CYSTIC FIBROSIS TRUST

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2009

CYSTIC FIBROSIS TRUST
REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2009

CYSTIC FIBROSIS TRUST
LEGAL AND ADMINISTRATIVE INFORMATION
FOR THE YEAR ENDED 31 MARCH 2009

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CYSTIC FIBROSIS TRUST
TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2009

The trustees present their annual report and financial statements of the charity for the year ended 31 March 2009. 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.

WHO WE ARE

OUR MISSION STATEMENT

Founded in 1964, the Cystic Fibrosis Trust is the only national 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. It also 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. It is caused by a single defective gene. 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.

The defective gene that causes Cystic Fibrosis is carried by 1 person in 25 in the UK. If two carriers have a baby, the child has a 1 in 4 chance of having Cystic Fibrosis.

There are over 8,000 people in the UK with Cystic Fibrosis.

WHAT WE DO

OBJECTIVES AND ACTIVITIES FOR PUBLIC BENEFIT

The charitable objects of the Cystic Fibrosis Trust are:

- to fund medical and scientific **research** to develop a cure and to provide effective treatments for Cystic Fibrosis;
- to ensure appropriate **clinical care** for those with Cystic Fibrosis; and
- to provide **information, advice and support** and, where appropriate, financial assistance 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 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. This research has resulted in significant improvements in symptom control that have vastly increased the quality and length of life for people with Cystic Fibrosis: in 1964 this was only around 5 years, whereas a baby born today with Cystic Fibrosis can expect to live to over fifty years, even before taking into account the impact of potential new therapies that treat the basic defect and not just the symptoms caused by Cystic Fibrosis.

However, only half of those living with Cystic Fibrosis in the UK today are predicted to survive into their late thirties; more research into the understanding of mechanisms of disease and the development of improved treatments are required to enable this group to have the opportunity to

benefit from gene therapy and other treatments currently being developed that are aimed at correcting the basic defect.

Grant making policy
We aim to fund high-quality research that is ground-breaking and of imminent and/or important clinical relevance to people with Cystic Fibrosis, for which funding is not available from other sources and which is not being carried out elsewhere.

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 in accordance with good research practice and the guidelines of the Association of Medical Research Charities, of which the charity is a member.

Applications are then reviewed by the Research Advisory Committee against specific criteria, taking into account the external reviewers' comments and the charity's research policy and objectives. The Research Advisory Committee makes recommendations to the trustees for funding.

Projects are usually funded for up to three years and are monitored on an annual basis. Annual and final reports are required for each research grant awarded. Funding can be withdrawn at any time although it is normally continued subject to the research fulfilling pre-agreed criteria and resources continuing to be available.

Applications for Studentships are invited from experienced researchers wishing to supervise a student to carry out research relevant to Cystic Fibrosis leading to a doctoral qualification.

Small grants are also given to researchers and health professionals for travel abroad to scientific and medical meetings and symposia relevant to Cystic Fibrosis.

In order to gain maximum value from the research it funds, the Cystic Fibrosis Trust is keen to leverage the funds committed to research through joint funding with other organisations, or by taking advantage of other specific funding opportunities when they arise.

For example, the three-year programme of research carried out by the UK CF Microbiology Consortium that was completed during the year was substantially funded by the Big Lottery Fund research grants scheme.

The Cystic Fibrosis Trust is also funding 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.

The first award was made in June 2008 and the decision has been taken to repeat this scheme annually for the next two years in order to increase the pool of clinical researchers in Cystic Fibrosis.

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. Our commitment to and compliance with these policies was confirmed by receiving a Certificate of Best Practice in Medical & Health Research Peer Review from the AMRC after its last audit of peer review practice among its member charities in 2006.

How our research grant programmes delivered public benefit
Overall, the benefits arising from the funds spent on research are the development of new therapies; greater understanding both of the mechanisms of specific disease and of the basic defect in general, that will contribute to the development of therapies and inform clinical guidelines and practice; the dissemination of research findings; the development of new researchers in Cystic Fibrosis; all of which will contribute to improving the length and quality of life for people with Cystic Fibrosis.

Review of achievements and performance
The nature of research is that specific achievements may be hard to identify on an annual basis. Some research is directed towards a specific tangible outcome such as the development of a new therapy, whereas other research contributes to the improvement of knowledge both in the general understanding of the condition as well in specific areas of disease that arise from the condition. Even when developing a specific therapy, a positive outcome may not be apparent for many years and annual achievements can only be measured in terms of encouraging progress towards the ultimate objective. In the case of more general research, projects funded by the charity may provide crucial knowledge that leads to further research in the future from which a therapy is subsequently developed, although this may only be identified retrospectively.

Research currently funded by the Cystic Fibrosis Trust falls into two major categories:

Gene Therapy
We currently spend around £3.5m each year on a medium-term 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 in the foreseeable future.

To achieve this, we have brought together a consortium of three centres of excellence in gene therapy research for CF based at Imperial College London, Oxford University and Edinburgh University, which now work collaboratively as the **UK CF Gene Therapy Consortium**.

Progress made by the UK CF Gene Therapy Consortium over the past seven years has been impressive. It has now 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. If successful, this phase I study will lead to a phase II multi-dose clinical trial in 100 patients over twelve months beginning in 2011.

The amount spent on the programme has increased significantly over the past three years as, in preparation for the phase I and phase II trials, some £9m of extra funds have been required to pay for the production and purchase of the gene transfer agent and the DNA construct that together comprise the gene therapy product.

In addition, the UK CF Gene Therapy Consortium is already considering products for a wave 2 programme, in recognition of the fact that development of a therapy that is at the cutting-edge of science and medical practice will require ongoing refinement over many years as scientific and medical knowledge progresses.

In total, the Cystic Fibrosis Trust has raised and committed nearly £35m to the gene therapy research programme since 2001. This is the first time that so much time, money and effort has been put into research to correct the basic defect, rather than controlling the symptoms of Cystic Fibrosis. If successful, the prognosis for people with Cystic Fibrosis will be significantly improved, increasing the length and quality of life and reducing the daily burden of treatment.

Other Medical and Scientific Research
Although we believe that gene therapy will provide an effective treatment for Cystic Fibrosis, we are committed to funding research into improving the wellbeing of people with Cystic Fibrosis, as well as funding basic research into understanding the basic defect in the *cystic fibrosis transmembrane conductance regulator* (CFTR), the faulty protein produced by the defective CF gene. We therefore continue to fund research into alternative approaches to treatment and improvements in symptom control, recognising that Cystic Fibrosis affects other organs besides the lungs and that new complications are arising as people with Cystic Fibrosis live longer.

We are also funding research into potential drug therapies that will correct the basic defect in CFTR, as well as basic research that will add to our understanding and knowledge of the condition.

The three year programme of research under the umbrella of the **UK CF Microbiology Consortium**, which was funded substantially by the Big Lottery Fund, came to an end during the year.

Led by Professor John Govan at the University of Edinburgh, the research – with the overall title of *''Superbugs' and other life threatening lung infection in Cystic Fibrosis'* – addressed several key aspects of the control of infection in people with Cystic Fibrosis. These included the faster identification of specific strains of pathogens; gaining a better understanding of factors that cause virulence and transmissibility; and identifying new approaches to using and developing novel antibiotics for CF lung infections.

The research was carried out by four PhD students at Belfast, Cardiff, Edinburgh and Liverpool Universities, plus a post doctoral researcher at Edinburgh University, who was also responsible for co-ordinating the programme.

Achievements from the research include a novel assay for *Burkholderia cepacia* complex along with the refinement and further development of assays for both *B. cepacia* and *Pseudomonas aeruginosa.* Research into disinfectants identified those which are unsuitable for use in controlling infection, as well as which of the bacteria common in CF are very resistant to commonly used disinfectants.

In addition, further understanding was gained of the mechanisms that cause virulence and inflammation in *Burkholderia cepacia* complex; this knowledge will provide new avenues for further research and the development of therapeutic approaches.

Finally, 5 young scientists were introduced to Cystic Fibrosis research, three of whom are continuing to research into Cystic Fibrosis microbiology.

In response to the difficulty in obtaining suitable lungs for transplant, we are also funding a research project into **increasing the availability of donor organs**. A three-year grant worth £464k was awarded in February 2008 to a group of researchers at Newcastle University to assess methods of transforming donor lungs that are currently considered unusable, into lungs suitable for transplant, whilst ensuring that excellent outcomes are maintained post transplant.

Other research currently funded by the Cystic Fibrosis Trust includes projects investigating: pharmacological approaches both to protein repair and to bypassing the loss of CFTR function; the early detection of lung disease in children; understanding and controlling inflammation, infections and mucus in the Cystic Fibrosis lung; as well as improving the basic understanding of various aspects of how CFTR works. In addition, a grant was awarded to contribute to the UK arm of an international study into the prevalence and impact of depression and anxiety in people with Cystic Fibrosis and their caregivers.

CLINICAL CARE

The Cystic Fibrosis Trust continues to campaign for the appropriate provision and funding of specialist clinical care for people with Cystic Fibrosis throughout the UK to government, the Department of Health, the devolved administrations, those responsible for commissioning care services, and any other relevant bodies. In addition we continue to draw attention to geographical differences in the availability of drugs and access to care along with discrepancies in funding and staffing at specialist centres throughout the UK.

How our work on clinical care delivered public benefit

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 a specialist CF Consultant and multidisciplinary team of specialist 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.

Review of performance and achievements
The charity's resources were directed in the following major areas:

Commissioning CF care
Following the major submission made to the Review of Commissioning Arrangements for Specialised Services in England instigated by the then Minister of State for Health, Lord Warner in 2005, we were pleased to see that most of our suggestions were included in the final report published by the Department of Health (*Review of Commissioning Arrangements for Specialised Services – May 2006)*. We are now monitoring the implementation of these recommendations and working with the Specialised Commissioning Groups within the Strategic Health Authorities in England to ensure that Cystic Fibrosis is on their early agenda for implementation of the new commissioning arrangements.

Development of 'Payment by Results' to fund CF care
The Department of Health has recognised that chronic, long-term, specialised conditions such as Cystic Fibrosis do not fit easily into the general system of payment by results used by the National Health Service in England, which funds each episode of care received by the patient. As a result of our ongoing discussions with the Department of Health, Cystic Fibrosis has been designated as a 'development site' to develop and implement a form of payment by results for specialised conditions based on an annual tariff that varies according to the treatment required at several defined levels of severity of the condition.

We recruited a Clinical Care and Commissioning Manager who has experience of running a CF Centre in a large NHS Trust to drive and expedite this project. Significant progress was made during the year in the two main aims of this project:

i) undertaking a detailed patient level activity and costing analysis over a 12 month period taking into account all direct, indirect and corporate costs of providing care for patients with Cystic Fibrosis;
ii) testing a proposed system of categorisation (banding of patients according to disease severity) against the patient level activity and costing data collected in i).

Data was collected by 10 pilot sites covering over 1300 patients and an interim report was submitted to the Department of Health in March 2009. Initial findings are that the proposed funding model has significant strengths; further work is now required to refine the costing taking account of various specific medical complications of Cystic Fibrosis as well as different models of delivering care.

This work was described by the Department of Health as being of a *'world-class nature'*. We anticipate that, if implemented successfully in England, similar methods of commissioning and payment for specialised services will be adopted in the devolved administrations in the UK.

Peer review of specialist CF Centres and large clinics
Peer review is a tool for assisting CF Centres and network clinics to develop their services and thereby improve clinical outcomes. It provides an opportunity for a small team of clinicians and allied health professionals from a similar unit, plus a patient or parent and a representative of the Cystic Fibrosis Trust, to review the service provided by a specialist CF Centre or network clinic and identify both areas of good practice, and areas that need further resources or re-evaluation to improve practice. The resultant report is sent to the Centre Director, the Chief Executive of the NHS Trust, and the Specialist Commissioners for the region.

During the year the programme was extended to cover the review of specialist CF Centres and their associated networks, carried out at the same time over a period of a week or more. Peer reviews were carried out at 16 specialist centres and large clinics along with a further 13 network clinics associated with 2 of the specialist centres.

The programme of peer review continues to be highly successful at significantly increasing resources at specialist CF Centres and spreading best practice, thereby improving the quality of care provided to people with Cystic Fibrosis. Peer reviews are very demanding on senior time, both within the charity

and the specialist CF teams who provide the peer reviewers – a demand that will increase as we continue to extend the programme to the larger paediatric care networks. A 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.

However, due to the success of the programme, we will continue to give it a high priority and peer reviews are planned at the rate of at least one specialist CF Centre or complete network a month for at least six months ahead.

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

In May 2009 the CF Registry published its Annual Data Report 2007 – the first from the new web-based technology of Port CF now implemented in all 50 specialist CF Centres and more than 60 network clinics throughout the UK.

The CF Registry 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. From this, best practice can be identified and shared between care centres.

A highlight from the Annual Data Report 2007 is that the median predicted survival for 2007 is 35.2 years. This is the first time that this figure has been calculated from the CF Registry data for the UK, and represents a significant improvement over the previously quoted figure of 31 years.

As well as improving clinical outcomes through regular local and national audit, the CF Registry is also providing 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.

The CF Registry will also be invaluable as a research tool, the more so since it will be possible to compare data with that collected by CF Registries in the US and Europe.

Development grants
The Cystic Fibrosis Trust continues to give 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 five trainees who have completed the year's training under this scheme, four 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 that are produced with the assistance of experts in the relevant area. Most of these, along with 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 helplines are staffed by full-time employees and we give modest grants to those in need for specific purposes and at times of crisis.

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 parents and patients have all the information they need to understand the condition in all its manifestations, as well as the level of care they should expect to receive. In this way all those affected by Cystic Fibrosis are empowered to make fully informed decisions about their lives.

Review of performance and achievements

Publications and factsheets

Our publications and factsheets continue to be widely used in the CF Community. They cover many issues, such as new diagnosis, healthy eating, housing, genetics and Cystic Fibrosis related diabetes. Most are also available on the Cystic Fibrosis Trust website – www.cftrust.org.uk – which contains much information about Cystic Fibrosis. Publications and factsheets are produced and updated as required.

Consensus documents

The Cystic Fibrosis Trust has produced, and regularly updates, a number of consensus 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.

'Antibiotic treatment for Cystic Fibrosis – third edition May 2009' was finalised during the year by the Antibiotics Working Group and published shortly after the year end. The Standards of Care Working Group continues to work on revising 'Guidelines for the care of children and adults with Cystic Fibrosis in the UK - 2001', which will be finalised during 2009/10.

In addition, a working group of CF Consultant microbiologists and other relevant experts was set up to draft a new consensus document covering standards and guidelines for the processing of microbiological samples in Cystic Fibrosis.

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.

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 future plans and activities by understanding their concerns. The 2009 meeting was held in Birmingham in May and was well attended.

The annual one-day Medical Conference, whose purpose is to update the wider CF professional community on the latest issues in CF care, took place in September 2008 in Manchester. This conference continues to be well supported and well received by the specialist CF teams.

Helplines
The national telephone helplines continue to be an important resource for those with concerns about Cystic Fibrosis. The helplines take over 3,000 calls in a year and make almost as many, following up and dealing with the questions asked and returning calls left on the answerphones. 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 benefits and how to apply for them, particularly in respect of the Disability Living Allowance.

'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.

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. 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 also 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.

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 early in 2010 and, all being well, will lead to a twelve month multi-dose phase II clinical trial commencing 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 2008 as well as continuing to implement the registry in the remaining shared-care and other small clinics;
- continuation and development of the project with the Department of Health to develop an 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 RAISED AND SPENT FUNDS

Income
As a result of the economic situation our income for the year fell to £9,274,000 (2008: £11,530,000). Nearly all categories of income showed a decrease compared to prior year (see note 2 to the accounts) with only Legacy income showing a significant increase, albeit from a low base. However the decrease compared to prior year is exaggerated by the grant received in the prior year from the Department of Health for the gene therapy research programme (£962,000).

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 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, given the levels of income achieved over the past few years, the cost of generating income is appropriate for the charity.

Expenditure
Expenditure in the year rose to £10,301,000 (from £9,681,000 in 2008). Some 50% of this was spent on research (£5,278,000), 85% of which (£4,503,000) was committed to the gene therapy research programme. The increase in expenditure this year arises from an increase in funding other research (largely the transplant research project at Newcastle University), and an increase in the cost of generating funds.

The Cost of generating funds rose by some £200k (8%) compared to the prior year. This arises mainly from the increased direct costs of fundraising events. Expenditure on Clinical Care increased in the current year in line with the activities outlined above.

HOW WE ARE GOVERNED

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 a person 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. Each new Trustee is given appropriate induction and training relevant to their responsibilities.

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 on a six-monthly basis and regularly reviews the investment policy and the appointment of the Investment Manager. The members of the Finance and Investment Committee are appointed by the Trustees.

The **Nomination and Management 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 committee comprises at least three trustees, including the Chairman, and meets at least twice a year.

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 for a period of four years, renewable by invitation of 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 for a period of four years, renewable by invitation of 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 Chairman is Professor Stuart Elborn (a Trustee) and 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.

Other expert medical and scientific committees and advisory groups are appointed and convened as required and report to the Trustees through the Research and Medical Advisory Committees.

Executive Management
Responsibility for strategy, planning and the day-to-day management of 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 by the Trustees 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. Means of minimising and mitigating risk have been implemented. The charity's internal controls have been reviewed. The Trustees seek to ensure that all internal controls, and in particular financial controls, comply in all respects with the guidelines issued by the Charity Commission.

In keeping with many charities of a similar size, the main risk for both the charity and its trading subsidiary has been identified as the inevitable dependence on a small number of key employees. The Trustees and Executive Management continually monitor this to ensure that appropriate professional staff are in place and that key tasks are shared and delegated appropriately.

In addition, the potential impact on fundraising of an epidemic of swine flu (or similar infectious condition) is considered to be a high risk for the charity. Over 50% of the charity's income is raised at community events that usually require a number of people to congregate in one place. A recommendation by government to avoid public events where there is close contact with other people is likely to impact severely on that source of income. This eventuality is largely outside the control of the charity and in order to mitigate this potential loss, the charity continues to research other methods of income generation.

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

Investment policy and performance
The Trustees have the power to invest in such stocks, shares, investments and property in any part of the world as they see fit. The Trustees have engaged Schroder & Co Ltd as investment managers. During the year the Trustees continued to follow a total return policy, whilst having regard to a fair balance between income and capital growth, and continued to follow a medium risk investment strategy. Performance is monitored against a variety of indices and was considered satisfactory for the year ended 31 March 2009.

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 £236,000 (2008: £205,000) and taxable profit was £32,000 (2008: £39,000). 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 for the foreseeable future.

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 £5,671,000 (2008: £3,608,000). However, these are being held against the deficit on the Gene Therapy Consortium restricted fund of £9,479,000 (2008: £5,725,000); 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. The reserves policy will be reviewed annually taking into account current forecasts of cash flows and income and expenditure budgets for the coming year.

Gene Therapy Consortium Restricted Fund
The Gene Therapy Consortium restricted fund shows a deficit of £9,479,000 at the end of the year compared to £5,725,000 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.

In view of the importance of the Gene Therapy Consortium to the charity's strategic plan over the coming years, the Trustees have also agreed, if necessary and where sufficient funds exist, to make funds available in the future from general funds to meet the costs of the gene therapy programme as they arise.

STATEMENT OF TRUSTEES' RESPONSIBILITIES
The Directors, as Trustees, are responsible for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the incoming resources and the application of resources of the charity during the year, and of the state of affairs as at the end of the financial year. In preparing those financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements 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 accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 1985 and the Charities Accounts (Scotland)

Regulations 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.

The trustees' are responsible for the maintenance and integrity of the corporate and financial information included on the charity's website.

So far as each of the Trustees at the date of this report is aware, there is no relevant audit information of which the Charity's auditors are unaware. Each Trustee has taken all the steps that he/she ought to have taken as a Trustee in order to make himself/herself aware of any relevant audit information and to establish that the charity's auditors are aware of that information.

Auditors
Horwath Clark Whitehill LLP have expressed their willingness to continue in office as auditors and a resolution proposing their reappointment will be submitted to the forthcoming Annual General Meeting.

This report was approved by the Trustees on 6 October 2009
and signed on their behalf by:

Dr JM Littlewood
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 2009 set out on 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 Section 235 of the Companies Act 1985 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 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) are set out in the Statement of Trustees' Responsibilities.

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 the Companies Act 1985 and comply with the requirements of regulation 8 of the Charities Accounts (Scotland) Regulations 2006. We also report to you if in our opinion the information given in the Trustees' Report is consistent with the financial statements.
In addition we report to you if, in our opinion, the charitable company has not kept proper accounting records, if we have not received all the information and explanations we require for our audit or if information specified by law regarding trustees' remuneration and other transactions with the charity is not disclosed.

We read the Trustees' Report and consider the implications for our report if we become aware of any apparent misstatements within it. Our responsibilities do not extend to other information.

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, in accordance with United Kingdom Generally Accepted Accounting Practice, of the state of the affairs of the charitable company and of the group as at 31 March 2009 and of the group's incoming resources and application of resources, including the group's income and expenditure, for the year then ended;
- the financial statements have been prepared in accordance with the Companies Act 1985 and comply with the requirements of regulation 8 of the Charities Accounts (Scotland) Regulations 2006; and
- the information given in the Trustees Report is consistent with the financial statements.

Horwath Clark Whitehill LLP
Chartered Accountants and Registered Auditors
14 October 2009

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 2009

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total 2009 £'000**	*Total 2008 £'000*
INCOMING RESOURCES						
Incoming resources from generated funds						
Voluntary income	2	7,574	1,107	-	**8,681**	*10,905*
Activities for generating funds						
Trading and merchandising		236	-	-	**236**	*205*
Investment & interest income		306	51	-	**357**	*420*
Total incoming resources		8,116	1,158	-	**9,274**	*11,530*
RESOURCES EXPENDED						
Cost of generating funds						
Costs of generating voluntary income		2,549	-	-	**2,549**	*2,385*
Trading and merchandising		193	-	-	**193**	*161*
Costs of generating funds		2,742	-	-	**2,742**	*2,546*
Charitable activities						
Research		775	4,503	-	**5,278**	*4,982*
Clinical Care		1,116	25	-	**1,141**	*1,121*
Information, advice & support		950	123	-	**1,073**	*957*
Governance costs		67	-	-	**67**	*75*
Total resources expended	3	5,650	4,651	-	**10,301**	*9,681*
NET (OUTGOING)/ INCOMING RESOURCES		2,466	(3,493)	-	**(1,027)**	*1,849*
Realised Investment gains		11	-	-	**11**	-
Gain on asset disposal		1	-	-	**1**	*11*
NET (EXPENDITURE) /INCOME FOR THE YEAR		2,478	(3,493)	-	**(1,015)**	*1,860*
Unrealised investment (losses)		(439)	(5)	(99)	**(543)**	*(361)*
Transfers between funds	5	119	(119)	-	**-**	-
NET MOVEMENT IN FUNDS		2,158	(3,617)	(99)	**(1,558)**	*1,499*
Funds brought forward		4,816	(5,306)	920	**430**	*(1,069)*
FUNDS CARRIED FORWARD	5	6,974	(8,923)	821	**(1,128)**	*430*

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 2009

	Notes	Consolidated Total 2009 £'000	Consolidated *Total 2008 £'000*	Charity Total 2009 £'000	Charity *Total 2008 £'000*
Fixed assets					
Tangible assets	6	**1,282**	*1,145*	**1,282**	*1,145*
Investments	7	**3,698**	*4,071*	**3,698**	*4,071*
		4,980	*5,216*	**4,980**	*5,216*
Current assets					
Debtors	8	**526**	*964*	**585**	*989*
Cash held as short term investment		**1,548**	*1,218*	**1,548**	*1,218*
Cash at bank & in hand		**4,066**	*3,849*	**3,889**	*3,742*
		6,140	*6,031*	**6,022**	*5,949*
Creditors: amounts due within one year					
Grants payable	9	**(11,866)**	*(10,502)*	**(11,866)**	*(10,502)*
Creditors and accrued charges	10	**(382)**	*(315)*	**(264)**	*(233)*
		(12,248)	*(10,817)*	**(12,130)**	*(10,735)*
Net current (liabilities)		**(6,108)**	*(4,786)*	**(6,108)**	*(4,786)*
Net (liabilities)/assets		**(1,128)**	*430*	**(1,128)**	*430*
Represented by:					
Endowment funds	5	**821**	*920*	**821**	*920*
Restricted funds	5				
Gene Therapy Consortium		**(9,479)**	*(5,725)*	**(9,479)**	*(5,725)*
Other Restricted funds		**556**	*419*	**556**	*419*
Unrestricted funds	5				
General fund		**5,671**	*3,608*	**5,671**	*3,608*
Designated funds		**1,303**	*1,208*	**1,303**	*1,208*
	1	**(1,128)**	*430*	**(1,128)**	*430*

Approved and authorised for issue by the trustees on 6 October 2009 and signed on their behalf by:

Dr JM Littlewood
AM Halsey
} Trustees

CYSTIC FIBROSIS TRUST
CONSOLIDATED CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2009

	2009 £'000	*2008* *£'000*
Net cash inflow from operating activities	**712**	*246*
Returns on investments and servicing of finance		
Investment income	**357**	*420*
	357	*420*
Capital expenditure and financial investment		
Purchase of fixed assets	**(381)**	*(248)*
Purchase of investments	**(170)**	*(293)*
Proceeds of sales of fixed assets	**18**	*16*
	(533)	*(525)*
Management of liquid resources		
(Increase)/decrease in cash held as short term investments	**(330)**	*390*
Increase in cash	**206**	*531*

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

	2009 £'000	*2008* *£'000*
Net (outgoing)/incoming resources	**(1,027)**	*1,849*
Depreciation	**227**	*194*
Investment income	**(357)**	*(420)*
Decrease/(increase) in debtors	**438**	*(251)*
Increase/(decrease) in creditors	**1,431**	*(1,126)*
	712	*246*

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

	2009 £'000	*2008* *£'000*
Net cash resources at 1 April 2008	**5,067**	*4,926*
Net increase in cash at bank & in hand	**206**	*531*
Increase arising from revaluation of foreign currency account	**11**	-
Increase/(decrease) in short term investments	**330**	*(390)*
Net cash resources at 31 March 2009 (being cash at bank & in hand and cash held as short term investments)	**5,614**	*5,067*

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 1985.

At 31st March the charity had a deficit on funds of £1,128,000. 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. 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 230 of Companies Act 1985.

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.

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 2009 £'000**	*Total 2008 £'000*
Branches, Groups & Community	4,377	254	222	**4,853**	*6,109*
Individual donations	651	205	-	**856**	*957*
Corporate	741	37	-	**778**	*975*
Regular giving	602	-	-	**602**	*765*
Trusts	197	37	245	**479**	*438*
Legacies	484	-	-	**484**	*283*
Gift Aid	388	-	-	**388**	*-*
Appeals	94	-	-	**94**	*191*
Big Lottery Fund	-	-	87	**87**	*225*
NHS National Services Scotland	40	-	-	**40**	*-*
Department of Health	-	-	20	**20**	*962*
Total Voluntary income	7,574	533	574	**8,681**	*10,905*

3. RESOURCES EXPENDED

	Grants £'000	Direct costs £'000	Support costs allocated £'000	**Total 2009 £'000**	*Total 2008 £'000*
Cost of generating funds					
Fundraising	-	1,863	686	**2,549**	*2,385*
Trading-Merchandising	-	193	-	**193**	*161*
Charitable activities					
Research	4,998	82	198	**5,278**	*4,982*
Clinical care	150	709	282	**1,141**	*1,121*
Information, advice & support	206	717	150	**1,073**	*957*
Governance		39	28	**67**	*75*
	5,354	3,603	1,344	**10,301**	*9,681*

Analysis of allocated Support Costs	Management £'000	Finance £'000	IT Support £'000	Admin & Facilities £'000	**Total 2009 £'000**
Fundraising	26	119	103	438	**686**
Research	26	25	51	96	**198**
Clinical care	86	25	51	120	**282**
Information, advice & support	17	20	51	62	**150**
Governance	17	10	-	1	**28**
	172	199	256	717	**1,344**

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

Analysis of Governance Costs

	2009 £'000	*2008 £'000*
External audit fee	**18**	*18*
Trustees' travel expenses	**10**	*13*
Managing strategy & compliance	**39**	*44*
Total Governance costs	**67**	*75*

4. STAFF COSTS

Staff costs comprise the following:

	2009	*2008*
	£'000	*£'000*
Salaries	**1,845**	*1,758*
Social security costs	**190**	*183*
Other pension costs	**61**	*56*
	2,096	*1,997*

Analysis of average staff numbers by category:

	2009	*2008*
	No.	*No.*
Fundraising	**28.40**	*27.50*
Research	**1.75**	*2.67*
Clinical care	**8.00**	*4.25*
Information, advice & support	**8.00**	*8.50*
Management	**2.00**	*2.33*
Finance	**2.25**	*3.00*
IT support	**2.00**	*2.00*
Administration & facilities	**10.60**	*10.75*
Average number of employees during the year	**63.00**	*61.00*

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

	2009	*2008*
	No.	*No.*
£60,001 - £70,000	**1**	*1*
£70,001 - £80,000	**-**	*1*
£80,001 - £90,000	**1**	*1*
£90,001 - £100,000	**1**	-

Pension contributions to defined contribution pension schemes for these employees totalled £17,744 (2008 - £16,765).

No remuneration was paid to the trustees. Travel expenses of £9,627 (2008 - £13,393) were settled for three trustees (2008 – two).

5. FUNDS

	Balance April 1 2009 £'000	Investment (losses) and income £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance March 31 2009 £'000**
Endowment funds:						
Ena Bennie Memorial fund *To fund the Gene Therapy Consortium*	*471*	(63)	-	-	-	**408**
EW Joseph fund *For community home care support*	*164*	(8)	-	-	-	**156**
Joseph Levy Memorial fund *For education*	*246*	(18)	-	-	-	**228**
Other Endowment funds	*39*	(10)	-	-	-	**29**
Total Endowment funds	*920*	**(99)**	**-**	**-**	**-**	**821**
Restricted funds:						
Gene Therapy Consortium *For gene therapy research*	*(5,725)*	-	533	(4,311)	24	**(9,479)**
Big Lottery fund *for UK CF Microbiology Consortium*	*(111)*	-	87	(2)	24	**(2)**
Department of Health *for information for parents*	-	-	20	(20)	-	**-**
Ena Bennie Memorial fund *to fund the Gene Therapy Consortium*	*64*	24	-	-	(24)	**64**
EW Joseph fund *for community home care support*	*127*	9	-	(5)	-	**131**
Joseph Levy Memorial fund *for education*	*37*	11	40	(49)	-	**39**
for transplant research	*150*	-	150	(153)	(133)	**14**
for Transplant Donor co-ordinator	*59*	-	50	(39)	(10)	**60**
for Sheffield Adult CF Centre at Northern General Hospital	*-*	-	145	-	-	**145**
Various sundry Restricted funds	*93*	2	82	(72)	-	**105**
Sub total Other Restricted funds	*419*	46	574	(340)	(143)	**556**
Unrestricted funds:						
General funds	*3,608*	(121)	7,810	(5,650)	24	**5,671**
Designated funds:						
Fixed asset fund	*1,145*	-	-	-	137	**1,282**
Grants fund	*63*	-	-	-	(42)	**21**
Sub total Designated funds	*1,208*	-	-	-	95	**1,303**
Total funds	*430*	(174)	8,917	(10,301)	-	**(1,128)**

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) £24,000 from the Ena Bennie Memorial fund to the Gene Therapy Consortium fund being interest income for the year.

c) £137,000 from General funds to the designated Fixed asset fund to reflect the higher book value of the fixed assets at the end of the year.

d) £42,000 from the designated Grants fund to General funds leaving £21,000 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) £119,000 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	1,282	-	-	-	**1,282**
Investments	2,547	821	-	330	**3,698**
Current assets	4,100	-	1,129	911	**6,140**
Current liabilities	(955)	-	(10,608)	(685)	**(12,248)**
	6,974	821	(9,479)	556	**(1,128)**

6. TANGIBLE ASSETS

Group and charity	Freehold property £'000	Furniture & fittings £'000	Computer equipment £'000	Cars £'000	Total £'000
Cost					
At 1 April 2008	948	193	629	256	2,026
Additions	-	40	287	54	381
Disposals	-	-	(50)	(51)	(101)
At 31 March 2009	**948**	**233**	**866**	**259**	**2,306**
Depreciation					
At 1 April 2008	178	135	477	91	881
Disposals	-	-	(50)	(34)	(84)
Charge for the year	17	29	126	55	227
At 31 March 2009	**195**	**164**	**553**	**112**	**1,024**
Net book value at 31 March 2009	**753**	**69**	**313**	**147**	**1,282**
Net book value at 31 March 2008	*770*	*58*	*152*	*165*	*1,145*

7. INVESTMENTS

Group and Charity	Unrestricted funds £'000	Restricted funds £'000	**Total 2009 £'000**	*Total 2008 £'000*
Market value as at 1 April 2008	2,867	1,204	**4,071**	*4,139*
Additions at cost	-	-	**-**	*66*
Dividends/interest held in portfolio	119	51	**170**	*227*
Realised and unrealised investment (losses) in the year	(439)	(104)	**(543)**	*(361)*
Market value as at 31 March 2009	2,547	1,151	**3,698**	*4,071*
Represented by:				
Investments held in Unit Trusts				
Equities	1,349	329	**1,678**	*2,017*
Fixed interest	696	449	**1,145**	*1,174*
Cash held as part of portfolio	502	373	**875**	*880*
	2,547	1,151	**3,698**	*4,071*
Investments held in Unit Trusts:				
Historical cost as at 31 March 2009	2,356	855	**3,211**	*3,036*
Unrealised (losses)/gains at 31 March	(311)	(77)	**(388)**	*155*

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

8. DEBTORS

	Group 2009 £'000	*Group 2008 £'000*	Charity 2009 £'000	*Charity 2008 £'000*
Trade debtors	**21**	*13*	**-**	*-*
Amount due from subsidiary undertaking	**-**	*-*	**80**	*39*
Prepayments and accrued income	**505**	*784*	**505**	*784*
Sundry debtors	**-**	*41*	**-**	*41*
Taxation recoverable	**-**	*1*	**-**	*-*
Interest free loan	**-**	*125*	**-**	*125*
	526	*964*	**585**	*989*

9. GRANTS PAYABLE

	2009 £'000	*2008 £'000*
Grant creditor at 1 April 2008	**10,502**	*11,610*
Grants paid during the year (note 14)	**(3,990)**	*(6,222)*
Grants approved before 31 March 2009 and payable within one year	**5,354**	*5,114*
Grant creditor at 31 March 2009	**11,866**	*10,502*
Represented by		
Grants awaiting claim at 31 March 2009	**7,000**	*4,843*
Grants due within one year at 31 March 2009	**4,866**	*5,659*
	11,866	*10,502*

10. CREDITORS

	Group 2009 £'000	*Group 2008 £'000*	Charity 2009 £'000	*Charity 2008 £'000*
Trade creditors	**248**	*193*	**147**	*114*
Other creditors	**90**	*59*	**76**	*59*
Accruals and deferred income	**44**	*63*	**41**	*60*
	382	*315*	**264**	*233*

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 2009 £'000**	*Total 2008 £'000*
Sales and sundry income	236	**236**	*205*
Cost of sales and administration	(204)	**(204)**	*(166)*
Net profit received by the charity	32	**32**	*39*

At 31 March 2009 CF Merchandising Limited had net assets of £2 (2008 - £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:

	2009 £'000	*2008 £'000*
Payable between two and five years	**1,569**	*6,079*

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.

14. GRANTS PAID DURING THE YEAR

	2009 £	*2008 £*
Research grants paid – Restricted funds		
UK CF Gene Therapy Consortium	**3,117,124**	*5,450,255*
UK CF Microbiology Consortium	**149,281**	*211,268*
Total Research grants paid – Restricted funds	**3,266,405**	*5,661,523*
Research grants paid – General funds		
Controlling infection		
Queen's University, Belfast	**15,961**	*15,808*
University of Edinburgh	**25,566**	*58,822*
University of Edinburgh	**37,635**	*35,659*
University of Warwick	**22,378**	*31,568*
Queen's University, Belfast	**-**	*12,158*
Understanding & controlling inflammation		
Queen's University, Belfast	**2,278**	-
University of Portsmouth	**4,037**	*19,081*
University of Portsmouth	**-**	*3,070*
UK CF Database		
University of Dundee, Tayside Institute of Child Health	**-**	*6,429*
Understanding & correcting the CF protein (CFTR)		
Newcastle University	**29,063**	*6,193*
University of Bristol	**22,900**	*47,581*
University of Cambridge	**1,062**	*1,859*
University of Dundee, Tayside Institute of Child Health	**44,360**	*33,045*
University of Bristol	**13,515**	-
University of Cambridge	**-**	*1,712*
University of Oxford, John Radcliffe Hospital	**-**	*79*
Clinical & other studies		
Institute of Child Health, University College, London	**16,349**	*43,444*
Newcastle University	**39,624**	-
Research models	**861**	-
University of Liverpool	**-**	*7,941*
Total Research grants paid – General funds	**275,589**	*324,449*

14. GRANTS PAID DURING THE YEAR (CONTINUED)

	2009	*2008*
	£	*£*
Development and other grants paid		
Harefield Hospital	**38,785**	*10,699*
Gartnavel Hospital – Glasgow	**50,000**	*-*
Bristol Royal Infirmary	**-**	*3,000*
British Society for Gene Therapy	**-**	*5,000*
European Cystic Fibrosis Society	**-**	*3,487*
Llandough Hospital, Wales	**-**	*3,900*
Various re Patient Care Plus Programme	**-**	*8,718*
Total Development and other grants paid	**88,785**	*34,804*
Training grants paid		
Birmingham Heartlands Hospital	**56,250**	*18,750*
Wythenshawe Hospital, Manchester	**18,750**	*75,000*
Royal Brompton Hospital, London	**75,000**	*-*
Total Training grants paid	**150,000**	*93,750*
Grants to Individuals	**209,928**	*107,774*
Total grants paid	**3,990,707**	*6,222,300*