis, campaigns for improved services and aims to ensure that people with Cystic Fibrosis receive the best possible care and support in all aspects of their lives.

About Cystic Fibrosis

Cystic Fibrosis is one of the UK's most common life-threatening inherited diseases with over 9000 people in the UK now affected by Cystic Fibrosis; a number that is increasing annually due to increasing life expectancy. It is caused by a single defective gene that is carried by 1 in 25 persons in the UK (over 2 million people) resulting with an average of five babies with Cystic Fibrosis born every week. As a result, the internal organs, especially the lungs and the digestive system, become clogged with thick sticky mucus resulting in difficulty in digesting food and chronic infections and inflammation in the lungs; resulting in considerably shortened life expectancy.

What we do:-

- We fund medical and scientific **research and development** to find effective treatments for Cystic Fibrosis and their translation into clinic;
- We ensure appropriate **clinical care** for those with Cystic Fibrosis and monitor standards and best practice; and
- We provide **information, advice and support** to anyone affected by Cystic Fibrosis.

The Cystic Fibrosis Trust achieves these objectives and public benefit through the activities described below, all of which are currently carried out in England, Scotland, Wales and Northern Ireland.

RESEARCH

Since it was founded, the Cystic Fibrosis Trust has been a major funder of research into the causes and treatment of Cystic Fibrosis. In 1964 life expectancy was only around five years. Median Survival for people living with CF today is 41.4 (*UKCF Registry report 2010*) but life expectancy of a baby born today is between 50 and 60 years (*Dodge et al.Eur Respir J 2007; 29: 522–526*). The goal is to improve the quality of life and further extend life expectancy.

Grant making policy

The charity invites applications for research grants annually from researchers through an announcement on the charity's website and by email promotion to all eligible institutions. Applicants are invited to submit their proposals in a specific format; all applications are reviewed by external referees before being reviewed internally by the Research Advisory Committee who put forward their final recommendations; a consensus arising from external and internal peer review, to the Trust Board for final approval.

Projects are usually funded for up to three years and are subject to an annual review. Research currently funded by the Cystic Fibrosis Trust falls into the following categories:

Training Fellowships

The Cystic Fibrosis Trust funds a joint Clinical Research Training Fellowship with the Medical Research Council. The purpose of this Fellowship is to provide up to three years' support for a clinically qualified professional to undertake specialised or further research training in the bio-medical sciences focusing on Cystic Fibrosis. Fellows are required to register for a research degree, normally a PhD, based on research undertaken during the fellowship especially into understanding and correcting the defect in the *cystic fibrosis transmembrane conductance regulator* (CFTR), the faulty protein.

Gene Therapy

At the start of the millennium the CF Trust brought together researchers in gene therapy from Imperial College London, Oxford University and Edinburgh University to form the UK CF Gene Therapy Consortium (GTC). The GTC has researched a programme to develop gene therapy as a means of alleviating the lung disease that is the cause of 90% of deaths from Cystic Fibrosis. In total, the Cystic Fibrosis Trust has granted over £30 million to the gene therapy research programme since 2001. This has been significantly more expensive than was first envisaged.

In 2010/11 the trustees realised that as income to the CF Trust had reduced over the last few years, they could not commit to being the sole funder of the programme at the required rate. Reductions have now been made in the level of commitment to the programme and a new grant was made to support the multi-dose phase 2b trial for the current potential therapy.

The programme has two phases, Wave 1 and Wave 2. The Wave 1 product is currently at a pre phase 2b stage and the Wave 2 product at an earlier stage of development. The Trust is committed to assisting the Gene Therapy Consortium to raise the funds required to facilitate a phase 2b clinical study starting in 2012. If this programme is successful and the therapy taken into the clinic, the prognosis for people with Cystic Fibrosis is likely to be significantly improved.

Lung Reconditioning Research

The Trust approved a new grant for a project at Newcastle University aimed at transforming currently unusable donated lungs into viable lungs for transplantation. Currently around 70% of donated lungs are not used and approximately 50% of people with CF die whilst waiting on the transplant list. To-date four sets of lungs have been treated using an ex-vivo perfusion technique and have been

successfully transplanted. New grants have been made to enable this programme to be rolled out to the other 5 transplant centres to make this more widely available and the Trust has received restricted funds to cover most of this. Transplants however do require that people are prepared to be organ donors and the Trust advocates that everyone eligible should register as donors.

Lung Function Testing and Early Detection of Lung Damage

A grant was made to fund a cross-London programme based at University College London to detect the earliest signs of lung damage in infants with Cystic Fibrosis. It is believed that lung function may be impaired even if there are no respiratory symptoms. This project will measure lung function of infants with CF diagnosed by the newborn screening programme at [three and/or 12 months] with follow up monitoring over a three year period.

Social Impact of CF

We funded the UK section of an international study based at the Leeds Teaching Hospital into the prevalence and impact of depression and anxiety in people with CF and their caregivers (TIDES study), which is thought may have an impact on adherence to treatment and longer term health outcomes.

Microbiology

Research funded by the Trust continued at Belfast City Hospital to assess the impact of bacterial infection in those with CF and how this affects exacerbations of chest infection by using samples from patients chronically infected with one of the most common and destructive organisms in CF: *Pseudomonas aeruginosa*.

Basic Science

An important area of research is the use of specific drugs or combinations of drugs to rescue the activity of CFTR – the protein that controls the movement of salts through the cell lining and which is faulty in people with Cystic Fibrosis – the basic defect. This class of drug is called a potentiator and we funded a project at the University of Bristol to use a novel analytical method of testing how different potentiators and new chemicals enhance the activity of CFTR.

Inflammation

A grant was continued at Queen's University Belfast for work into a receptor in the airways, which controls inflammation. This receptor is stronger and lasts longer in the CF lung, and the project will help scientists understand the process that regulates infection and inflammation with a view to developing new therapies to combat this cycle.

The joint Medical Research Council Clinical Fellowship project at Newcastle University continued to investigate a chemical produced by the body, which drives inflammation in the CF airway. This research also aims to further understanding of inflammation and the potential for new treatments to alleviate lung damage.

A project investigating the control of inflammation at the molecular level was continued at the University of Dundee to explore the group's findings in previous research. The team believe that inflammation may be controlled at the site of the CFTR, which is commonly absent in the most common CF gene mutation F508del.

A grant was made to Belfast City Hospital to investigate the inflammatory reaction of airway cells to the common presence of yeasts and fungi in the lungs of people with Cystic Fibrosis. It is hoped that the work may lead to drug treatments for these airway fungi.

How our research grant programmes delivered public benefit

Public benefit from funds spent on research is achieved through the expected development of new therapies, a greater understanding of the mechanisms of disease and the basic CF defect, which in turn can lead to new and improved ways of treating Cystic Fibrosis. As people with CF live longer and grow older there are new CF related complications and greater social impact on patients and carers. Clinical research helps inform and improve treatment and the clinical guidelines for CF care, and through the dissemination of research findings and the nurturing of new CF scientists, we contribute to improving the length and quality of life for people with Cystic Fibrosis and their carers.

Activities in Scotland

We provide support for those living with Cystic Fibrosis throughout the United Kingdom including Scotland. Grants *(details of which are shown in the notes to these financial statements)* have been provided to the following Scottish based research and educational institutions:

- University of Edinburgh *(part of the Gene Therapy Consortium)*

The Scottish Clinical Consultation Group, an advisory body, gives specific guidance to the Trust on matters relating to Scotland.

CLINICAL CARE

It is of vital importance that people with Cystic Fibrosis receive the best possible care from birth, which is now possible with the implementation of newborn screening throughout the UK. Appropriate monitoring and treatment from the date of diagnosis and throughout life by CF specialists and multidisciplinary teams of nursing and allied health professionals at a specialist CF Centre improves the quality and length of life for people with Cystic Fibrosis. Our work in this area continues to improve the provision of such care throughout the UK.

The charity's resources were directed in the following major areas:

Commissioning CF care

We continued to monitor the implementation of the recommendations from the Review of Commissioning Arrangements for Specialised Services. We work closely with the 10 regional Specialised Commissioning Groups across England and the specialist CF commissioners in each of the devolved nations, along with local healthcare commissioners and NHS Trust management teams that have responsibility for provision of CF care. We have made representation to political parties prior to the election to ensure that the specialised commissioning arrangements for Cystic Fibrosis continued to be on the healthcare agenda and would not be lost in a new parliament.

Implementation of a National Tariff for Cystic Fibrosis – Payment by Results (PbR)

Following a 4 year project, funded and facilitated by the CF Trust, to develop an annual banded national tariff for Cystic Fibrosis care, the Department of Health agreed the phased implementation of a mandatory tariff for CF from 1 April 2013. For the period 2012/13, CF services will be reimbursed for CF care provision according to the established banding framework, which is based on severity of disease and level of resource required to care for patients in a given year, and the amount of funding agreed during this period will be agreed locally, pending full implementation of a 'mandatory' tariff with nationally agreed prices from 1 April 2013.

Peer review of specialist CF Centres and Clinics

During 2011-12 a full review of the CF Trust's Peer Review process has been undertaken and a revised process developed which is designed to make best use of available resource and be less burdensome for centres being reviewed, in terms of documentation, preparation and time taken on the day of a Peer Review visit.

An Extranet facility has been designed in order to make the new process more efficient and electronically based. Documents and supporting evidence provided by the centres can now be uploaded onto the Extranet, along with validated patient clinical outcome data from the UK CF Registry.

The new process is due to be launched in September 2012, with a programme of 6 Peer Reviews taking place between September 2012 and March 2013. A full report will be provided in April 2013, with individual Peer Review reports on each service that has been reviewed being published on the CF Trust website; this being a major change from the previous process.

CF Registry

The Cystic Fibrosis Trust is unique among organisations representing specialised conditions in the UK in having developed a high quality patient registry/database containing information about the location and health outcomes of people with Cystic Fibrosis. In January 2012 we published the UK CF Registry Annual Data Report 2010 – the fourth from Port CF. Port CF has now been implemented in all specialist CF Centres and 120 network clinics throughout the UK.

The Registry is helping us to monitor patient care and treatment and is an important tool in helping to raise the standard of care by, a) providing annual reports of demographic and clinical outcome data, b) enabling services to compare clinical outcomes with one another and determine where their service stands against the national average and, c) consider possible factors involved in the different patient outcomes.

In the latest Annual Data Report (CF Registry Report 2010), the median predicted survival is 41.4 years. This figure represents an increase on the previous year which revealed a median predicted survival of 34.8 years, but it must be borne in mind when studying survival on a year to year basis thre may be random fluctuations due to a number of factors, which might include periods where there were a higher number of deaths, such as in 2009 (140 in 2009 versus 100 in 2008). It is therefore more useful to assess clinical outcomes over a longer period of time.

The CF Registry is becoming increasingly valuable as a research tool, particularly since it one of the most comprehensive data sets on CF in the world, with 99% coverage of the UK CF population and over 85% complete data for all patients. It has now become possible to compare data with that collected by CF Registries in the US and Europe. It also provides information to commissioners for the planning of future services, which will include capacity planning due to a year on year growth in the number of adult patients, potentially requiring an extension of the number of adult specialist CF Centres over time, as people with CF continue to live longer.

Clinical Care Patient Advisers

The Cystic Fibrosis Trust employs seven adults with Cystic Fibrosis as clinical care patient advisers. Their role has been one of advocacy, using their knowledge of CF and experience to influence anyone who is involved with the commissioning or provision of care and services for people with Cystic Fibrosis. They also represent the Cystic Fibrosis Trust at various local, regional and national meetings and conferences. Throughout 2011-12 several of the team have participated in Advisory Board meetings regarding the development of new treatments and devices.

INFORMATION, ADVICE AND SUPPORT

Information, advice and support are provided by an extensive range of publications, factsheets and consensus documents, which are produced with the assistance of experts in the relevant area. Most of these, and much further information, are available from our website. We run annual medical meetings and conferences for those involved in the delivery of CF care and for those affected by Cystic Fibrosis.

How our information, advice and support delivered public benefit

Cystic Fibrosis is a complex multi-system condition that is progressive and requires life-long 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. In this way all those affected by CF are empowered to make fully informed decisions about their lives and their care.

Publications and factsheets

Our factsheets and publications are very widely used across the CF community. They cover many medical issues such as genetics, CF-related diabetes and infections, along with social issues such as benefits and housing, growing older with CF, new parent information etc. Most are available from the CF Trust website, which also contains further information.

CF Today, the flagship magazine, is produced three times a year containing articles on research, care, social issues and news. It has a circulation of around 18,000.

Consensus documents

The Cystic Fibrosis Trust produces and regularly updates a number of documents in association with its specialist expert medical advisers. These cover a range of topics and are aimed at ensuring that people with Cystic Fibrosis receive an appropriate and consistent level of clinical care throughout the UK. Consensus documents are available to both clinicians and people with CF and their families, as well as to the wider public, and can be downloaded from our website.

We have developed a Clinical Care Pathway for Cystic Fibrosis – a web based resource giving information of the care expected from pre-diagnosis through to end stage disease, palliative care and end of life care. This is a dynamic tool that will be edited to reflect any changes in clinical practice, new treatments etc.

Medical meetings

In May 2011 the Cystic Fibrosis Trust hosted its annual meeting for the Directors of the specialist CF Centres in the UK in Birmingham. The purpose of the meeting is to have an effective dialogue with the 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 plans and activities by understanding their concerns.

In September 2011 the Cystic Fibrosis Trust were due to host its annual Medical Conference but this was postponed to May 2012 due to clinician feedback that it would be difficult for individuals to be released from their clinical duties to attend, pending the NHS reforms and degree of uncertainty about what this would mean in terms of jobs.

Helplines

The Trust continued to provide national telephone helplines - an important contact point for those with concerns about Cystic Fibrosis. The helplines receive over 3,000 calls a year and make almost as

many, following up and dealing with the questions asked and returning messages left on the answer phones. The main helpline provides a confidential service that enables anyone to obtain advice, support and information on any aspect of Cystic Fibrosis. The Benefits Advice Line provides information and advice about which benefits people may be eligible to receive and how to apply for them.

Welfare Grants

The Trust continues to provide financial assistance for specific purposes to those experiencing particular difficulty at a time of stress or crisis relating to Cystic Fibrosis including funeral grants and home start-up grants. During the year the Trust made 266 welfare grants (2011: 284 grants).

Community forums

The website provides several very popular community forums. These include a forum for adults and one for teenagers with Cystic Fibrosis, as well as forums for parents and carers, partners of people with Cystic Fibrosis, fundraisers, and others. By posting messages in the appropriate forum, users can talk to others in a similar situation and get advice and support from their peers, who have had similar experiences.
This is particularly important for people with Cystic Fibrosis, who are unable to meet with each other face to face because of the increased risk of cross-infecting each other with harmful bacteria. The forum for adults with Cystic Fibrosis alone gets nearly 30,000 postings a year, with over 2,000 different conversation topics; this is from a population of around 4,000 mainly young adults with Cystic Fibrosis in the UK. The forums are moderated by a panel of volunteer adults with Cystic Fibrosis.

HOW WE FUNDED OUR ACTIVITIES AND THE FUNDS THAT WE RAISED

Income

In part due to the response to our Gene Therapy campaign, our income for the year increased by 18.9% to £10,426,000 (2011: £8,767,000). Income from individuals, branches, groups & community showed the biggest increases as individuals and community groups responded to the appeal. The corporate donations did fall as businesses have less to give in the current climate. (See note 2 to the accounts).

Well over 90% of the charity's total incoming resources continues to arise from voluntary income. Income from community fundraising and branches and groups also continues to represent over 50% of this, reflecting the commitment and enthusiasm shown by the charity's volunteers and supporters and underlining the importance of the branch and regional fundraising network to the work of the Cystic Fibrosis Trust.

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. The Trustees consider that although the cost of generating this income may appear high it is appropriate for the charity.

Expenditure

The cost of generating the funds rose marginally from £2.79m to £2.89m whereas overall expenditure in the year increased from £5.05m to £5.63m. The vast majority (£476,000) of this overall expenditure increase being made in charitable expenditure. These costs include the trading and merchandising operations. The core Governance costs for the year were £95,000 (£90,000 in 2011).

CORPORATE GOVERNANCE

The Board of Trustees is responsible for the overall governance, policy and strategic direction of the Cystic Fibrosis Trust. The members of the Board of Trustees have the legal responsibility for the operations of the Trust and the use of resources in accordance with the objects of the charity. The Trustees who have served during the year and since the year end are set out on page 1. The Trust is bound by its memorandum and articles which were last reviewed and amended in April 2012.

Since it was founded, the Cystic Fibrosis Trust has been governed mainly by individuals with close personal experience of or interest in Cystic Fibrosis.

Appointment of new Trustees, their induction and training

Following a review where Trustees consider the relevant skillset (e.g. legal, scientific, financial etc) required to enable effective oversight and proper governance of the organisation, new Trustees are appointed on the basis of recommendation or through advertising in the national press.

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 i.e. copies of board minutes, the most recent annual audited accounts along with finance committee reports, Trust objectives and strategic plan and a copy of charity commission's briefing document 'The Essential Trustee'. Opportunities are also provided for the new trustee to meet with the Chair and CEO as well as meeting staff relevant to their own area of specialism.

Trustees serve on the Board for a period of three years that is renewable.

The Board of Trustees meets quarterly to review progress and policies and is supported by a number of committees:

The **Finance and Investment Committee** meets quarterly and monitors, oversees and reviews progress and policies relating to cash flow, operational and investment matters. It reviews the audited financial statements of the charity and recommends them to the Board of Trustees. It also monitors the audit process and any management actions recommended by the auditors. The committee monitors the performance of the charity's investment portfolio and is responsible for the appointment of the Investment Manager.

The **Nomination and Development Committee** monitors the membership and succession of the Board of Trustees as well as its structure, size and composition. It also ensures plans are made for succession to the Officers of the board, the Chief Executive and other senior employees.

The **Research Advisory Committee** advises the Trustees on research matters. It is responsible for considering applications for research funding and recommending to the Trustees those applications that might be funded. It also reviews and assesses the research that has been funded. Its members include distinguished scientific and clinical researchers who are representative of the various areas of research relevant to Cystic Fibrosis. Its members also include an adult patient and a parent of a child with Cystic Fibrosis.

The **Medical Advisory Committee** advises the Trustees generally on medical matters and on the provision of appropriate care for people with Cystic Fibrosis. It is also responsible for producing the Cystic Fibrosis Trust's consensus guidelines and standards that help ensure that people with Cystic Fibrosis receive the best possible standard of care. Its members are distinguished clinicians and health professionals who are representative of the various disciplines relevant to Cystic Fibrosis. Its members include an adult patient and a parent of a child with Cystic Fibrosis.

The **CF Gene Therapy Scientific Advisory Committee** advises the Trustees on matters relating to the UK CF Gene Therapy Consortium. Its members include an international expert in the field of gene therapy research, specialist Cystic Fibrosis clinicians, an adult with Cystic Fibrosis and a parent of a Cystic Fibrosis patient.

The **Registry Committee** advises the Trustees on all matters relating to the UK CF Registry including the content of the annual Registry Report. The Committee membership includes the Caldicott Guardian and acts as the ethics committee for requests for data from the registry from third party researchers.

Executive Management

Responsibility for planning, co-ordination and the day-to-day management of staff and operations is delegated to an executive team of managers led by the Chief Executive. Formal reporting by the Chief Executive to the Trustees takes place regularly at meetings of the Board of Trustees and informally as appropriate throughout the year. The systems of internal control, which are designed to provide reasonable assurance against material misstatement or loss, include:

- A strategic plan;
- An annual budget approved by the Trustees;
- Regular consideration of financial results, variance from budgets and non-financial performance indicators;
- Delegation of authority and segregation of duties;
- Identification and management of risks.

Risk Management

The Trustees have overall responsibility for ensuring that the Cystic Fibrosis Trust is managing risk in a professional, responsible and constructive manner. This has involved identifying the types of risks the charity may face and assessing and balancing them in terms of potential impact and likelihood of occurrence. The Trustees seek to ensure that all internal controls, and in particular financial controls, comply in all respects with best practice and inter alia the guidelines issued by the Charity Commission.

The Trustees considered that the principal risk to the Trust were:

- The impact of the present economic climate on the Trust's ability to generate income streams to budgeted levels;
- Significant reliance on fundraising from branches and community groups which presently raised over 50% of voluntary income.

These risks were mitigated by:

- Regular review of cashflow forecasts and management accounts, ensuring that expenditure remained well within budgeted levels and achieving cost savings where appropriate;
- The new marketing strategy particularly with increased focus on building up revenue via direct marketing and utilising the website more effectively as a fundraising and information tool.

The Trustees will continue to assess risk in a constructive manner to safeguard the efficacy of the Cystic Fibrosis Trust.

Trading

The Trust had one wholly owned trading subsidiary at the year end: Cystic Fibrosis Services Limited (which changed its name from CF Merchandising Limited during the year), a company registered in England. The company carries out non-charitable trading activities for the charity. Results of the subsidiary are disclosed in note 11 of the consolidated financial statements and in the separate financial statements of CF Merchandising Limited.

Investment Policy

The Finance and Investment Committee sets the investment policy and sets objectives. These are reviewed on a quarterly basis and are compared with investment benchmarks for the sector.

Reserves

As explained above the charity carries out a diverse range of activities, some of which comprise short-term whilst others comprise longer-term projects requiring significant ongoing financial commitment and investment. Some of those can be funded internally whilst others require external funding.

The Trustees have examined the requirement for free reserves, i.e. those unrestricted funds not invested in tangible fixed assets, designated for specific purposes, or otherwise committed or required for development and strategic reserve purposes.

The level of reserves after allowing for designated and restricted reserves – the 'free reserves' – as at 31 March 2012 is £9,760,000 (2011: £6,996,000). However, these are being held against the deficit on the Gene Therapy restricted fund of £6,031,000 (2011: £7,144,000); thus there is a net surplus of freely available reserves as at 31 March 2012 of £3,729,000.

Having reviewed the expected cash flows over the next twelve months, the Trustees are satisfied that sufficient reserves will be available for the Trust to meet all its commitments as they fall due. The Trustees therefore consider that the level of reserves is in accordance with the charity's reserves policy.

Gene Therapy Restricted Fund

The Gene Therapy restricted fund shows a deficit of £ 6,031,000 at the end of the year compared to £7,144,000 at the end of the prior year. This deficit arises because grants committed at and prior to the year-end both paid and not yet paid have been charged to the statement of financial activities in accordance with the charity's normal accounting policy. The deficit will be met by income already pledged but not yet received; income that will be raised in subsequent years and transfers from free reserves.

CYSTIC FIBROSIS COMMUNITY AND SUPPORTERS

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

There are around 100 fundraising Branches, Groups and Committees in the UK which organise fundraising events for the CF Trust or take part in our own events. Alongside these, individual fundraisers often directly affected by CF also support our work, many by simply making donations.

We work hard to ensure our fundraisers receive support and encouragement in their fundraising endeavours. We employ 20 regional fundraising managers across the UK, and we also have a dedicated team managing, amongst others, our challenge events such as runs and swims which raised almost £2.3m last year.

Our annual CF Week is an opportunity for us to unite and focus the CF community in a week of fundraising and awareness. Last year over £270,000 was raised during CF Week (a 17% increase on 2011).

Companies are 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.

FUTURE PLANS

DELIVERING THE FUTURE

In January 2012, the Cystic Fibrosis Trust published a strategy – "Living Longer, Living Better" - setting out the overall direction for the organisation over the next four years. Its purpose is to ensure that the Trust is focused on achieving a positive impact on the lives of all people with cystic fibrosis.

Trust Leadership

To strengthen the Trusts ability to deliver the strategy, two important appointments have been made, that of Ed Owen as Chief Executive and George Jenkins OBE as Trust Chairman

Over 2012/13, the Trust is focused on improving its impact in its four key areas of activity:

i) Investing in cutting-edge research
"Living Longer, Living Better" identified the development of an ambitious research strategy as key part of the Trust's future plans and 2012/13 will see a number of steps taken to develop and deliver it.

In July 2012, the Trust appointed a new Director of Research charged with leading this work. It also announced plans to increase the capacity of the UK's specialist CF clinics to undertake clinical trials by part-funding a number of research co-ordinators to work within particular centres.

The new research strategy – to be published in the first part of 2013 - will be drawn up after consultation with clinicians and scientists, as well as with people with cystic fibrosis, their families and wider supporters. It will help shape the Trust's future research work and build vital partnerships with funding councils, industry and other organisations in order to maximise investment in work that has a real potential impact on the lives of people with cystic fibrosis.

ii) Driving up standards of care

The Trust is committed to ensure that everyone with cystic fibrosis has access to the best possible care in a specialist clinic. The development of the Quality Improvement Programme (QIP) to be rolled out in 2012/13 will play an important role in helping to achieve this.

The QIP includes a new and improved Peer Review process set to be launched in September 2012, and will measure and benchmark centre performance against agreed standards of care. The programme will help identify and communicate best practice to improve standards across the NHS.

The UK CF's Registry will be a vital tool of the QIP and continues to provide rich data to the Trust and the clinical community relating to clinical performance and trends. The Registry is also of great interest to third parties, including the Department of Health and the pharmaceutical industry. The Trust is planning to agree contractual arrangements with a number of pharmaceutical companies in 2012/13 who are seeking to use it as part of Phase IV industry studies. The DoH have already commissioned the CF Trust to provide NHS commissioners with patient banding information which is generated by the Registry. All patient data is anonymised and confidentiality of individual patient data will be maintained. These partnerships are an important means of helping the Cystic Fibrosis Trust and CF specialist centres achieve their main objective of driving up standards of care through an increasingly rich data patient registry. Income generated through these partnerships will also help cover the costs of maintaining and enhancing the registry.

iii) Providing high quality information, advice and support

The Trust provides a range of trusted materials providing advice and information to people with cystic fibrosis and their families – from diagnosis at birth to issues relating to transplantation. It also provides a telephone helpline as a means of providing further help where needed.

The Trust is seeking to improve the quality of all its information to ensure it covers all areas of concern and is delivered in as user-friendly way as possible. The Trust's investment during 2012/13 in web and digital platforms will be a major part of this. The Trust will also be reviewing the financial support it provides to people with cystic fibrosis and their families to ensure it is properly targeted where it is needed most.

iv) Raising awareness and influencing policy

During 2012/13, the Trust is developing and launching a new brand to help communicate what the Trust does and promote the interests of people with cystic fibrosis to wider audiences. In doing so, it should help wider plans to raise more funds for research and clinical care, and help enhance the Trust's influence where it matters.

The Trust is also seeking to improve the way it communicates with key groups including people with cystic fibrosis, their families, clinicians, researchers and other interested stakeholders.

Further plans

The Trust has embarked on a new direct marketing campaign as part of an effort to deliver challenging objectives of a net 5% increase in core voluntary income by March 2013. Plans are also being put in place to mark the Trust's 50th anniversary in 2014.

The Trust has embarked on a series of staff and organisational changes in 2012/13. It had undergone a pay audit to ensure fair and consistent salary arrangements across the organisation. A new performance management system is to be introduced and the recruitment of a new Manager of HR and Organisational Development is underway.

The Trust is planning a review of its governance arrangements to include the roles, responsibilities and membership of the board of trustees, as well as all committees.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The Trustees (who are also directors of 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 Accounting 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 view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable UK accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company 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 the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) and the provisions 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.

Auditors
Crowe Clark Whitehill LLP have expressed their willingness to continue as auditors for the next financial year.

Finally we would like to thank all patients, carers and supporters for their continuing support. And also the commitment and dedication of all staff that combine to enable the Cystic Fibrosis Trust to continue to improve the quality of life for those touched by CF.

This report was approved by the Trustees on 16 October 2012
and signed on their behalf by:

Mr George Jenkins
Chair

Independent Auditor's Report to the Members and Trustees of Cystic Fibrosis Trust

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2012 which comprise the Group Statement of Financial Activities, the Group and Company Balance Sheets, the Group Cash Flow Statement and the related notes numbered 1 to 14.

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 and to the charitable company's trustees, as a body, in accordance with section 44(1c) of the Charities and Trustee Investment (Scotland) Act 2005. 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 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 Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purpose 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 as auditor under section 44(1c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

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

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the directors; and the overall presentation of the financial statements.

In addition, we read all the financial and non-financial information in the Trustees' Annual Report to identify material inconsistencies with the audited financial statements. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

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 charitable company's affairs as at 31 March 2012 and of the group's incoming resources and application of resources, including its 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,the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Independent Auditor's Report to the Members and Trustees of Cystic Fibrosis Trust (Continued)

Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the Trustees Annual 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 or the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- the parent charitable company has not kept adequate accounting records; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Michael Hicks

Senior Statutory Auditor

For and on behalf of

Crowe Clark Whitehill LLP

Statutory Auditor

St Bride's House

10 Salisbury Square

London EC4Y 8EH

Date 3.12.12

Crowe Clark Whitehill LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

CYSTIC FIBROSIS TRUST
CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES
(Incorporating an Income and Expenditure Account)
FOR THE YEAR ENDED 31 MARCH 2012

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total 2012 £'000**	*Total 2011 £'000*
INCOMING RESOURCES						
Incoming resources from generated funds						
Voluntary income	2	7,879	2,241	-	**10,120**	*8,397*
Activities for generating funds						
Trading and merchandising	11	154	-	-	**154**	*221*
Investment & interest income		110	33	9	**152**	*149*
Total incoming resources		8,143	2,274	9	**10,426**	*8,767*
RESOURCES EXPENDED						
Cost of generating funds						
Costs of generating voluntary Income		2,180	619	-	**2,799**	*2,648*
Trading and merchandising	11	93	-	-	**93**	*140*
Costs of generating funds		2,273	619	-	**2,892**	*2,788*
Charitable activities						
Research		792	176	-	**968**	*263*
Clinical Care		1,012	-	-	**1,012**	*1,008*
Information, advice & support		587	79	-	**666**	*899*
Governance costs		95	-	-	**95**	*90*
Total resources expended	3	4,759	874	-	**5,633**	*5,048*
NET INCOMING RESOURCES		3,384	1,400	9	**4,793**	*3,719*
Gain on asset disposal		3	-	-	**3**	*3*
NET INCOME FOR THE YEAR		3,387	1,400	9	**4,796**	*3,722*
Unrealised investment (losses)/ gains		(3)	-	-	**(3)**	*(1)*
NET MOVEMENT IN FUNDS		3,384	1,400	9	**4,793**	*3,721*
Funds brought forward		9,980	(6,456)	976	**4,500**	*779*
FUNDS CARRIED FORWARD	5	13,364	(5,056)	985	**9,293**	*4,500*

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

CYSTIC FIBROSIS TRUST
BALANCE SHEETS
AS AT 31 MARCH 2012

	Notes	Consolidated Total 2012 £'000	Consolidated *Total 2011 £'000*	Charity Total 2012 £'000	Charity *Total 2011 £'000*
Fixed assets					
Tangible assets	6	**845**	*985*	**845**	*985*
Investments	7	**4,962**	*4,839*	**4,962**	*4,839*
		5,807	*5,824*	**5,807**	*5,824*
Current assets					
Debtors	8	**536**	*364*	**616**	*449*
Cash held as short term investment		**848**	*839*	**848**	*839*
Cash at bank & in hand		**4,676**	*3,428*	**4,531**	*3,229*
		6,060	*4,631*	**5,995**	*4,517*
Creditors: amounts due within one year					
Grants payable	9	**(1,047)**	*(2,402)*	**(1,047)**	*(2,402)*
Creditors and accrued charges	10	**(1,527)**	*(3,553)*	**(1,462)**	*(3,439)*
		(2,574)	*(5,955)*	**(2,509)**	*(5,841)*
Net current asset / (liabilities)		**3,486**	*(1,324)*	**3,486**	*(1,324)*
Net assets		**9,293**	*4,500*	**9,293**	*4,500*
Represented by:					
Designated funds	5	**3,604**	*2,984*	**3,604**	*2,984*
General Reserves					
Unrestricted general funds		**9,760**	*6,996*	**9,760**	*6,996*
Restricted Reserves	5				
Deficit on restricted funds - GTC		**(6,031)**	*(7,144)*	**(6,031)**	*(7,144)*
Surplus on restricted funds - other		**975**	*688*	**975**	*688*
Endowment funds	5	**985**	*976*	**985**	*976*
		9,293	*4,500*	**9,293**	*4,500*

Approved and authorised for issue by the Trustees on 16 October 2012 and signed on their behalf by:

Trustees — Mr George Jenkins, Chair; Mr Rupert Pearce Gould, Treasurer

CYSTIC FIBROSIS TRUST
CONSOLIDATED CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2012

		2012 £'000	*2011 £'000*
Net cash Inflow from operating activities	**(Note A)**	**1,268**	*1,100*
Returns on investments and servicing of finance			
Investment income		**152**	*149*
Capital expenditure and financial investment			
Purchase of fixed assets		**(40)**	*(109)*
Purchase of investments		**(126)**	*(93)*
Proceeds of sales of fixed assets		**3**	*11*
		(163)	*(191)*
Management of liquid resources			
(Increase)/decrease in cash held as short term investments		**(9)**	*239*
Increase in cash	**(Note B)**	**1,248**	*1,297*

NOTES TO CASHFLOW STATEMENT

A. RECONCILIATION OF NET INCOMING RESOURCES TO NET CASH INFLOW FROM OPERATING ACTIVITIES

	2012 £'000	*2011 £'000*
Net incoming resources	**4,793**	*3,719*
Depreciation	**180**	*248*
Investment income	**(152)**	*(149)*
(Increase) in debtors	**(172)**	*(92)*
(Decrease) in creditors	**(3,381)**	*(2,626)*
	1,268	*1,100*

B. ANALYSIS OF CHANGES IN NET CASH RESOURCES DURING THE YEAR

	2012 £'000	*2011 £'000*
Net cash resources at 1 April 2011	**4,267**	*3,211*
Net increase in cash at bank & in hand	**1,248**	*1,297*
(Decrease) from revaluation of foreign currency account	**(0)**	*(2)*
Increase/(Decrease) in short term investments	**9**	*(239)*
Net cash resources at 31 March 2012 (being cash at bank & in hand and cash held as short term investments)	**5,524**	*4,267*

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.

At 31st March the charity had a surplus on funds of £9,293,000. Nevertheless a substantial part of the grants committed and due within the next twelve months will need to be met, as in previous years, out of funds generated in the future. 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 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.

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	33⅓%
Furniture and fittings	25%
Cars	20%
Freehold buildings	2%

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 and the bank balances at the year end are incorporated in these financial statements. 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. All income arises from continuing activities.

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.

1. ACCOUNTING POLICIES (CONTINUED)

- 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

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 payable within one year are included in the statement of financial activities when approved and when all conditions relating to the grant have been fulfilled. Grants payable after one year, which are approved, but where certain conditions relating to the grant have yet to be met, are not accrued for, but are noted as financial commitments in the notes to the financial statements.

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. Payments are charged to the Statement of Financial Activities in the period to which they relate.

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 funds are those which the Trustees are free to use for any purpose in furtherance of the charitable objects. Designated funds are set aside out of unrestricted funds by the Trustees, for particular purposes.
Restricted Funds 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.

2. VOLUNTARY INCOME

	Unrestricted Funds £'000	Restricted Funds Gene Therapy Research £'000	Restricted Funds Other Restricted Funds £'000	**Total 2012 £'000**	*Total 2011 £'000*
Branches, Groups & Community	4,536	603	87	**5,226**	*4,499*
Legacies	857	5	25	**887**	*895*
Individual donations	478	726	87	**1,291**	*712*
Corporate	414	72	18	**504**	*576*
Gift Aid	651	-	-	**651**	*555*
Regular giving	600	-	-	**600**	*553*
Trusts	128	147	233	**508**	*463*
Appeals	40	237	1	**278**	*144*
NHS National Services Scotland	51	-	-	**51**	-
Department of Health	124	-	-	**124**	-
Total Voluntary income	7,879	1,790	451	**10,120**	*8,397*

3. RESOURCES EXPENDED

	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs allocated £'000	**Total 2012 £'000**	*Total 2011 £'000*
Cost of generating funds						
Fundraising	619	-	1,474	706	**2,799**	*2,648*
Trading-Merchandising	-	-	93	-	**93**	*140*
Charitable activities						
Research	176	399	24	369	**968**	*263*
Clinical care	-	-	765	247	**1,012**	*1,008*
Information, advice & support	79	105	309	173	**666**	*899*
Governance	-	-	47	48	**95**	*90*
	874	504	2,712	1,543	**5,633**	*5,048*

Analysis of allocated Support Costs	Management £'000	Finance £'000	IT Support £'000	Admin & Facilities £'000	**Total 2012 £'000**
Fundraising	54	119	145	388	**706**
Research	180	25	73	91	**369**
Clinical care	54	25	73	95	**247**
Information, advice & support	36	20	73	44	**173**
Governance	36	10	-	2	**48**
	360	199	364	620	**1,543**

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

3. RESOURCES EXPENDED (CONTINUED)

Analysis of Governance Costs

	2012 £'000	2011 £'000
External audit fee	16	15
Trustees' travel expenses	4	18
Managing strategy & compliance	75	57
Total Governance costs	95	90

4. STAFF COSTS

Staff costs comprise the following:

	2012 £'000	2011 £'000
Salaries	1,960	2,072
Social security costs	209	214
Other pension costs	65	71
	2,234	2,357

Analysis of average staff numbers by category:

	2012 No.	2011 No. restated	2011 No
Fundraising	28	28	31.40
Research	2	3	1.15
Clinical care	8	6	10.00
Information, advice & support	6	8	8.50
Management	2	2	2.00
Finance	3	3	3.05
IT support	2	2	2.00
Administration & facilities	9	10	10.80
Average number of employees during the year	60	62	68.90

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

	2012 No.	2011 No.
£60,001 - £70,000	2	1
£90,001 - £100,000	1	1

Pension contributions to defined contribution pension schemes for these employees totalled £19,192 (2011 - £9,387).

No remuneration was paid to the trustees. Travel expenses of £3,448 (2011 - £17,744) were settled for three trustees (2011 – 3).

5. FUNDS

	Balance April 1 2011 £'000	Investment gains and income £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance March 31 2012 £'000**
Designated funds:						
Fixed Asset Fund	*985*	-	-	-	(140)	**845**
Development & strategic reserve	*1,999*	-	-	-	760	**2,759**
Total Designated Funds	*2,984*	-	-	-	**620**	**3,604**
General Reserves:						
Unrestricted Funds						
Unrestricted General Fund	*6,996*	110	8,033	(4,759)	(620)	**9,760**
Restricted Funds						
With a deficit						
Gene Therapy Research *For gene therapy research*	*(7,144)*	-	1,791	(694)	16	**(6,031)**
Free Reserves	*(148)*	110	9,824	(5,453)	(604)	**3,729**
Total Unrestricted Funds	*2,836*	110	9,824	(5,453)	16	**7,333**
Restricted funds:						
Department of Health *for information for parents*	*7*	-	-	-	-	**7**
Ena Bennie Memorial fund *to fund Gene Therapy Research*	*64*	16	-	-	(16)	**64**
EW Joseph fund *for community home care support*	*141*	4	-	(9)	-	**136**
Joseph Levy Memorial fund *for education*	*41*	9	45	(56)	-	**39**
Transplant research	*201*	-	175	-	-	**376**
Transplant Donor co-ordinator	*60*	-	-	-	-	**60**
Diabetes & CF lung research	*-*	-	18	-	-	**18**
Kings College CF Unit appeal	*-*	-	128	-	-	**128**
Waterloo Foundation *for dietician at the Children's Hospital for Wales, Cardiff*	*30*	-	-	-	-	**30**
Various sundry Restricted funds	*144*	4	84	(115)	-	**117**
Total Other Restricted funds	*688*	33	450	(180)	(16)	**975**
Endowment funds:						
Ena Bennie Memorial fund *To fund Gene Therapy Research*	*495*	-	-	-	-	**495**
EW Joseph fund *For community home care support*	*180*	9	-	-	-	**189**
Joseph Levy Memorial fund *For education*	*258*	-	-	-	-	**258**
Other Endowment funds	*43*	-	-	-	-	**43**
Total Endowment funds	*976*	9	-	-	-	**985**
TOTAL FUNDS	*4,500*	**152**	**10,274**	**(5,633)**	-	**9,293**

The Fixed asset fund comprises 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.

5. FUNDS (CONTINUED)

During the year transfers between funds were made as follows:

a) £16,000 from the Ena Bennie Memorial fund to the Gene Therapy Research fund being investment income for the year.

b) £140,000 from the designated fixed asset fund to general funds to reflect the lower book value of fixed assets at the end of the year.

c) £760,000 from unrestricted general funds to designated development and strategic reserve fund. The development and strategic reserve is to provide the Trust with the ability to offer commitment to and recognise the contingent liabilities in long term projects and work packages. This is reviewed each year and reflects the change in contingent liabilities on an annual basis.

Analysis of funds

	Unrestricted funds £'000	Endowment funds £'000	Gene Therapy Research restricted fund £'000	Other restricted funds £'000	**Total £'000**
Tangible fixed assets	845	-	-	-	**845**
Investments	3,573	985	-	404	**4,962**
Current assets	3,990	-	953	1,117	**6,060**
Current liabilities	4,956	-	(6,984)	(546)	**(2,574)**
	13,364	985	(6,031)	975	**9,293**

6. TANGIBLE ASSETS

Group and charity	Freehold property £'000	Furniture & fittings £'000	Computer equipment £'000	Cars £'000	Total £'000
Cost					
At 1 April 2011	948	235	1,011	261	2,455
Additions	-	-	40	-	40
Disposals	-	(46)	(340)	(13)	(399)
At 31 March 2012	**948**	**189**	**711**	**248**	**2,096**
Depreciation					
At 1 April 2011	229	215	881	145	1,470
Disposals	-	(46)	(340)	(13)	(399)
Charge for the year	17	14	105	44	180
At 31 March 2012	**246**	**183**	**646**	**176**	**1,251**
Net book value at 31 March 2012	**702**	**6**	**65**	**72**	**845**
Net book value at 31 March 2011	*719*	*20*	*130*	*116*	*985*

7. INVESTMENTS

Group and Charity	Unrestricted funds £'000	Restricted funds £'000	**Total 2012 £'000**	*Total 2011 £'000*
Market value as at 1 April 2011	3,484	1,355	**4,839**	*4,745*
Dividends/interest held in portfolio	94	32	**126**	*95*
Realised and unrealised investment gains/(losses) in the year	(4)	1	**(3)**	*(1)*
Market value as at 31 March 2012	3,574	1,388	**4,962**	*4,839*
Represented by:				
Investments held in Unit Trusts				
Equities	1,323	487	**1,810**	*1,822*
Fixed interest	1,059	490	**1,549**	*1,540*
Cash held as part of portfolio	1,192	411	**1,603**	*1,477*
	3,574	1,388	**4,962**	*4,839*
Investments held in Unit Trusts:				
Historical cost as at 31 March 2012	1,943	892	**2,835**	*2,835*
Unrealised gains at 31 March	439	85	**524**	*527*

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment.

8. DEBTORS

	Group 2012 £'000	*Group 2011 £'000*	Charity 2012 £'000	*Charity 2011 £'000*
Trade debtors	**35**	*45*	**-**	*-*
Amount due from subsidiary undertaking	**-**	*-*	**115**	*130*
Prepayments and accrued income	**501**	*319*	**501**	*319*
	536	*364*	**616**	*449*

9. GRANTS PAYABLE

	2012 £'000	*2011 £'000*
Grant creditor at 1 April 2011	**2,402**	*8,204*
Grants paid during the year (note 14)	**(2,096)**	*(5,907)*
Grants approved before 31 March 2012 awarded but withdrawn	**(19)**	*-*
Grants approved before 31 March 2012 awarded (GTC)	**75**	*(2,096)*
Grants approved before 31 March 2012 and payable within one year	**685**	*2,201*
Grant creditor at 31 March 2012	**1,047**	*2,402*
Represented by		
Grants awaiting claim at 31 March 2012	**612**	*477*
Grants due within one year at 31 March 2012	**435**	*1,925*
	1,047	*2,402*

10. CREDITORS

	Group 2012 £'000	*Group 2011 £'000*	Charity 2012 £'000	*Charity 2011 £'000*
Trade creditors	**490**	*3,114*	**435**	*3,004*
Other creditors	**972**	*284*	**969**	*286*
Accruals and deferred income	**64**	*155*	**58**	*149*
	1,526	*3,553*	**1,462**	*3,439*

11. INTEREST IN SUBSIDIARY

Cystic Fibrosis Services Limited is a wholly owned subsidiary of the charity, incorporated in England, and inter alia provides support to the Cystic Fibrosis Trust including medical services, information and data system support and merchandising of marketing materials.

The profit and loss account of Cystic Fibrosis Services Limited for the years ended 31 March can be summarised as follows:

	Total 2012 £'000	*Total 2011 £'000*
Sales and sundry income	**154**	*221*
Cost of sales and administration	**(93)**	*(142)*
Net profit received by the charity	**61**	*79*

At 31 March 2012 Cystic Fibrosis Services Limited had net assets of £2 (2011 - £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.

12. GRANT COMMITMENTS

At the balance sheet date the charity had commitments in respect of grants approved, but which are not accrued in these financial statements, as all of the criteria relating to payment of the grant in subsequent years have not been met, as follows:

	2012 £'000	*2011 £'000*
Payable between two and five years	**367**	*218*

13. 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 has made three grants in prior years which remain active in the current year and in which Professor Stuart Elborn is either applicant or co-applicant. These grants vary in period between 12 and 36 months. The original sum of the grants made in which Professor Elborn has an interest was £303,281. Professor Elborn was not involved in the selection process of the successful grants by the Trustees where he was either an applicant or co-applicant.

Any other transactions between the Trust and its trustees are disclosed in note 4.

14. GRANTS PAID DURING THE YEAR

	2012	2011
	£	£
Research grants paid – Restricted funds		
GTC: University of Edinburgh; Oxford University; Imperial College	**1,393,939**	*4,980,174*
Newcastle University	**108,213**	*142,645*
Total Research grants paid – Restricted funds	**1,502,152**	*5,122,819*
Research grants paid – General funds		
Controlling infection		
Queen's University, Belfast	**12,749**	*45,176*
Understanding & controlling inflammation		
Queen's University, Belfast	**28,633**	*47,178*
Newcastle University	**-**	*33,021*
(MRC Joint Clinical Research Training Fellowship)		
Queen's University, Belfast	**-**	*29,209*
University of Dundee, Tayside Institute of Child Health	**-**	*6,055*
Understanding & correcting the CF protein (CFTR)		
University of Bristol	**-**	*51,648*
University of Cambridge	**584**	*1,604*
NBS and lung function detection		
University College London	**90,956**	-
Microbiology – therapeutic targets to combat bacterial infection		
Cardiff University	**26,921**	-
Correcting sodium channel dysfunction		
Queen's University, Belfast	**50,000**	-
Clinical & other studies		
Leeds Teaching Hospitals NHS Trust	**9,477**	-
Total Research grants paid – General funds	**219,320**	*213,891*

14. GRANTS PAID DURING THE YEAR (CONTINUED)

	2012 £	2011 £
Development and other grants paid		
Harefield Hospital	**12,895**	*33,816*
Gartnavel Hospital – Glasgow	**-**	*50,000*
Papworth Hospital	**35,889**	*31,446*
Northern General Hospital, Sheffield	**50,000**	*50,000*
St James' University Hospital	**29,410**	*5,810*
Cardiff University	**30,000**	-
Royal Victoria Infirmary, Newcastle	**40,584**	*34,047*
Total Development and other grants paid	**199,048**	*205,119*
Training grants paid		
Southampton General Hospital	**(18,996)**	*37,500*
Papworth Hospital	**-**	*56,250*
Wythenshawe Hospital, Manchester	**-**	*75,000*
Exeter University	**13,705**	-
Manchester University	**15,701**	-
Total Training grants paid	**10,410**	*168,750*
Grants to Individuals	**184,522**	*196,140*
Total grants paid	**2,115,452**	*5,906,719*

Research Advisory Committee

Professor Stuart Elborn *(Chair)* MD FRCP
Adult Physician, Belfast City Hospital; Professor of Respiratory Medicine, Queen's University Belfast
Dr Mike Gray *(Deputy Chair)* PhD
Reader in Cellular Physiology; University of Newcastle upon Tyne
Mrs Giorgia Arnold
Trustee and Parent Representative
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Molecular Geneticist, University of Edinburgh
Dr Judy Bradley PhD BSc (Hons) MCSP
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Microbiologist, University of Edinburgh
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Adult Physician, Seacroft Hospital, Leeds
Mr Peter Sharp
Trustee and Patient Representative
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Reader in Pharmacology, University of Portsmouth
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Microbiologist, University of Liverpool
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Chairman of Trustees, Cystic Fibrosis Trust
Matthew Reed *(until 11 May 2012)*
Chief Executive, Cystic Fibrosis Trust
Ed Owen *(from 8 May 2012)*
Chief Executive, Cystic Fibrosis Trust

Medical Advisory Committee

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Medical Advisory Committee (Continued)

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Chief Executive, Cystic Fibrosis Trust
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