CYSTIC FIBROSIS TRUST

ANNUAL REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2010

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CYSTIC FIBROSIS TRUST
LEGAL AND ADMINISTRATIVE INFORMATION
FOR THE YEAR ENDED 31 MARCH 2010

Royal Patron
HRH Princess Alexandra KG GCVO

President
Duncan Bluck CBE *(until 28 February 2010)*

Vice President
Peter Levy OBE FRICS

TRUSTEES

Chair
Dr James Littlewood OBE MD FRCP FRCPE DCH

Vice Chair
Allan Gormly CMG CBE #

Honorary Treasurer
Rupert Pearce Gould FCA FCMA # *(appointed 18 May 2010)*
Alison Halsey FCA *(resigned 10 March 2010)*

Jenny Agutter #
Giorgia Arnold #
Duncan Bluck *(resigned 28 February 2010)*
Sir Peter Cresswell
Katrina Dujardin # *(appointed 30 March 2010)*
Professor Stuart Elborn MD FRCP *
Brian Henderson #
Sir Robert Johnson *(resigned 8 December 2009)*
Archie Norman
Ed Owen #
Professor John Price MD FRCP FRCPCH *(appointed 30 March 2010)*
Martyn Rose #
Peter Sharp #

** Chair of Research Advisory Committee*
 # indicates either CF patient, carrier or relative of a carrier of the defective gene

Finance and Investment Committee
Rupert Pearce Gould *Chair (from 18 May 2010)*
Alison Halsey *Chair (until 10 March 2010)*
Allan Gormly
Guy Harington
Sir Robert Johnson *(until 8 December 2009)*
Dr James Littlewood
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
Martyn Rose

Charity Management
Matthew Reed – Chief Executive *(from 6 September 2010)*
Rosie Barnes – Chief Executive *(retired 6 August 2010)*
Alan Larsen ACA – Director of Research and Finance *(until 30 June 2010)*
Sarah Guthrie – Director of Fundraising
Malcolm Moore – Director of Operations
Jo Osmond – Director of Clinical Care and Commissioning *(from 12 July 2010)*
Phil Smith FCCA – Finance Manager

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Company Limited by Guarantee
Company registration number: 3880213
Charity registration number:
England & Wales – 1079049
Scotland – SC40196

Principal Advisers

Auditors
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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
ADVISORY COMMITTEES
FOR THE YEAR ENDED 31 MARCH 2010

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
Parent Representative
Dr Chris Boyd BSc, PhD
Molecular Geneticist, University of Edinburgh
Dr Judy Bradley PhD BSc (Hons) MCSP
Physiotherapist, Belfast City Hospital
Professor John Govan BSc, PhD, DSc
Microbiologist, University of Edinburgh
Dr Andy Jones BSc, MB.ChB, MD, FRCP
Adult Physician, Wythenshawe Hospital, Manchester
Dr Daniel Peckham DM, FRCP
Adult Physician, Seacroft Hospital, Leeds
Mr Peter Sharp
Patient Representative
Dr Janis Shute BSc, PhD
Reader in Pharmacology, University of Portsmouth
Dr Colin Wallis MRCP, FRCPCH, MD, DCH
Consultant Paediatrician, Great Ormond Street Hospital
Dr Craig Winstanley BSc, PhD, FSB
Microbiologist, University of Liverpool
Dr Jim Littlewood OBE
Chairman of Trustees, Cystic Fibrosis Trust
Mrs Rosie Barnes *(retired 6 August 2010)*
Chief Executive, Cystic Fibrosis Trust

Medical Advisory Committee

Dr Diana Bilton *(Chair)* MD FRCP
Adult Physician, Royal Brompton Hospital, London
Dr Iolo Doull *(Deputy Chair)* MRCP, DM, FRCP CH
Consultant Paediatrician, Children's Hospital for Wales, Cardiff
Penny Agent, BSc (Hons) DMS
CF Specialist Physiotherapist, Royal Brompton Hospital, London
Dr Ian Balfour-Lynn, BSc MBBS MD FRCP FRCPCH FRCS (Ed) DHMSA
Consultant in Paediatric Respiratory Medicine, Royal Brompton Hospital, London
Maxine Bedford
Parent Representative
Dr Mandy Bryon PhD
Consultant Clinical Psychologist, Great Ormond Street Hospital, London
Sarah Collins, MSc, BSc (Hons) SRD
CF Specialist Dietitian, Royal Brompton Hospital, London
Dr Gary Connett, MB, ChB, DCH, FRCPCH, MD FRCPCH DHMSA
Consultant Paediatrician, Southampton General Hospital
(Continued)

Medical Advisory Committee (Continued)

Clare Cox, BPharm DipClin Pharm MRPharmS
Pharmacist, Papworth Hospital, Cambridge
Milly Dack, RGN, MSc
CF Nurse Specialist, Royal Brompton Hospital, London
Dr David Honeybourne, MD, MSc, FRCP
Adult Physician, Heartlands Hospital, Brimingham
Dr Alastair Innes, PhD, FRCP (Ed)
Adult Physician, Western General Hospital, Edinburgh
Lynsey Morton
Patient Representative
Dr Rosie Rayner, DM (CF), MBBS, MRCP, DCH, MA, FRCPCH
Consultant Paediatrician, New Cross Hospital, Wolverhampton
Mrs Rosie Barnes *(retired 6 August 2010)*
Chief Executive, Cystic Fibrosis Trust
Dr Jim Littlewood OBE
Chairman, Cystic Fibrosis Trust
Joanne Osmond
Director of Clinical Care and Commissioning, Cystic Fibrosis Trust

UK CF Gene Therapy Consortium - Scientific Advisory Committee and Steering Group

Professor Stuart Elborn *(Chair)* MD, FRCP
School of Medicine, Queen's University of Belfast and Belfast City Hospital
Mrs Rosie Barnes *(retired 6 August 2010)*
Chief Executive, Cystic Fibrosis Trust
Mr Allan Gormly
Vice Chairman, Cystic Fibrosis Trust
Mrs Donna Harcombe
Parent Representative
Professor Pierre Lehn MD
Laboratoire de Biogenetique et HLA INSERM, France
Dr Jim Littlewood OBE
Chairman, Cystic Fibrosis Trust
Professor Gerry McElvaney MB, FRCPI, FRCPC
Department of Medicine, Royal College of Surgeons in Ireland
Mrs Nikki Samsa
Parent Representative
Professor Brandon Wainwright BSc (Hons) PhD
Institute for Molecular Bioscience, University of Queensland, Australia

CYSTIC FIBROSIS TRUST
TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2010

The trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2010. 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 1993 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 8,500 people in the UK now affected by Cystic Fibrosis; a number that is increasing annually. It is caused by a single defective gene that is carried by 1 in 25 persons in the UK 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 chronic infections and inflammation in the lungs, and difficulty digesting food.

What we do:-

- We fund medical and scientific **research** to develop a cure and to provide effective treatments for Cystic Fibrosis;
- We ensure appropriate **clinical care** for those with Cystic Fibrosis; 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, whereas a baby born today with Cystic Fibrosis can expect to live to over 50 years, before taking into account the impact of potential new therapies that treat the basic defect and not just the symptoms caused by Cystic Fibrosis.

It is hoped that a better understanding of mechanisms of disease and the development of improved treatments will enable this group to have the opportunity to benefit from gene therapy and other treatments currently being developed.

Grant making policy
The charity invites applications for research grants annually from researchers based at recognised institutions through an announcement on the charity's website and by advertising to specialist researchers. Applicants are invited to submit their proposals in a specific format; all applications are reviewed by external referees.

The Cystic Fibrosis Trust is a member of the Association of Medical Research Charities (AMRC) and complies with its policies on research and peer review.

Projects are funded for up to a usual limit of three years and are monitored on an annual basis. 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, active professional to undertake specialised or further research training in the bio-medical sciences within the UK, 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 the defect in the *cystic fibrosis transmembrane conductance regulator* (CFTR), the faulty protein produced by the defective CF gene.

Gene Therapy
We currently spend around £3 million each year on a research programme to develop gene therapy as a means of alleviating the lung disease that is the cause of 90% of deaths from Cystic Fibrosis. The aim is to make gene therapy a clinical reality by using the best available products and techniques to produce a treatment that can be used in the clinic.

To achieve this we have funded the **UK CF Gene Therapy Consortium** at Imperial College London, Oxford University and Edinburgh University. Over the past eight years this consortium has developed the best currently available method of delivering a working copy of the CF gene into the lungs of people with Cystic Fibrosis. A single dose phase I pilot study of the chosen therapy commenced in February 2009. The purpose of this study is to test the safety of the therapy by nebulising it once into the lungs of patients. Preliminary results were presented to the Scientific Advisory Committee in November 2009 who recommended completing this phase I study and further recommended the trustees to allow work to begin on the multi-dose animal toxicology study leading to a phase II multi-dose clinical trial in around 100 patients over 12 months beginning in 2011.

A run-in to the multi-dose clinical trial involving around 200 people with CF was carried out during the year. People attended multiple sessions to measure several clinical markers, which may be used to assess the success of the multi-dose trial.

In total, the Cystic Fibrosis Trust has now committed over £40 million to the gene therapy research programme since 2001. If successful, the prognosis for people with Cystic Fibrosis will be significantly improved.

Lung Reconditioning Research
We approved a new grant to 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 many people with CF die whilst waiting on the transplant list. Four lungs have been treated using an ex-vivo perfusion technique and have been successfully transplanted. Work continues to refine this technique with a view to making it a clinical norm.

Lung Function Detection
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 and follow on tests for three years.

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, which may have an impact on adherence to treatment and health outcomes.

Microbiology
Research funded by the Trust continued at Belfast City Hospital to assess the impact bacterial infection in those with CF affects lung exacerbations 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 in CF 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 enhance the activity of CFTR and to test new chemicals.

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 a molecular level was continued at the University of Dundee to explore the group's findings in previous CF Trust funded 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. Clinical research helps inform and improve treatment and the clinical guidelines and practice 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.

Although we believe that gene therapy could provide an effective treatment for Cystic Fibrosis, we are committed to funding other research into improving the wellbeing of people with Cystic Fibrosis. Other important areas of research include symptom control, improving current treatments and diagnostics, investigating related CF complications, which are increasing as people with CF live longer and its social impact of patients and carers,

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 specialists and multidisciplinary teams of 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 Specialised Commissioning Groups and individual regional commissioners and made representations to political parties prior to the election to ensure that the specialised commissioning 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)
Since April 2008 the Cystic Fibrosis Trust has been working closely with the Department of Health (DoH) and has funded consultancy to develop a proposal for the implementation of an annual banded national tariff for Cystic Fibrosis care.

This has involved a costing exercise based on a sample size of 1,785 patient data sets, a third of all of patients in England, collected from 12 individual CF Specialist Centres across England. This data has been analysed in detail by PricewaterhouseCoopers working closely with the Clinical Care and Commissioning Manager of the CF Trust and the Project's lead CF Clinician in order to refine the data set in advance of a final report.

The Department of Health required all CF service providers to give feedback on the impact on their service in terms of income received. A questionnaire was sent to each provider (hospital trust) asking for current income received for provision of CF care versus the likely predicted income when applying the relevant cost per band for the new tariff to their current patient cohort. This 'Sense Check' is a necessary step to understand the impact of the new tariff arrangements, and test its suitability as a more appropriate and sustainable way of funding CF care.

Detailed analysis and the above feedback were presented on 6 July 2010 to lead CF clinicians and hospital finance directors, together with representatives of the 10 Specialised Commissioning Groups in England. Also present was the Head of Developing the Scope for PbR from the Department of Health. There was discussion and debate about the new funding arrangements with the aim of reaching a consensus about whether to proceed towards implementation of the new tariff in April 2011.

It was concluded that work should progress towards full implementation of a mandatory annual banded tariff for CF in April 2011. In the coming year additional work will be carried out to reflect the cost of networked services.

Peer review of specialist CF Centres and large clinics
Our peer review programme continued throughout the year. The peer review is a tool for assisting CF Centres and network clinics to develop their services and improve clinical outcomes. During the year, peer reviews were carried out at eight Specialist CF Centres along with 23 CF clinics.

This programme continues to be highly successful at increasing resources at specialist CF Centres and spreading best practice, thereby improving the quality of care provided to people with Cystic Fibrosis. The final reports are now endorsed by the British Thoracic Society and the British Paediatric Respiratory Society as appropriate. Peer reviews are very demanding on time, both within the charity and the specialist CF teams who provide the peer reviewers; peer review visit can now involve visiting a specialist CF Centre for a day, plus thirteen network clinics at the rate of two a day over an intense period of two weeks or more.

Given the success of this work in providing an uplift in resources in the NHS for CF care, we are continuing with further reviews at approximately one Specialist CF Centre or complete network a month.

CF Registry
The Cystic Fibrosis Trust is unique among specialised conditions in the UK in having developed a high quality patient registry containing information about the location and health status of people with Cystic Fibrosis.

In October 2009, the CF Registry published its Annual Data Report 2008 – the second from Port CF. Port CF has now been implemented in all specialist CF Centres and 88 network clinics throughout the UK. Work continues to implement Port CF in the remaining small clinics.

This initiative is helping us to monitor patient treatment and is an important tool in raising the standard of care by providing a national 'snapshot' of demographic and clinical outcome data, as well as comparing outcomes between specialist CF Centres and networks throughout the country.

In the latest Annual Data Report (CF Registry Report 2008), the median predicted survival is 38.8 years. This figure is an increase on the previous year and represents a more accurate figure given there is an increased amount of full patient data available.

The CF Registry is becoming increasingly valuable as a database and research tool, the more so since it will be 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 as more adult specialist CF Centres are required as people with CF continue to live longer.

Development grants
The Cystic Fibrosis Trust continues aims to either give or arrange development grants to NHS hospitals to assist with development of new specialist CF Centres, or to help an existing specialist Centre that is experiencing a crisis in staffing. These are usually provided on the understanding that the NHS Trust will take over the responsibility for resourcing the posts funded within a reasonable timeframe.

Training grants
Many of the current directors of Specialist CF Centres were trained through Fellowship awards from the Cystic Fibrosis Trust and the specialist multidisciplinary teams were built up with the help of our Clinical Support and Improvement Grants. In recognition of the fact that people with CF are living longer the Cystic Fibrosis Trust now provides grants for training the specialist CF Consultants and Adult Centre Directors of the future.

Seven grants have been awarded over the past four years to selected specialist CF Centres to fund a one-year training programme for an adult physician. Two further grants were awarded under this scheme during the year. Of the six trainees who have completed the training under this scheme, five have been appointed as specialist CF Consultants and one is working as a locum in a CF Centre awaiting an appropriate opportunity.

Expert Patient Advisers
The Cystic Fibrosis Trust employs seven adults with Cystic Fibrosis as expert patient advisers, whose role is to use their knowledge 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 as patients at meetings and conferences.

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 the medical community and for those affected by Cystic Fibrosis. Our telephone help lines are staffed by full-time employees.

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 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.

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. 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 committees. 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.

'Antibiotic treatment for Cystic Fibrosis – third edition May 2009' was published early in the year. In addition, a working group of CF Consultant microbiologists and other relevant experts has finalised a new consensus document covering standards and guidelines for the processing of microbiological samples in Cystic Fibrosis, which will be published in summer 2010.

Work continued on the Clinical Care Pathway for Cystic Fibrosis – a web based resource giving information of the care expected from pre-diagnosis to death. This will launch in 2010.

Medical meetings
The Cystic Fibrosis Trust hosts an annual meeting for the Directors of the specialist CF Centres in the UK. 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. The 2009 meeting was held in Birmingham in May.

Helplines
The national telephone helplines continue to be an important resource 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.

'Ask the expert'
As well as containing much information about Cystic Fibrosis, the charity's website also provides access to its 'Ask the expert' service. Specific medical and scientific questions are forwarded to a panel of experts, who provide an appropriate reply. Edited anonymous versions of these questions also appear in the CF Today magazine.

Welfare Grants
The charity provides 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 for adults with CF. This service continues to be fully utilised and it remains a struggle to contain the amount of grants awarded within the budget.

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 increasing 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 3,000 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.

FUTURE PLANS

Our ongoing annual objectives mirror the overall charitable objectives as outlined above.

The work of the UK CF Gene Therapy Consortium to develop a gene therapy for the lungs of people with CF remains our main focus of research. The phase I clinical trial started in February 2009; this single dose safety study is due to be completed in 2010 and with the expected positive results, will lead to a 12 month multi-dose phase II clinical trial starting in 2011.

Our focus during the coming year will be in the following areas:

- the successful conclusion of the phase I pilot study of the gene therapy research, leading on to the phase II multi-dose clinical trial that is planned to commence in 2011;
- continuation of the programme of peer review and especially the review of major paediatric shared-care networks;
- further analysis of the CF Registry and publication of the Annual Report for 2009 de-anonymised by centre, as well as continuing to implement the registry in the remaining small clinics;
- working with the Department of Health, commissioners, hospital management and clinicians to refine and to implement the effective system of payment by results based on an annual tariff that varies according to the treatment required at several defined levels of severity of the condition.

HOW WE FUNDED OUR ACTIVITIES AND THE FUNDS THAT WE RAISED

Income

Despite the economic situation, our income for the year fell only slightly to £9,172,000 (2009: £9,274,000). Income from Branches, Groups & Community and Individual donations again showed the biggest falls as individuals have less to give in the current climate. This was offset by another significant increase in Legacy income,

Approximately half of the categories of income showed a decrease compared to prior year (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.

The challenge for the coming two years will be to maintain income at the current level in order that we can meet continuing commitments to the Gene Therapy Consortium for the multi dose clinical trial that is due to commence in 2011.

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, which requires much organisation and nurturing. The Trustees consider that the cost of generating income is appropriate for the charity.

Expenditure
Expenditure in the year dropped to £8,180,000 (from £10,301,000 in 2009). Nearly 40% of this was spent on research (£3,107,000), 91% of which (£2,835,000) was committed to the gene therapy research programme. The reduction in expenditure this year arises from a recognition of the drop in income and the large initial grant for the Gene Therapy programme in the prior year.

Despite the difficult fundraising climate the cost of generating funds decreased by some £27,000 compared to the prior year.

CORPORATE GOVERNANCE

The Cystic Fibrosis Trust is a registered charity in England and Wales and in Scotland and was incorporated as a charitable company limited by guarantee on 1 April 2000. It is governed by memorandum and articles of association, which were adopted on incorporation and were amended in December 2008 as required by the Office of the Scottish Charity Regulator in order to register as a charity in Scotland. The charity was founded in 1964 as the Cystic Fibrosis Research Trust.

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 are volunteers and, as charitable trustees and company directors, have the legal responsibility for the effective 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.

Since it was founded, the Cystic Fibrosis Trust has been governed mainly by individuals with close personal experience of Cystic Fibrosis. This continues and, in addition, a review carried out in 2004 identified key skills that are needed by the Trustees in order properly to oversee the running of a national charity. These skills are now well represented among the Trustees, all of whom have a strong personal interest in Cystic Fibrosis and one of whom is living with Cystic Fibrosis.

The Board of Trustees meets quarterly to review progress and policies. Trustees serve on the Board for a period of three years (which is renewable by invitation of the Board). New Trustees are appointed by the Trustees, taking into account the skills required and not represented among the current members of the Board of Trustees.

The Trustees are supported by a number of committees:

The **Finance and Investment Committee** meets quarterly and monitors, oversees and reviews progress and policies relating to financial and investment matters. It reviews the audited financial statements of the charity and recommends them to the Board of Trustees. It also reviews reports from the auditors and monitors management actions to implement recommendations. The committee monitors the performance of the charity's investment portfolio and is responsible for the appointment of the Investment Manager. The members of the Finance and Investment Committee are appointed by the Trustees.

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, as well as for reviewing and assessing the research that has been funded. Its members are distinguished scientific and clinical researchers who are representative of the various areas of research relevant to Cystic Fibrosis. Its members, who include an adult patient and a parent of a child with Cystic Fibrosis, are appointed by the Trustees.

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, who include an adult patient and a parent of a child with Cystic Fibrosis, are appointed by the Trustees.

The **UK CF Gene Therapy Consortium Scientific Advisory Committee and Steering Group** advises the Trustees on matters relating to the UK CF Gene Therapy Consortium. Its members include: international experts in the field of gene therapy research; specialist Cystic Fibrosis clinicians; an adult with Cystic Fibrosis; parents of people with Cystic Fibrosis; and the Chief Executive and Director of Research of the Cystic Fibrosis Trust. Its members are appointed by the Trustees.

Executive Management
Responsibility for strategy, planning 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 the guidelines issued by the Charity Commission.

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

Trading
The Charity had one wholly owned trading subsidiary at the year end: CF Merchandising Limited, a company registered in England. The company carries out non-charitable trading activities for the charity, comprising mainly mail order trading with particular reference to Christmas cards and other catalogue merchandise. Turnover for the year was £234,000 (2009: £236,000) and taxable profit was £58,000 (2009: £32,000). During the year the company made a payment under a deed of covenant transferring all its taxable profits to the charity.

Results of these activities are disclosed in note 11 of the consolidated financial statements and in the separate financial statements of CF Merchandising Limited.

Reserves
As explained above the charity carries out a diverse range of activities, some of which comprise short-term and externally funded projects, whilst others comprise longer-term projects requiring significant ongoing financial commitment and investment.

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. Consideration was given to the nature of the income and expenditure streams, current research imperatives and the current composition of the reserves. The Trustees concluded that:

- annual income is sufficiently reliable and consistent to ensure that commitments will be met for the foreseeable future;
- expenditure not covered by restricted or designated funds is sufficiently flexible to be met out of current income as it is raised; and
- forecasts of unrestricted fund cash flows demonstrate that the charity will be able to meet its liabilities as they fall due in the next year.

In view of this the Trustees consider that, given the nature of the charity's work, any surplus income is best employed in funding research projects that contribute to the delivery of its objectives.

The level of 'free reserves' at the balance sheet date is £ 5,710,000 (2009: £5,671,000). However, these are being held against the deficit on the Gene Therapy Consortium restricted fund of £7,515,000 (2009: £9,479,000); thus, 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. Should it prove unnecessary to offset further free reserves against the deficit on the Gene Therapy Consortium Restricted Fund, free reserves will be used to fund research projects in accordance with the charity's reserves policy as stated above. The Trustees therefore consider that the level of reserves is in accordance with the charity's reserves policy.

Gene Therapy Consortium Restricted Fund
The Gene Therapy Consortium restricted fund shows a deficit of £7,515,000 at the end of the year compared to £9,479,000 at the end of the prior year. This deficit arises because grants committed at the year-end but 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 both by income already pledged but not yet received and income that will be raised in subsequent years.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The Trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and regulations.

Company law requires the trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards) and applicable law.

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 of its net incoming resources for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue to operate.

The trustees are responsible for keeping proper accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity 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 company's auditor is aware of that information.

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

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

Chairman

INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF CYSTIC FIBROSIS TRUST

We have audited the group and parent company financial statements of Cystic Fibrosis Trust for the year ended 31 March 2010 set out pages 17 to 30. These financial statements have been prepared in accordance with the accounting policies set out therein.

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 charity's trustees, as a body, in accordance with section 44(1)(c) 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 auditors

The trustees' (who are also the directors of Cystic Fibrosis Trust for the purpose of company law) responsibilities for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and for being satisfied that the financial statements give a true and fair view are set out in the Statement of Trustees' Responsibilities.

We have been appointed auditors under the Companies Act 2006 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and report to you in accordance with those Acts.

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (United Kingdom and Ireland).

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice and have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006. We also report to you if in our opinion the information given in the Trustees' Annual Report is not consistent with the financial statements.

In addition, we report to you if, in our opinion, the charitable company has not kept adequate accounting records, if the charity's financial statements are not in agreement with those records, if we have not received all the information and explanations we require for our audit or if certain disclosures of trustees' remuneration specified by law are not made.

Basis of opinion

We conducted our audit in accordance with International Standards on Auditing (United Kingdom and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgments made by the trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charitable company's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF CYSTIC FIBROSIS TRUST (continued)

Opinion

In our opinion:

- the financial statements give a true and fair view of the state of the group's and the parent company's affairs as at 31 March 2010 and of the group's incoming resources and application of resources, including its income and expenditure, for the year then ended;
- the financial statements have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- the financial statements have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006; and
- the information given in the Trustees' Annual Report is consistent with the financial statements.

Michael Hicks
Senior Statutory Auditor
For and on behalf of
Horwath Clark Whitehill LLP
Statutory Auditor
London

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

Horwath Clark Whitehill LLP
Chartered Accountants and Registered Auditors

St Bride's House
10 Salisbury Square
London EC4Y 8EH

CYSTIC FIBROSIS TRUST
CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES
(Incorporating an Income and Expenditure Account)
FOR THE YEAR ENDED 31 MARCH 2010

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total 2010 £'000**	*Total 2009 £'000*
INCOMING RESOURCES						
Incoming resources from generated funds						
Voluntary income	2	8,073	691	-	**8,764**	*8,681*
Activities for generating funds						
Trading and merchandising	11	234	-	-	**234**	*236*
Investment & interest income		136	38	-	**174**	*357*
Total incoming resources		8,443	729	-	**9,172**	*9,274*
RESOURCES EXPENDED						
Cost of generating funds						
Costs of generating voluntary income		2,545	-	-	**2,545**	*2,549*
Trading and merchandising	11	170	-	-	**170**	*193*
Costs of generating funds		2,715	-	-	**2,715**	*2,742*
Charitable activities						
Research		517	2,590	-	**3,107**	*5,278*
Clinical Care		1,214	154	-	**1,368**	*1,141*
Information, advice & support		801	111	-	**912**	*1,073*
Governance costs		78	-	-	**78**	*67*
Total resources expended	3	5,325	2,855	-	**8,180**	*10,301*
NET (OUTGOING)/ INCOMING RESOURCES		3,118	(2,126)	-	**992**	*(1,027)*
Realised Investment gains		-	-	-	**-**	*11*
Gain on asset disposal		1	-	-	**1**	*1*
NET INCOME/(EXPENDITURE) FOR THE YEAR		3,119	(2,126)	-	**993**	*(1,015)*
Unrealised investment gains		742	10	162	**914**	*(543)*
Transfers between funds	5	(3,993)	3,993	-	**-**	*-*
NET MOVEMENT IN FUNDS		(132)	1,877	162	**1,907**	*(1,558)*
Funds brought forward		6,974	(8,923)	821	**(1,128)**	*430*
FUNDS CARRIED FORWARD	5	6,842	(7,046)	983	**779**	*(1,128)*

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 2010

	Notes	Consolidated Total 2010 £'000	Consolidated *Total 2009 £'000*	Charity Total 2010 £'000	Charity *Total 2009 £'000*
Fixed assets					
Tangible assets	6	**1,132**	*1,282*	**1,132**	*1,282*
Investments	7	**4,745**	*3,698*	**4,745**	*3,698*
		5,877	*4,980*	**5,877**	*4,980*
Current assets					
Debtors	8	**272**	*526*	**360**	*585*
Cash held as short term investment		**1,075**	*1,548*	**1,075**	*1,548*
Cash at bank & in hand		**2,136**	*4,066*	**1,966**	*3,889*
		3,483	*6,140*	**3,401**	*6,022*
Creditors: amounts due within one year					
Grants payable	9	**(8,204)**	*(11,866)*	**(8,204)**	*(11,866)*
Creditors and accrued charges	10	**(377)**	*(382)*	**(295)**	*(264)*
		(8,581)	*(12,248)*	**(8,499)**	*(12,130)*
Net current (liabilities)		**(5,098)**	*(6,108)*	**(5,098)**	*(6,108)*
Net (liabilities)/assets		**779**	*(1,128)*	**779**	*(1,128)*
Represented by:					
Endowment funds	5	**983**	*821*	**983**	*821*
Restricted funds	5				
Gene Therapy Consortium		**(7,515)**	*(9,479)*	**(7,515)**	*(9,479)*
Other Restricted funds		**469**	*556*	**469**	*556*
Unrestricted funds	5				
General fund		**5,710**	*5,671*	**5,710**	*5,671*
Designated funds		**1,132**	*1,303*	**1,132**	*1,303*
		779	*(1,128)*	**779**	*(1,128)*

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

} Trustees

CYSTIC FIBROSIS TRUST
CONSOLIDATED CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2010

	2010 £'000	*2009* *£'000*
Net cash outflow from operating activities	**(2,325)**	*712*
Returns on investments and servicing of finance		
Investment income	**174**	*357*
	174	*357*
Capital expenditure and financial investment		
Purchase of fixed assets	**(129)**	*(381)*
Purchase of investments	**(132)**	*(170)*
Proceeds of sales of fixed assets	**11**	*18*
	(250)	*(533)*
Management of liquid resources		
Decrease/(Increase) in cash held as short term investments	**473**	*(330)*
(Decrease)/Increase in cash	**(1,928)**	*206*

A. RECONCILIATION OF NET (OUTGOING)/INCOMING RESOURCES TO NET CASH OUTFLOW FROM OPERATING ACTIVITIES

	2010 £'000	*2009* *£'000*
Net incoming/(outgoing) resources	**992**	*(1,027)*
Depreciation	**270**	*227*
Investment income	**(174)**	*(357)*
Decrease in debtors	**254**	*438*
(Decrease)/Increase in creditors	**(3,667)**	*1,431*
	(2,325)	*712*

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

	2010 £'000	*2009* *£'000*
Net cash resources at 1 April 2009	**5,614**	*5,067*
Net (Decrease)/increase in cash at bank & in hand	**(1,928)**	*206*
(Decrease)/Increase from revaluation of foreign currency account	**(2)**	*11*
(Decrease)/Increase in short term investments	**(473)**	*330*
Net cash resources at 31 March 2010 (being cash at bank & in hand and cash held as short term investments)	**3,211**	*5,614*

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 £779,000. 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.
- 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.

1. ACCOUNTING POLICIES (CONTINUED)

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. 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 notes to the financial statements.

h) Stocks
Stocks are stated at the lower of cost and net realisable value.

i) 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.

j) 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.

k) 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.

2. VOLUNTARY INCOME

		Restricted Funds			
	Unrestricted Funds £'000	Gene Therapy Consortium £'000	Other Restricted Funds £'000	**Total 2010 £'000**	*Total 2009 £'000*
Branches, Groups & Community	4,499	170	37	**4,706**	*4,853*
Legacies	965	-	-	**965**	*484*
Corporate	650	63	15	**728**	*778*
Regular giving	588	39	-	**627**	*602*
Individual donations	475	70	59	**604**	*856*
Gift Aid	516	-	-	**516**	*388*
Trusts	202	47	203	**452**	*479*
Appeals	138	-	-	**138**	*94*
NHS National Services Scotland	40	-	-	**40**	*40*
Department of Health	-	-	7	**7**	*20*
Big Lottery Fund	-	-	(19)	**(19)**	*87*
Total Voluntary income	8,073	389	302	**8,764**	*8,681*

3. RESOURCES EXPENDED

	Grants £'000	Direct costs £'000	Support costs allocated £'000	**Total 2010 £'000**	*Total 2009 £'000*
Cost of generating funds					
Fundraising	-	1,891	654	**2,545**	*2,549*
Trading-Merchandising	-	170	-	**170**	*193*
Charitable activities					
Research	2,826	80	201	**3,107**	*5,278*
Clinical care	341	740	287	**1,368**	*1,141*
Information, advice & support	184	567	161	**912**	*1,073*
Governance	-	49	29	**78**	*67*
	3,351	3,497	1,332	**8,180**	*10,301*

Analysis of allocated Support Costs	Management £'000	Finance £'000	IT Support £'000	Admin & Facilities £'000	**Total 2010 £'000**
Fundraising	26	101	134	393	**654**
Research	26	21	67	87	**201**
Clinical care	89	21	67	110	**287**
Information, advice & support	18	17	67	59	**161**
Governance	18	9	-	2	**29**
	177	169	335	651	**1,332**

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

Analysis of Governance Costs

	2010 £'000	*2009 £'000*
External audit fee	**19**	*18*
Trustees' travel expenses	**12**	*10*
Managing strategy & compliance	**47**	*39*
Total Governance costs	**78**	*67*

4. STAFF COSTS

Staff costs comprise the following:

	2010	*2009*
	£'000	*£'000*
Salaries	**1,915**	*1,845*
Social security costs	**201**	*190*
Other pension costs	**73**	*61*
	2,189	*2,096*

Analysis of average staff numbers by category:

	2010	*2009*
	No.	*No.*
Fundraising	**28.00**	*28.40*
Research	**1.75**	*1.75*
Clinical care	**9.10**	*8.00*
Information, advice & support	**8.50**	*8.00*
Management	**2.00**	*2.00*
Finance	**3.25**	*2.25*
IT support	**2.00**	*2.00*
Administration & facilities	**11.00**	*10.60*
Average number of employees during the year	**65.60**	*63.00*

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

	2010	*2009*
	No.	*No.*
£60,001 - £70,000	**1**	*1*
£80,001 - £90,000	**1**	*1*
£90,001 - £100,000	**1**	*1*

Pension contributions to defined contribution pension schemes for these employees totalled £17,744 (2009 - £17,744).

No remuneration was paid to the trustees. Travel expenses of £12,324 (2009 - £9,627) were settled for three trustees (2009 – 3).

5. FUNDS

	Balance April 1 2009 £'000	Investment gains and income £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance March 31 2010 £'000**
Endowment funds:						
Ena Bennie Memorial fund *To fund the Gene Therapy Consortium*	*408*	91	-	-	-	**499**
EW Joseph fund *For community home care support*	*156*	24	-	-	-	**180**
Joseph Levy Memorial fund *For education*	*228*	32	-	-	-	**260**
Other Endowment funds	*29*	15	-	-	-	**44**
Total Endowment funds	*821*	162	**-**	**-**	**-**	**983**
Restricted funds:						
Gene Therapy Consortium *For gene therapy research*	*(9,479)*	-	389	(2,441)	4,016	**(7,515)**
Department of Health *for information for parents*	-	-	7	-	-	**7**
Ena Bennie Memorial fund *to fund the Gene Therapy Consortium*	*64*	16	-	-	(16)	**64**
EW Joseph fund *for community home care support*	*131*	20	-	(6)	-	**145**
Joseph Levy Memorial fund *for education*	*39*	8	54	(49)	-	**52**
for transplant research	*14*	-	150	(138)	-	**26**
for Transplant Donor co-ordinator	*60*	-	-	-	-	**60**
for Sheffield Adult CF Centre at Northern General Hospital	*145*	-	-	(145)	-	**-**
Waterloo Foundation *for dietitian at the Children's Hospital for Wales, Cardiff*	-	-	30	-	-	**30**
Various sundry Restricted funds	*103*	4	61	(76)	(7)	**85**
Sub total Other Restricted funds	*556*	48	302	(414)	(23)	**469**
Total Restricted funds	*(8,923)*	48	691	(2,855)	3,993	**(7,046)**
Unrestricted funds:						
General funds	*5,671*	879	8,307	(5,325)	(3,822)	**5,710**
Designated funds:						
Fixed asset fund	*1,282*	-	-	-	(150)	**1,132**
Grants fund	*21*	-	-	-	(21)	**-**
Sub total Designated funds	*1,303*	-	-	-	(171)	**1,132**
Total Unrestricted funds	*6,974*	879	8,307	(5,325)	(3,993)	**6,842**
Total funds	*(1,128)*	1,089	8,998	(8,180)	-	**779**

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.

The Grants fund represents grants due within one year but approved after the balance sheet date and therefore not included in the consolidated statement of financial activities for the year.

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 Consortium fund being investment income for the year.

b) £4,000,000 from General funds to the Gene Therapy Consortium fund being unrestricted funds made available to the Gene Therapy Consortium fund in line with the charity's reserves policy.

c) £150,000 from the designated Fixed asset fund to General funds to reflect the lower book value of fixed assets at the end of the year.

d) £21,000 from the designated Grants fund to General funds leaving £0 representing grants due within one year but approved after the balance sheet date and therefore not included in the consolidated statement of financial activities for the year.

e) £7,000 from various Restricted funds to General funds being amounts paid from general funds in the prior year for which restricted income had been received.

Analysis of funds

	Unrestricted funds £'000	Endowment funds £'000	Gene Therapy Consortium restricted fund £'000	Other restricted funds £'000	**Total £'000**
Tangible fixed assets	1,132	-	-	-	**1,132**
Investments	3,383	983	-	379	**4,745**
Current assets	2,529	-	183	771	**3,483**
Current liabilities	(202)	-	(7,698)	(681)	**(8,581)**
	6,842	983	(7,515)	469	**779**

6. TANGIBLE ASSETS

Group and charity	Freehold property £'000	Furniture & fittings £'000	Computer equipment £'000	Cars £'000	Total £'000
Cost					
At 1 April 2009	948	233	866	259	2,306
Additions	-	1	99	29	129
Disposals	-	-	-	(38)	(38)
At 31 March 2010	**948**	**234**	**965**	**250**	**2,397**
Depreciation					
At 1 April 2009	195	164	553	112	1,024
Disposals	-	-	-	(29)	(29)
Charge for the year	17	27	175	51	270
At 31 March 2010	**212**	**191**	**728**	**134**	**1,265**
Net book value at 31 March 2010	**736**	**43**	**237**	**116**	**1,132**
Net book value at 31 March 2009	*753*	*69*	*313*	*147*	*1,282*

7. INVESTMENTS

Group and Charity	Unrestricted funds £'000	Restricted funds £'000	**Total 2010 £'000**	*Total 2009 £'000*
Market value as at 1 April 2009	2,547	1,151	**3,698**	*4,071*
Dividends/interest held in portfolio	95	38	**133**	*170*
Realised and unrealised investment gains/(losses) in the year	742	172	**914**	*(543)*
Market value as at 31 March 2010	3,384	1,361	**4,745**	*3,698*
Represented by:				
Investments held in Unit Trusts				
Equities	1,300	492	**1,792**	*1,678*
Fixed interest	1,075	495	**1,570**	*1,145*
Cash held as part of portfolio	1,009	374	**1,383**	*875*
	3,384	1,361	**4,745**	*3,698*
Investments held in Unit Trusts:				
Historical cost as at 31 March 2010	1,943	892	**2,835**	*3,211*
Unrealised gains/(losses) at 31 March	432	95	**527**	*(388)*

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

8. DEBTORS

	Group 2010 £'000	*Group 2009 £'000*	Charity 2010 £'000	*Charity 2009 £'000*
Trade debtors	**20**	*21*	**-**	*-*
Amount due from subsidiary undertaking	**-**	*-*	**108**	*80*
Prepayments and accrued income	**252**	*505*	**252**	*505*
	272	*526*	**360**	*585*

9. GRANTS PAYABLE

	2010 £'000	*2009 £'000*
Grant creditor at 1 April 2009	**11,866**	*10,502*
Grants paid during the year (note 14)	**(7,012)**	*(3,990)*
Grants approved before 31 March 2010 and payable within one year	**3,350**	*5,354*
Grant creditor at 31 March 2010	**8,204**	*11,866*
Represented by		
Grants awaiting claim at 31 March 2010	**3,618**	*7,000*
Grants due within one year at 31 March 2010	**4,586**	*4,866*
	8,204	*11,866*

10. CREDITORS

	Group 2010 £'000	*Group 2009 £'000*	Charity 2010 £'000	*Charity 2009 £'000*
Trade creditors	**252**	*248*	**183**	*147*
Other creditors	**86**	*90*	**81**	*76*
Accruals and deferred income	**39**	*44*	**31**	*41*
	377	*382*	**295**	*264*

11. INTEREST IN SUBSIDIARY – CF MERCHANDISING LIMITED

CF Merchandising Limited is a wholly owned subsidiary of the charity, incorporated in England, and is engaged in the sale of Christmas cards and other merchandise and the operation of events and activities. The profit and loss account of CF Merchandising Limited for the years ended 31 March can be summarised as follows:

	Merchandising £'000	**Total 2010 £'000**	*Total 2009 £'000*
Sales and sundry income	234	**234**	*236*
Cost of sales and administration	(176)	**(176)**	*(204)*
Net profit received by the charity	58	**58**	*32*

At 31 March 2010 CF Merchandising Limited had net assets of £2 (2009 - £2).

The charity owns the whole of the issued ordinary share capital of CF Merchandising 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:

	2010 £'000	*2009 £'000*
Payable between two and five years	**9,966**	*1,569*

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.

14. GRANTS PAID DURING THE YEAR

	2010	2009
	£	£
Research grants paid – Restricted funds		
UK CF Gene Therapy Consortium	**5,989,369**	*3,117,124*
Newcastle University	**117,232**	*39,624*
UK CF Microbiology Consortium	**230**	*149,281*
Total Research grants paid – Restricted funds	**6,106,831**	*3,306,029*
Research grants paid – General funds		
Controlling infection		
University of Edinburgh	**42,791**	*37,635*
Queen's University, Belfast	**40,020**	-
Queen's University, Belfast	**-**	*15,961*
University of Edinburgh	**-**	*25,566*
University of Warwick	**-**	*22,378*
Understanding & controlling inflammation		
Queen's University, Belfast	**61,515**	*2,278*
Newcastle University	**33,021**	-
(MRC Joint Clinical Research Training Fellowship)		
Queen's University, Belfast	**25,045**	-
University of Dundee, Tayside Institute of Child Health	**16,743**	-
University of Portsmouth	**-**	*4,037*
Understanding & correcting the CF protein (CFTR)		
Newcastle University	**8,389**	*29,063*
University of Cambridge	**13,289**	*1,062*
University of Dundee, Tayside Institute of Child Health	**23,642**	*44,360*
University of Bristol	**77,800**	*13,515*
University of Cambridge	**588**	-
University of Bristol	**-**	*22,900*
Clinical & other studies		
Leeds Teaching Hospitals NHS Trust	**196**	-
Institute of Child Health, University College, London	**-**	*16,349*
Research models	**-**	*861*
Total Research grants paid – General funds	**343,039**	*235,965*

14. GRANTS PAID DURING THE YEAR (CONTINUED)

	2010 £	*2009 £*
Development and other grants paid		
Harefield Hospital	**3,972**	*38,785*
Gartnavel Hospital – Glasgow	**100,000**	*50,000*
Papworth Hospital	**14,787**	-
Northern General Hospital, Sheffield	**195,000**	-
Royal Victoria Infirmary, Newcastle	**7,506**	-
Llandough Hospital, Wales	**20,000**	-
Total Development and other grants paid	**341,265**	*88,785*
Training grants paid		
Southampton General Hospital	**37,500**	-
Birmingham Heartlands Hospital	**-**	*56,250*
Wythenshawe Hospital, Manchester	**-**	*18,750*
Royal Brompton Hospital, London	**-**	*75,000*
Total Training grants paid	**37,500**	*150,000*
Grants to Individuals	**183,679**	*209,928*
Total grants paid	**7,012,314**	*3,990,707*