CYSTIC FIBROSIS TRUST

ANNUAL REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2011

CYSTIC FIBROSIS TRUST

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TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2011

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Royal Patron
HRH Princess Alexandra KG GCVO

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

TRUSTEES

Chair
Dr James Littlewood OBE MD FRCP FRCPE DCH *(until 31 August 2011)*

Vice Chair
Allan Gormly CMG CBE # *(Chair from 1 September 2011)*

Honorary Treasurer
Rupert Pearce Gould FCA FCMA # *(appointed 18 May 2010)*

Jenny Agutter #
Giorgia Arnold #
Sir Peter Cresswell #
Katrina Dujardin #
Professor Stuart Elborn MD FRCP
Brian Henderson #
Archie Norman
Ed Owen #
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 (from 18 May 2010)*
Allan Gormly
Guy Harington
Dr James Littlewood *(until 31 August 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
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)*
Phil Smith FCCA FMAAT – Director of Finance *(from 1 April 2011)*
Sarah Guthrie – Director of Fundraising *(until 18 March 2011)*
Malcolm Moore – Director of Operations
Jo Osmond – Director of Clinical Care and Commissioning *(from 12 July 2010)*
Tamsyn Clark – Director of Marketing *(from 12 September 2011)*

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Charity registration number:
England & Wales – 1079049
Scotland – SC040196

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Research Advisory Committee

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Reader in Cellular Physiology; University of Newcastle upon Tyne
Mrs Giorgia Arnold
Trustee and 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
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Adult Physician, Wythenshawe Hospital, Manchester
Dr Daniel Peckham DM, FRCP
Adult Physician, Seacroft Hospital, Leeds
Mr Peter Sharp
Trustee and 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 *(retired 31 August 2011)*
Chairman of Trustees, Cystic Fibrosis Trust
Mrs Rosie Barnes *(retired 6 August 2010)*
Chief Executive, Cystic Fibrosis Trust
Matthew Reed *(from 6 September 2010)*
Chief Executive, Cystic Fibrosis Trust

Medical Advisory Committee

Dr Diana Bilton *(Chair)* MD FRCP
Adult Physician, Royal Brompton Hospital, London
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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, Birmingham
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 *(Retired 31 August 2011)*
Chairman, Cystic Fibrosis Trust
Joanne Osmond
Director of Clinical Care and Commissioning, Cystic Fibrosis Trust
Matthew Reed *(from 6 September 2010)*
Chief Executive, 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
Matthew Reed *(from 6 September 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 (retired 31 August 2011)
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Mrs Nikki Samsa
Parent Representative
Professor Brandon Wainwright BSc (Hons) PhD
Institute for Molecular Bioscience, University of Queensland, Australia

CF Registry Committee

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Consultant Paediatrician, Royal London Hospital
Dr Geoffrey Carroll
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Kathy Collins MSc, RGN, Dip Adv Nursing
Nursing and Quality Adviser, National Services Division, Scotland
Dr Steve Cunningham MBChB, PhD, FRCPCH
Consultant Paediatrician, Royal Hospital for Sick Children, Edinburgh
Marian Dmochowska
Parent Representative
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Paediatrician, Children's Hospital for Wales, Cardiff
Dr Caroline Elston MBBS, FRCP
Adult Physician, King's College Hospital, London
Dominic Kavanagh
Expert Patient Adviser, Cystic Fibrosis Trust
Dr Stephanie McNeil PhD
Statistician, Imperial College
Jo Osmond
Director of Clinical Care, Cystic Fibrosis Trust
Matthew Reed
Chief Executive, Cystic Fibrosis Trust
Kenny Naughton PG Dip Health & Public Leadership
South West Specialised Commissioning Group
Dr Kevin Smith MB, ChB, FFPH
Medical Advisor Yorks & Humber SCG
Sandra Tribe
Divisional Director, London Specialised Commissioning Group
Dr Sarah Walters BSc, MB, FRCP, FFPH, OBE
Patient Representative Epidemiologist, Birmingham University
Dr Martin Wildman MBChB, DTM&H Dip Evidence Based Healthcare, BSc, MSc, PhD, MRCP
Adult Physician, Northern General Hospital, Sheffield

The trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2011. 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 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 AND DEVELOPMENT

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 the people living with CF today is 34.8 (*UKCF Registry report 2009*) but life expectancy of a baby born today is between 50 and 60 (*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 advertising. Applicants are invited to submit their proposals in a specific format; all applications are reviewed by external referees before being decided on by the Research Advisory Committee.

Projects are usually funded for up to a 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 funding the programme at the desired 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 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 will 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 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. 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 encourages all to register as donors.

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 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 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.

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 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. We were assisted in the analysis 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.

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 (shared care) services.

Peer review of specialist CF Centres and Clinics
Our peer review programme for assessing services in terms of their application and ability to deliver CF specialist care in accordance with the national Standards of Care for Adults and Children with CF, 2001 continued throughout the year in co-operation with the British Thoracic Society. During the year, peer reviews were carried out at eight Specialist CF Centres and 23 CF network clinics.

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

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 March 2011, we published the UK CF Registry Annual Data Report 2009 – the third from Port CF. Port CF has now been implemented in all specialist CF Centres and 120 network clinics throughout the UK. Work continues to implement Port CF in a remaining small number of network CF clinics.

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 2009), the median predicted survival is 34.8 years. This figure represents a decrease on the previous year which revealed a median predicted survival of 38.8 years, but it must be borne in mind that there were also a higher number of deaths in 2009 (140 in 2009 versus 100 in 2008) and it may also reflect random fluctuation which can be more accurately assessed when comparing 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 and 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, requiring an extension of the number of adult specialist CF Centres over time, as people with CF continue to live longer.

Development grants
The Cystic Fibrosis Trust has continued to offer selective development grants to NHS hospitals to assist with the improvement of facilities on a shared basis. These grants have also been used to pump prime multidisciplinary professional posts when services have been found, usually through the process of Peer Review, to be severely under-resourced in a particular area. These grants are provided on the understanding that the NHS Trust will take over the responsibility for resourcing the posts funded within an agreed timeframe.

Training grants
Many of the current directors of Specialist CF Centres were trained through Fellowship awards from the Cystic Fibrosis Trust and many of the existing 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 and as a result the overall number of patients is increasing, the Cystic Fibrosis Trust continues to provide grants for training the specialist Directors and CF Consultants 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, one has chosen to work as a CF consultant in Australia 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. 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. In June 2010 one of the EPAs attended the European Cystic Fibrosis Conference in Valencia, having submitted a poster based on a Dietetic Project called 'Food for Thought'.

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 2010 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 2010 the Cystic Fibrosis hosted its annual Medical Conference themed on interventional treatments and transition from paediatric to adult care. This conference was for all those involved in the delivery of CF care, which includes all multi-disciplinary CF team members, health and social care professionals allied to the CF service and relevant academic professionals.

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.

'Ask the expert'
The Trust continued to maintain its website and its 'Ask the expert' service. Specific medical and scientific questions are forwarded to a panel of experts, who provide an appropriate and timely reply. Edited anonymous versions of these questions also appear in the CF Today magazine. This is an important area for future development.

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 284 welfare grants (2009: 255 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 common with the majority of the British economy, our income for the year fell in the year by 4.4% to £8,767,000 (2010: £9,172,000). Income from branches, groups & community and corporate donations showed the biggest falls as individuals and companies have less to give in the current climate. 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.

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 £2.72m to £2.79m whereas overall expenditure in the year dropped from £8.18m to £5.05m. This was due to the reduction in grant expenditure following lower than anticipated income over the past few years.
The core Governance costs for the year were £90,000 (£78,000 in 2010).

Although costs were reduced in other areas it was necessary to reduce the commitment to research as a result of a review that concluded that the Trust could not continue to support the planned programme at expected levels. The cash outflow has remained in line with previous years but forward commitments have been reduced. This has not been an easy process and the Trust expresses its thanks to those involved in the review both third parties and employees.

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.

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

The Board of Trustees meets quarterly to review progress and policies. Trustees serve on the Board for a period of three years that is renewable. New Trustees are appointed by the Trustees, taking into account the skills required by the Board.

The Trustees are supported by a number of committees (all members are subject to appointment by the Trustees):

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 will continue to assess risk in a constructive manner to safeguard the efficacy of the Cystic Fibrosis Trust. The board are conscious of the challenges that the Trust faces in light of the present world economic problems.

Trading
The Trust 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. Results of the subsidiary 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 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 2011 is £6,996,000 (2010: £5,710,000). However, these are being held against the deficit on the Gene Therapy Consortium restricted fund of £7,144,000 (2010: £7,515,000); thus there is a net deficit of freely available reserves as at 31 March 2011 of £148,000. Therefore as in previous years, a part of the grants committed and due within the next twelve months may need to be met out of funds generated in those future periods.

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 Consortium Restricted Fund
The Gene Therapy Consortium restricted fund shows a deficit of £ 7,144,000 at the end of the year compared to £7,515,000 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.

FUTURE PLANS

The annual Trust Development Plan as of 1st April 2011 identified the following priorities for the financial year 2011/12:

A. To stabilise the Trust financially
B. To deliver a focused plan of work for 2011/12 with ever improving impact on CF patients and carers
C. To review and define the Trust's strategy for the next 5 years.

A. The Trust did not achieve its financial income target in 2010/11 and had to adjust its objectives accordingly; this reflected the economic trend in recent years. In 2010/11 we conducted a review of the fundraising and communications function and reduced internal and external expenditure commitments accordingly. During 2011/12 we will continue to build the marketing platform of the Trust with a view to improving core income and developing a financial framework to enable the Trust to deliver on its 5 year strategy.

B. In parallel to the strategic review the Trust has reviewed its Development Plan for 2011/12 and the core areas for its activities are below:

1. Continuing to support the work of the UK CF Gene Therapy Consortium (GTC) to develop and test gene therapy for the lungs of people with CF remains the main focus of our research expenditure for 2011/12. Over the last few years the GTC has developed a potential gene therapy treatment in the lungs of people living with CF, conducted satisfactory toxicology studies in animal models, concluded a single dose pilot study in humans, and prepared a phase 2 trial protocol. This study, planned to start in 2012, will deliver 12 monthly doses of the nebulised gene therapy product or a placebo into over 100 patients in Edinburgh and London. The trial will be phased so results are expected in early 2014.

   If this Phase 2 study is successful the GTC will aim to secure a commercial partner to take the therapy into phase 3 and the clinic.

   Concerns remain about the funding of the GTC and it has applied for funding from the NIHR/MRC EME fund. In parallel the CF Trust is conducting a special fundraising campaign with the aim of securing the full costs of this programme. Without full funding the programme is vulnerable.

2. In conjunction with physicians, other health care professionals and British Thoracic Society, the Trust will review and re-launch its Peer Review programme from the autumn of 2011. The revised programme will aim to build on the success and impact of the original scheme.

3. We will further develop the CF patient registry and seek industry partnerships that are in the interests of people living with CF.

4. We will work 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.

5. We will be active partners in CF Europe, the European CF Clinical Trials Network, and the European CF Society Young Investigators Programme.

6. We will part fund a capital programme at Kings College Hospital London to improve the inadequate adult CF inpatient facilities there and are negotiating providing support for a new capital scheme at the Nottingham University Hospitals.

7. As part of our desire to build capacity for the future we will aim to part fund several clinical fellowships in CF with the MRC

8. We will build our capacity and influence to advocate with politicians and officials in Whitehall and in the devolved national administrations to champion the right level of funding, clinical intervention and support for people living with CF.

9. We will develop our marketing function and programme including the presentation of the Trust and CF, digital marketing, and a sustainable fundraising programme. This will include investing in CF Week with the aim of building on this over the next few years.

C. During 2011/12 we will review our overall strategy to ensure that the Trust's influence and resources are being deployed in the most effective way to maximise improvements to the quality and length of life for people living with CF. The new strategy will be implemented from April 2012 and will be focused on impact statements in defined areas.

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
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 6 December 2011
and signed on their behalf by:

Mr Allan Gormly
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 2011which 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 2011 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 6/12/11

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 2011

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total 2011 £'000**	*Total 2010 £'000*
INCOMING RESOURCES						
Incoming resources from generated funds						
Voluntary income	2	7,697	700	-	**8,397**	*8,764*
Activities for generating funds						
Trading and merchandising	11	221	-	-	**221**	*234*
Investment & interest income		110	39	-	**149**	*174*
Total incoming resources		8,028	739	-	**8,767**	*9,172*
RESOURCES EXPENDED						
Cost of generating funds						
Costs of generating voluntary Income		2,648	-	-	**2,648**	*2,545*
Trading and merchandising	11	140	-	-	**140**	*170*
Costs of generating funds		2,788	-	-	**2,788**	*2,715*
Charitable activities						
Research		416	(153)	-	**263**	*3,107*
Clinical Care		936	72	-	**1,008**	*1,368*
Information, advice & support		713	186	-	**899**	*912*
Governance costs		90	-	-	**90**	*78*
Total resources expended	3	4,943	105		**5,048**	*8,180*
NET INCOMING RESOURCES		3,085	634	-	**3,719**	*992*
Gain on asset disposal		3	-	-	**3**	*1*
NET INCOME FOR THE YEAR		3,088	634		**3,722**	*993*
Unrealised investment (losses)/ gains		10	(4)	(7)	**(1)**	*914*
Transfers between funds	5	41	(41)		**-**	*-*
NET MOVEMENT IN FUNDS		3,139	589	(7)	**3,721**	*1,907*
Funds brought forward		6,842	(7,046)	983	**779**	*(1,128)*
FUNDS CARRIED FORWARD	5	9,981	(6,457)	976	**4,500**	*779*

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 2011

	Notes	Consolidated Total 2011 £'000	Consolidated *Total 2010 £'000*	Charity Total 2011 £'000	Charity *Total 2010 £'000*
Fixed assets					
Tangible assets	6	**985**	*1,132*	**985**	*1,132*
Investments	7	**4,839**	*4,745*	**4,839**	*4,745*
		5,824	*5,877*	**5,824**	*5,877*
Current assets					
Debtors	8	**364**	*272*	**449**	*360*
Cash held as short term investment		**839**	*1,075*	**839**	*1,075*
Cash at bank & in hand		**3,428**	*2,136*	**3,229**	*1,966*
		4,631	*3,483*	**4,517**	*3,401*
Creditors: amounts due within one year					
Grants payable	9	**(2,402)**	*(8,204)*	**(2,402)**	*(8,204)*
Creditors and accrued charges	10	**(3,553)**	*(377)*	**(3,439)**	*(295)*
		(5,955)	*(8,581)*	**(5,841)**	*(8,499)*
Net current (liabilities)		**(1,324)**	*(5,098)*	**(1,324)**	*(5,098)*
Net assets		**4,500**	*779*	**4,500**	*779*
Represented by:					
Designated funds	5	**2,984**	*1,132*	**2,984**	*1,132*
General Reserves					
Unrestricted general funds		**6,996**	*5,710*	**6,996**	*5,710*
Restricted Reserves	5				
Deficit on restricted funds - GTC		**(7,144)**	*(7,515)*	**(7,144)**	*(7,515)*
Surplus on restricted funds - other		**688**	*469*	**688**	*469*
Endowment funds	5	**976**	*983*	**976**	*983*
		4,500	*779*	**4,500**	*779*

Approved and authorised for issue by the trustees on 6 December 2011
and signed on their behalf by:

Trustees

Mr Allan Gormly — Chair
Mr Rupert Pearce Gould — Treasurer

CYSTIC FIBROSIS TRUST
CONSOLIDATED CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2011

		2011 £'000	2010 £'000
Net cash Inflow/(outflow) from operating activities	**(Note A)**	**1,100**	*(2,325)*
Returns on investments and servicing of finance			
Investment income		**149**	*174*
Capital expenditure and financial investment			
Purchase of fixed assets		**(109)**	*(129)*
Purchase of investments		**(93)**	*(133)*
Proceeds of sales of fixed assets		**11**	*12*
		(191)	*(250)*
Management of liquid resources			
Decrease in cash held as short term investments		**239**	*473*
Increase/(Decrease) in cash	**(Note B)**	**1,297**	*(1,928)*

NOTES TO CASHFLOW STATEMENT

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

	2011 £'000	2010 £'000
Net incoming resources	**3,719**	*992*
Depreciation	**248**	*270*
Investment income	**(149)**	*(174)*
(Increase)/Decrease in debtors	**(92)**	*254*
(Decrease) in creditors	**(2,626)**	*(3,667)*
	1,100	*(2,325)*

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

	2011 £'000	2010 £'000
Net cash resources at 1 April 2010	**3,211**	*5,614*
Net increase/(Decrease) in cash at bank & in hand	**1,297**	*(1,928)*
(Decrease) from revaluation of foreign currency account	**(2)**	*(2)*
(Decrease) in short term investments	**(239)**	*(473)*
Net cash resources at 31 March 2011 (being cash at bank & in hand and cash held as short term investments)	**4,267**	*3,211*

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 £4,500,000. 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. 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.

2. VOLUNTARY INCOME

		Restricted Funds			
	Unrestricted Funds £'000	Gene Therapy Consortium £'000	Other Restricted Funds £'000	**Total 2011 £'000**	*Total 2010 £'000*
Branches, Groups & Community	4,420	79	-	**4,499**	*4,706*
Legacies	851	-	44	**895**	*965*
Individual donations	583	104	25	**712**	*604*
Corporate	421	155	-	**576**	*728*
Gift Aid	555	-	-	**555**	*516*
Regular giving	528	25	-	**553**	*627*
Trusts	195	43	225	**463**	*452*
Appeals	144	-	-	**144**	*138*
NHS National Services Scotland	-	-	-	**-**	*40*
Department of Health	-	-	-	**-**	*7*
Big Lottery Fund	-	-	-	**-**	*(19)*
Total Voluntary income	7,697	406	294	**8,397**	*8,764*

3. RESOURCES EXPENDED

	Grants £'000	Direct costs £'000	Support costs allocated £'000	**Total 2011 £'000**	*Total 2010 £'000*
Cost of generating funds					
Fundraising	-	1,971	677	**2,648**	2,545
Trading-Merchandising	-	140	-	**140**	170
Charitable activities					
Research	(153)	140	276	**263**	3,107
Clinical care	72	708	228	**1,008**	1,368
Information, advice & support	186	549	164	**899**	912
Governance	-	62	28	**90**	78
	105	3,570	1,373	**5,048**	8,180

Analysis of allocated Support Costs	Management £'000	Finance £'000	IT Support £'000	Admin & Facilities £'000	**Total 2011 £'000**
Fundraising	28	98	151	400	**677**
Research	92	20	76	88	**276**
Clinical care	28	20	76	104	**228**
Information, advice & support	18	16	76	54	**164**
Governance	18	8	-	2	**28**
	184	162	379	648	**1,373**

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

Support costs include an amount of £59,928 paid to the Trust's Auditors in respect of review work completed on grant expenditure.

Analysis of Governance Costs

	2011 £'000	*2010 £'000*
External audit fee	**15**	*19*
Trustees' travel expenses	**18**	*12*
Managing strategy & compliance	**57**	*47*
Total Governance costs	**90**	*78*

4. STAFF COSTS

Staff costs comprise the following:

	2011 £'000	2010 £'000
Salaries	2,072	1,915
Social security costs	214	201
Other pension costs	71	73
	2,357	2,189

Analysis of average staff numbers by category:

	2011 No.	2010 No.
Fundraising	31.40	28.00
Research	1.15	1.75
Clinical care	10.00	9.10
Information, advice & support	8.50	8.50
Management	2.00	2.00
Finance	3.05	3.25
IT support	2.00	2.00
Administration & facilities	10.80	11.00
Average number of employees during the year	68.90	65.60

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

	2011 No.	2010 No.
£60,001 - £70,000	1	1
£80,001 - £90,000	-	1
£90,001 - £100,000	1	1

Pension contributions to defined contribution pension schemes for these employees totalled £ 9,387 (2010 - £17,744).

No remuneration was paid to the trustees. Travel expenses of £17,744 (2010 - £12,324) were settled for three trustees (2010 – 3). One trustee received an honorarium of £1,000 for work related to their professional qualifications.

5. FUNDS

	Balance April 1 2010 £'000	Investment gains and income £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance March 31 2011** £'000
Designated funds:						
Fixed Asset Fund	*1,132*	-	-	-	(147)	**985**
Development & strategic reserve		-	-	-	1,999	**1,999**
Total Designated Funds	***1,132***				**1,852**	**2,984**
General Reserves:						
Unrestricted Funds						
Unrestricted General Fund	*5,710*	120	7,921	(4,943)	(1,811)	**6,997**
Restricted Funds						
With a deficit						
Gene Therapy Consortium *For gene therapy research*	*(7,515)*	-	393	(22)	-	**(7,144)**
Free Reserves	***(1,805)***	**120**	**8,314**	**(4,965)**	**(1,811)**	**(147)**
Total Unrestricted Funds	***(673)***	***120***	***8,314***	***(4,965)***	***41***	***2,836***
Restricted funds:						
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*	*145*	9	-	(13)	-	**141**
Joseph Levy Memorial fund *for education*	*52*	9	38	(58)	-	**41**
for transplant research	*26*	-	175	-	-	**201**
for Transplant Donor co-ordinator	*60*	-	-	-	-	**60**
Waterloo Foundation *for dietician at the Children's Hospital for Wales, Cardiff*	*30*	-	-	-	-	**30**
Various sundry Restricted funds	85	1	94	(12)	(25)	**143**
Total Other Restricted funds	**469**	**35**	**307**	**(83)**	**(41)**	**687**
Endowment funds:						
Ena Bennie Memorial fund *To fund the Gene Therapy Consortium*	*499*	(4)	-	-	-	**495**
EW Joseph fund *For community home care support*	*180*	-	-	-	-	**180**
Joseph Levy Memorial fund *For education*	*260*	(2)	-	-	-	**258**
Other Endowment funds	*44*	(1)	-	-	-	**43**
Total Endowment funds	***983***	**(7)**	**-**	**-**	**-**	**976**
TOTAL FUNDS	***779***	**148**	**8,621**	**(5,048)**	**-**	**4,500**

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 Consortium fund being investment income for the year.

b) £25,000 from restricted income to general funds being the donation from Mr & Mrs Cresswell relating to research at Cambridge on lung function to be paid from general funds in the first instance.

c) £147,000 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) The Trustees have calculated that £1,999,000 of the general funds should be retained to create a development and strategic reserve fund. The strategic plan for the Trust envisages these funds being required within five years.

Analysis of funds

	Unrestricted funds £'000	Endowment funds £'000	Gene Therapy Consortium restricted fund £'000	Other restricted funds £'000	**Total £'000**
Tangible fixed assets	985	-	-	-	**985**
Investments	3,485	976	-	378	**4,839**
Current assets	3,824	-	183	624	**4,631**
Current liabilities	1,686	-	(7,327)	(314)	**(5,955)**
	9,980	976	(7,144)	688	**4,500**

6. TANGIBLE ASSETS

Group and charity	Freehold property £'000	Furniture & fittings £'000	Computer equipment £'000	Cars £'000	Total £'000
Cost					
At 1 April 2010	948	234	965	250	2,397
Additions	-	1	46	62	109
Disposals	-	-	-	(51)	(51)
At 31 March 2011	**948**	**235**	**1,011**	**261**	**2,455**
Depreciation					
At 1 April 2010	212	191	728	134	1,265
Disposals	-	-	-	(43)	(43)
Charge for the year	17	24	153	54	248
At 31 March 2011	**229**	**215**	**881**	**145**	**1,470**
Net book value at 31 March 2011	**719**	**20**	**130**	**116**	**985**
Net book value at 31 March 2010	*736*	*43*	*237*	*116*	*1,132*

7. INVESTMENTS

Group and Charity	Unrestricted funds £'000	Restricted funds £'000	**Total 2011 £'000**	*Total 2010 £'000*
Market value as at 1 April 2010	3,384	1,361	**4,745**	*3,698*
Dividends/interest held in portfolio	89	6	**95**	*133*
Realised and unrealised investment gains/(losses) in the year	10	(11)	**(1)**	*914*
Market value as at 31 March 2011	3,483	1,356	**4,839**	*4,745*
Represented by:				
Investments held in Unit Trusts				
Equities	1,332	490	**1,822**	*1,792*
Fixed interest	1,054	486	**1,540**	*1,570*
Cash held as part of portfolio	1,097	380	**1,477**	*1,383*
	3,483	1,356	**4,839**	*4,745*
Investments held in Unit Trusts:				
Historical cost as at 31 March 2011	1,943	892	**2,835**	*2,835*
Unrealised gains at 31 March	443	84	**527**	*527*

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

8. DEBTORS

	Group 2011 £'000	*Group 2010 £'000*	Charity 2011 £'000	*Charity 2010 £'000*
Trade debtors	**45**	*20*	**-**	*-*
Amount due from subsidiary undertaking	**-**	*-*	**130**	*108*
Prepayments and accrued income	**319**	*252*	**319**	*252*
	364	*272*	**449**	*360*

9. GRANTS PAYABLE

	2011 £'000	*2010 £'000*
Grant creditor at 1 April 2010	**8,204**	*11,866*
Grants paid during the year (note 14)	**(5,907)**	*(7,012)*
Grants approved before 31 March 2011 awarded but withdrawn	**(2,096)**	*-*
Grants approved before 31 March 2011 and payable within one year	**2,201**	*3,350*
Grant creditor at 31 March 2011	**2,402**	*8,204*
Represented by		
Grants awaiting claim at 31 March 2011	**477**	*3,618*
Grants due within one year at 31 March 2011	**1,925**	*4,586*
	2,402	*8,204*

10. CREDITORS

	Group 2011 £'000	*Group 2010 £'000*	Charity 2011 £'000	*Charity 2010 £'000*
Trade creditors	**3,114**	*252*	**3,004**	*183*
Other creditors	**284**	*86*	**286**	*81*
Accruals and deferred income	**155**	*39*	**149**	*31*
	3,553	*377*	**3,439**	*295*

11. INTEREST IN SUBSIDIARY

CF Merchandising Limited is a wholly owned subsidiary of the charity, incorporated in England, and inter alia is engaged in the sale of CF branded products 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:

	Total 2011 £'000	*Total 2010 £'000*
Sales and sundry income	**221**	*234*
Cost of sales and administration	**(142)**	*(176)*
Net profit received by the charity	**79**	*58*

At 31 March 2011 CF Merchandising Limited had net assets of £2 (2010 - £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:

	2011 £'000	*2010 £'000*
Payable between two and five years	**218**	*9,966*

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

	2011 £	2010 £
Research grants paid – Restricted funds		
UK CF Gene Therapy Consortium	**4,980,174**	*5,989,369*
Newcastle University	**142,645**	*117,232*
UK CF Microbiology Consortium	**-**	*230*
Total Research grants paid – Restricted funds	**5,122,819**	*6,106,831*
Research grants paid – General funds		
Controlling infection		
University of Edinburgh	**-**	*42,791*
Queen's University, Belfast	**45,176**	*40,020*
Understanding & controlling inflammation		
Queen's University, Belfast	**47,178**	*61,515*
Newcastle University	**33,021**	*33,021*
(MRC Joint Clinical Research Training Fellowship)		
Queen's University, Belfast	**29,209**	*25,045*
University of Dundee, Tayside Institute of Child Health	**6,055**	*16,743*
Understanding & correcting the CF protein (CFTR)		
Newcastle University	**-**	*8,389*
University of Cambridge	**-**	*13,289*
University of Dundee, Tayside Institute of Child Health	**-**	*23,642*
University of Bristol	**51,648**	*77,800*
University of Cambridge	**1,604**	*588*
Clinical & other studies		
Leeds Teaching Hospitals NHS Trust	**-**	*196*
Total Research grants paid – General funds	**213,891**	*343,039*

14. GRANTS PAID DURING THE YEAR (CONTINUED)

	2011 £	*2010* *£*
Development and other grants paid		
Harefield Hospital	**33,816**	*3,972*
Gartnavel Hospital – Glasgow	**50,000**	*100,000*
Papworth Hospital	**31,446**	*14,787*
Northern General Hospital, Sheffield	**50,000**	*195,000*
St James' University Hospital	**5,810**	-
Royal Victoria Infirmary, Newcastle	**34,047**	*7,506*
Llandough Hospital, Wales	**-**	*20,000*
Total Development and other grants paid	**205,119**	*341,265*
Training grants paid		
Southampton General Hospital	**37,500**	*37,500*
Papworth Hospital	**56,250**	-
Wythenshawe Hospital, Manchester	**75,000**	-
Total Training grants paid	**168,750**	*37,500*
Grants to Individuals	**196,140**	*183,679*
Total grants paid	**5,906,719**	*7,012,314*