Cystic Fibrosis Trust Annual Review 2008

Contents

A day in the life of Jennifer Grannell

The purpose of this annual review is to inform all of our families, supporters, fundraisers, donors and patrons from across the CF community about the activities of the Cystic Fibrosis Trust over the past year. But it is important not to lose sight of the human aspects of Cystic Fibrosis, and the realities of living with the disease on a daily basis.

Jennifer Grannell, 24, who lives in Essex, has agreed to share her daily routine with us. Jennifer, who works part time as an Expert Patient Adviser for the CF Trust, was diagnosed with CF at the age of two after a bout of pneumonia. She will explain how having CF affects her life - the medicines she has to take, the physiotherapy treatment, the battle to maintain a healthy weight - but also, how she manages to combine work, an active social life and even academic studies around the significant burden that this disease presents.

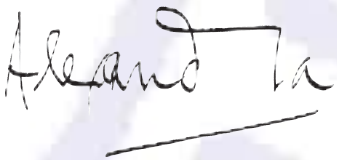
We hope you will be inspired by this insight into a day in the life of a young woman dealing with CF without letting it rule her life. One of the primary aims of the Cystic Fibrosis Trust is to improve the length and quality of life of those with Cystic Fibrosis. With the continuing and expanding help of our supporters, we can all strive to preserve the futures of those with CF, ensuring young people such as Jennifer are able to lead the fulfilling, active and independent lives that they deserve.

HRH Princess Alexandra KG GCVO

As Patron of the Cystic Fibrosis Trust, I am pleased to endorse this Annual Review. I know that you will find the continuing advances in research and in the treatment of Cystic Fibrosis as encouraging as I do.

I offer my thanks to the many doctors, nurses and other clinical staff who look after those with Cystic Fibrosis, and to all of the families who work so hard to raise the money needed to carry out the vital work of the Trust.

I hope that you will join me in supporting the Cystic Fibrosis Trust. We are all in the fight against Cystic Fibrosis together.



The Facts

Cystic Fibrosis (CF) is the UK's most common life-threatening inherited disease.

Cystic Fibrosis affects over 8,000 people in the UK.

Over two million people carry the faulty gene that causes CF - 1 in 25 of the population.

If two carriers start a family, each baby has a 1 in 4 chance of having Cystic Fibrosis.

Cystic Fibrosis affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. This makes it hard to breathe and digest food.

Each week five babies are born with Cystic Fibrosis.

Each week three young lives are lost to Cystic Fibrosis.

Average life expectancy is around 31 years, although improvements in treatments mean a baby born today could expect to live for longer.

The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis.

Highlights of the year

Implementation of the new Port CF database in all of the specialist CF Centres in the UK (see page 16)

Newborn screening for Cystic Fibrosis becoming universally available across the UK (see page 16)

Awarding £500,000 for transplant research in Newcastle-upon-Tyne, home to one of the UK's three main lung transplant hospitals (see page 15)

Our charity partnership with Manchester United (see page 29)

Expansion of the Cystic Fibrosis Trust Expert Patient Adviser scheme (see page 23)

The phenomenal LIV event - a record fundraiser for the CF Trust (see page 27)

Exciting developments in our gene therapy programme (see page 11)

The appointment of four new CF Consultants as a result of our CF training grants scheme (see page 16)

The excellent progress of our specialist CF Centre peer review scheme (see page 19)

The staunch and continuing support of the CF community in our aim to improve the lives of those with Cystic Fibrosis

Chairman's Statement

Dr James Littlewood
OBE MD FRCP FRCPE FRCPCH DCH
Chairman

Despite the general economic situation, the Cystic Fibrosis Trust continues to make steady progress both in terms of funding research and also in improving the clinical care of people with Cystic Fibrosis, thanks to the efforts of the staff and our many supporters from around the UK,

Since 2000 our major research funding has focused on supporting scientists and clinicians of the UK CF Gene Therapy Consortium, with the main purpose of bringing gene therapy to the clinic. Their research is now recognised worldwide and held in high regard. This autumn the first people with CF receive the gene therapy product that the Consortium has developed over the past decade, and we have well-founded high hopes that gene therapy will significantly improve the condition of many people with CF within the next 5 to 10 years.

It is reassuring for people with CF and their families that, despite the prospect of these exciting advances, Rosie Barnes and her colleagues at the CF Trust, and our many medical and other professional colleagues, continue to make a major and increasing contribution to improving the clinical care of people with Cystic Fibrosis. These include close and increasing collaboration with the Department of Health concerning the commissioning of care, peer review of CF Centres, introduction of a new national CF Patient Registry, production of consensus documents on care and treatment by our expert multidisciplinary committees, provision of training grants for respiratory physicians in training who wish to be CF consultants and major initiatives to improve the lung transplant situation. Neonatal CF screening was eventually introduced to all areas of the UK in 2007 - largely as a result of sustained pressure from the CF Trust over the past 10 years.

To fund this work we rely on the continuing efforts and support of very many people to whom we are very grateful. Some of the initiatives to improve clinical care are already having a favourable effect on the lives of many people with Cystic Fibrosis. The start of clinical trials of the gene therapy product developed by the Gene Therapy Consortium represents a major milestone on the road towards correcting the basic defect; also, mitigating the effects of the basic defect with various drugs is showing great promise. During the next year we will see the start of the successful practical application of some of the major advances that first became a possibility following the identification of the CF gene almost 20 years ago.

Chief Executive's Statement

Rosie Barnes
Chief Executive

Both research and clinical care have been high on our agenda this past year. It would be true to say that whilst most of our money has been spent on research, most of our time has been spent on improving the NHS care of those with Cystic Fibrosis.

Our commitment to make gene therapy a reality for those with CF remains a top priority. Whilst the first product our Gene Therapy Consortium has developed is about to go into clinical trials, the Consortium has continued to explore other gene therapy options and a second one has come to the fore which looks extremely promising. Initial research into this product indicates it might be 500 times as effective as our first product, so it is a very exciting prospect. We do have to ensure that this product will be effective in those with CF and, all importantly, that it will be safe.

Together, these two seams of product development are already costing well over £30million, and unless the current economic climate knocks us way off course, we are hopeful that as long as the science gives us a green light, we will be able to raise the necessary money.

In terms of clinical care, we are very pleased to be working with the Department of Health to identify and agree an appropriate annual tariff for proper CF care. Although this exercise has been done by various CF Consultants over the years, whose help we have found invaluable, it has never been done within the NHS to ensure proper and fair funding for those with Cystic Fibrosis, irrespective of where they live. We are optimistic that within months this will make a real difference to the many CF Centres and Clinics that are significantly underresourced.

Another key ingredient in the improvement of clinical care is our programme of peer reviews. Over 30 such reviews have already been completed with many more planned for 2009. These are taken seriously by hospital managers and NHS specialist commissioners and many significant improvements have been made as a result.

We continue to hope that in the near future we will see the introduction of treatments that will intervene in the course of this disease, to prevent many of the lung problems which are currently so worrying from developing. We also hope that the clinical care offered to those with CF will ensure better and consistently high care for all those affected. So whilst CF remains a very serious condition, we do expect to see significant improvements, both as a result of research and better clinical care. Your help in making these achievements possible is invaluable.

Gene Therapy Aiming to correct the basic fault in Cystic Fibrosis

Day in the life - Physiotherapy

Physiotherapy treatment is vital for people with CF in order to clear the sticky mucus that has built up in their lungs overnight. Each morning I do half an hour of physiotherapy - I use an inhaler and nebulise Hypertonic Saline (salt solution) before-hand in order to loosen as much of the mucus as possible and make it easier to cough up. To help me with physiotherapy, I use various techniques such as breathing through a PEP mask.

By the afternoon, I often feel chesty again.
I nebulise DNase (a drug to thin mucus) through my I-Neb, and do some more physiotherapy.
I may also use my PEP Mask or other breathing techniques.

In the evening I will do another twenty minutes of physiotherapy.

Gene Therapy

It has been a year of refinement and consolidation for the scientists in the UK CF Gene Therapy consortium. In the last financial year, the CF Trust spent and committed £4,156,000 to continue the work of the group.

Due to the unfortunate incident at Northwick Park where a pharmaceutical company clinical trial went wrong, the government altered the way in which clinical trials are carried out. This meant that the structure of the pilot study for gene therapy had to be altered causing a delay to the start of the trial and will mean that it will take longer than planned. This was not, however, a reflection on the gene therapy work. The pilot study will begin in November 2008.

The Consortium has begun to recruit young people with Cystic Fibrosis for the Run-in to clinical trial. Up to 200 people will have numerous clinical measurements taken until this begins, so that the scientists will be able to detect the effect and potential clinical benefit of gene therapy when it is applied.

The 80 dedicated scientists and clinicians who make up the Consortium have been working on the Wave I product, which is a combination of the healthy (non-CF) DNA and a carrier to get it to the right place in the airways. Although this is their focus, there have also been some interesting developments on a Wave II product, which uses a viral carrier, and which looks able to be given repeatedly (although a virus is good at getting to the lungs, they cannot normally be re-used as the body becomes immune).

We continue to work hard to fund this gene therapy research, and although we are in a period of waiting for the trials to begin, and more importantly for the results to become available, our scientists are pressing ahead to ensure all options are explored.

For all the latest information on gene therapy, visit www.cftrust.org.uk/research

Medical Research Different approaches to treat the symptoms and find a cure for Cystic Fibrosis

Day in the life - Work routine

I work part time for the Cystic Fibrosis Trust as an Expert Patient Adviser (EPA) for East Anglia. My role is to have a detailed understanding of the care that people with CF should expect and to use this knowledge to influence anyone who is involved with the commissioning or provision of care and services for people with Cystic Fibrosis. I work alongside patients and their families, as well as with the CF Centres, Clinics and the multidisciplinary teams, so that the voice of the CF community is heard at all levels.

I enjoy working because it gives me a sense of independence and working part time means that I do not get too tired.

Medical Research

Although we have high hopes for our gene therapy programme, we are also dedicated to funding smaller-scale research or other projects which may have important or imminent clinical benefits for those with Cystic Fibrosis. In the last financial year, the Cystic Fibrosis Trust spent £826,000 on non-gene therapy medical research.

We fund a diverse variety of research projects across the UK, such as the CF Microbiology Lab in Edinburgh, which provides diagnosis of strains of 'bugs' for clinics, and two further projects under Dr Baldwin at Warwick and Dr Kenna at Edinburgh to detect, analyse and understand virulent and epidemic strains of the bacteria *Pseudomonas aeruginosa* and *Burkholderia cepacia*, both of which can cause serious damage in the lungs of people with Cystic Fibrosis..

Dr Mehta at Dundee is researching a molecular link between the common Δ F508 mutation and inflammation in the lungs whilst in Belfast, Dr Schock is studying why people with CF have a stronger and longer inflammatory reaction to infections such as *Pseudomonas*.

In Bristol, Dr Sheppard is working to identify different drugs and combinations of drugs to correct the defect in CFTR (the protein that controls the movement of salts in the body) in CF mutations. Dr Fisher in Newcastle is investigating the potential for a drug related to Viagra♦ to correct the CFTR abnormality in the airways and Professor Cuthbert in Cambridge is investigating whether chloride can pass through a different 'gate' in cells as opposed to the CFTR route that doesn't work in people with Cystic Fibrosis.

Dr Haworth in Cambridge is assessing a drug to treat osteoporosis in CF and Professor Stocks in London is studying the lungs of infants with and without CF from birth to school age to aid early detection of lung disease.

In Newcastle, the Freeman Hospital was awarded a grant of £500,000 towards research into transplant, with the aim of improving the prognosis for those who are placed on the lung transplant waiting list.

At present, just 50% of those who are listed for transplant will go on to receive new lungs - the remaining 50% will die waiting.

The Lottery-funded Microbiology Consortium headed by Professor Govan examined different aspects of microbiology such as the genetic factors of CF 'bugs', a comparison of *Cepacia* with other infections, drug resistance and new treatments to clear infections.

We are fully committed to supporting medical research with potential benefits for people with CF, and these projects will help us to gain a better understanding of many aspects of CF disease, from the basic fault to symptoms and infection.

Day in the life - Medication

People with CF are prone to lung infections, which if not caught early, can become established and seriously endanger health. In order to prevent these infections, an aggressive regime of medication aimed at preventing these infections taking hold is recommended.

I take up to sixty tablets throughout the day. Many of these are Creon, which I need in order to digest food. I also take vitamins and oral antibiotics which help to prevent and fight infection (see the list on the right).

After my physiotherapy I take more inhalers and nebulise antibiotics, which help to fight the bugs which are growing in my lungs. In the evening I will take more oral antibiotics and inhalers, and will nebulise another antibiotic.

Dr Danie Watson, CF Trust training grant recipient, who trained with the CF team at Birmingham Heartlands Hospital and has recently accepted a consultant post at the London Chest Hospital. Dr Watson is pictured third from left with the Heartlands team.

"Working in CF is extremely rewarding but many doctors get only limited experience in this field in their general training. The CF Trust training grants are an excellent way to provide intensive specialised training for future CF Consultants and ensure appropriate care for adults with Cystic Fibrosis."

My daily medication

- Creon 10,000: up to 50 tablets a day
- Azithromycin antibiotic capsules: 500mg once daily.
- Salbutamol nebulising solution: 2.5ml up to three times daily
- Hypertonic Saline: 5ml twice daily
- Promixin Nebuliser or Tobramycin Nebuliser: 5ml twice daily
- Septrin Antibiotic: twice daily (this additional antibiotic is taken when I am not taking nebulised Tobramycin)
- Multivitamin: two tablets once daily
- Vitamin E: two tablets once daily
- Vitamin K: 10mg once daily
- Brincanyl Turbohaler: 500mg three puffs twice daily
- Dnase: 1 vial once daily
- Serevent Accuhaler: 50mg two puffs twice daily
- Scandishake nutritional supplement: three times daily

Care and Campaigning

Improving clinical care is one of the main aims of the Cystic Fibrosis Trust. In the past year, we spent over £1 million on care and campaigning, to help us fulfil this aim and secure a gold standard of care for patients.

The Cystic Fibrosis Trust recognises the importance of ensuring a high level of CF care, not just now, but in the future as well. For this reason, each year we offer training grants in CF care to doctors, who will then go on to become specialist CF Consultants.

The Cystic Fibrosis Trust started a process of reviewing CF Centres several years ago. In 2006, the current programme of peer reviews was established. The overall aim is to help improve the level of care that specialist CF Centres and networked clinics in the UK can offer to their patients. During a peer review, an independent panel of experts in CF care spend a day visiting a CF Centre or Clinic. They discuss with CF teams how they manage their service and identify any problem areas such as staff shortages.

A detailed report is then sent to hospital managers and commissioners, highlighting what is being done well and any areas that need attention. We have already carried out over 30 reviews, and some Centres have already received significant funding increases for their CF service as a result, showing that the time and effort required from all parties to coordinate and carry out these reviews is extremely worthwhile.

One of our newest campaigns has been to improve the level of dietetic support available for people with CF in the UK. It has long been known that a good nutritional status is linked strongly with favourable outcomes in CF, yet it became clear to us that some people with CF did not have access to appropriate nutritional guidance and support; indeed some had never seen a specialist CF dietitian. To remedy this, the CF Trust sent a questionnaire to all dietitians, as well as adults with CF and parents. Once the results have been analysed, we will have what we think will be a very strong case to ensure appropriate dietetic care and to persuade hospital managers and commissioners of the importance of specialist CF dietitians.

The implementation of newborn screening across the UK, which was completed in October 2007, was the result of over ten years of campaigning by the Cystic Fibrosis Trust. Diagnosis of Cystic Fibrosis in newborns enables treatment to be started within the first few weeks of life, which is associated with a significantly improved prognosis.

The Port CF database, a registry of all those with Cystic Fibrosis in the UK, will provide us with detailed information to help improve their treatment and prognoses. Over the past year, Port CF has been implemented in all of the 48 specialist CF Centres in the UK, as well as several networked clinics, with plans for full implementation in remaining clinics in the near future. This database is likely to be used by the Department of Health to determine the status of each CF patient to enable appropriate funding to be made available for their care.

We're also in the process of creating an exciting new online resource for both patients and clinical teams - a comprehensive care pathway which emphasises the importance of Specialist CF Centres and Clinics for the delivery of CF care, as well as the specific care that should be expected.

Day in the life - Nutrition

Because the CF mutation prevents the delivery of digestive enzymes, people with Cystic Fibrosis often have difficulty putting on and maintaining weight. A healthy, well-nourished body can deal more effectively with repeated chest infections or weight loss caused by illness, so it is essential that my daily energy and protein intake is high.

To remedy this, I take digestive enzymes, called Creon. I have eight with a meal and four to six with a snack.

In order to boost my daily calorie intake, I have three meals a day and at least one snack between each meal, as well as additional high calorie nutritional supplements such as Scandishake. I also take vitamin supplements.

Support and Education

Providing support and education to the CF community and all those involved in CF care is an integral part of the Trust's activities, and last year we spent over £950,000 ensuring that information and advice about CF was readily available and easily accessible.

The CF Trust helplines are often the first port of call for families when a child is newly diagnosed, providing a sympathetic voice as well as practical advice. The helplines are open five days a week from 9-5pm, and last year received around 3,500 calls, showing that they really are an invaluable resource for those affected by Cystic Fibrosis.

Our *Ask the Expert* enquiry service, which complements the helplines, is extremely popular, providing rapid answers from a team of medical and scientific experts to a wide range of CF-related queries.

In October 2007, we held our first conference aimed solely at parents and carers of children with Cystic Fibrosis. Looking after a child or children with CF can be stressful and draining, but by informing parents about the need-to-know aspects of the disease, as well as hot topics and emerging issues, we hope to empower them to deal with their child's Cystic Fibrosis with a greater level of confidence and positivity. We were so overwhelmed by the demand for places at this conference and the positive feedback afterwards that we decided to hold them on a yearly basis, and we are pleased to report that the Department of Health has awarded us a significant grant to facilitate this.

We also hold an annual medical conference aimed at the multidisciplinary CF teams who look after those with Cystic Fibrosis both in specialist CF centres and networked clinics - this is another well-attended event which allows the clinical teams to learn from one another and share best practice.

Families sometimes struggle with the financial burden of Cystic Fibrosis, with smaller costs such as hospital car parking which can all add up. Last year, the Trust provided Welfare Grants totalling around £100,000 to families who needed them, helping to alleviate some of the pressures of caring for someone with Cystic Fibrosis.

We have an extensive catalogue of publications covering all aspects of life with Cystic Fibrosis, which is constantly being reviewed and expanded. In the past year we've published a new specialist consensus document on MRSA, which clarifies the best clinical practice in this important area. We continue to publish our popular magazine *CF Talk*, which is unique in that it is written entirely by people with CF, as well as our regular publications *CF Today* and *Focus on Fundraising.*

The CF Trust is very much a patients' organisation, and as such, we have expanded our Expert Patient Adviser scheme this year. We now have a total of seven patient advocates, covering the whole of the UK, who are employed by the Trust to work with clinical and commissioning teams in to ensure the voices of CF patients are heard at all levels, so that CF care can be influenced favourably wherever possible. We also have a new Policy Adviser who has CF, which combined with our long-standing designer means we now have a total of nine employees with Cystic Fibrosis.

Engaging with the media to raise awareness of CF and inspire support for our work is an important part of what we do. We work hard to place stories in both national and local media and provide quotes, interviews and case studies whenever requested, whether for a smaller fundraising event or a major research story. This is doubly important as we know that, despite its devastating impact, Cystic Fibrosis is still something of a mystery to many who are not immediately affected by the disease.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Day in the life - Getting on with life

Although I have Cystic Fibrosis, I try not to let my daily routine of medication and physiotherapy stop me from living life to the full.

I have many dreams and aspirations for the future. I have been to university and now I work part time in a job I really enjoy. I am also studying part time for a Masters at the University of London.

I love socialising with my friends, who are a great support. We enjoy nights out, shopping trips and going on holiday together.

They understand that at times I feel unwell and can do less than they can, however they see me as their friend Jen rather than Jen who has CF.

Fundraising

It was once again a record year of fundraising for the Cystic Fibrosis Trust, thanks to the amazing efforts of people with CF and their families, extended families, friends and our partners in the corporate world. The CF community is indeed wide and strong.

In the last year, the CF Trust raised £11.5 million. Of this, £6.1 million came from community fundraising and events.

One of the highlights of the year was the LIV event in London. Sir Elton John, Natalie Imbruglia, Jimmy Carr and the Little Britain boys (pictured) performed in front of Prime Minister Gordon Brown and an audience of famous names from the worlds of business, sport and entertainment. The evening, organised by the Dein family and sponsored by Emirates, Pepsi and Nokia, raised £2.4 million to be split between the CF Trust and the US CF Foundation. The CF Trust is extremely grateful to all of the sponsors, celebrities, trusts and individuals who were so generous in their support.

Meanwhile the Sparkle Ball in London raised £151,000 whilst in Glasgow, a glamorous Ladies' Lunch raised over £100,000. And across the country, a series of fabulous 65 Roses Balls have blossomed into real earners for the Trust.

Another celebrity-studded event was the David Seaman Safe Hands golf tournament in Portugal, which pitted 23 teams of stars and businessmen against each other, raising £110,000 for the Trust.

Of course, the *Breathing Life Awards* continued to dazzle everyone who attended or watched on TV. On the evening, sponsored by Next, BT, Nestle and More Th>n, our celebrity guests and patrons presented awards to people with Cystic Fibrosis for their often remarkable achievements.

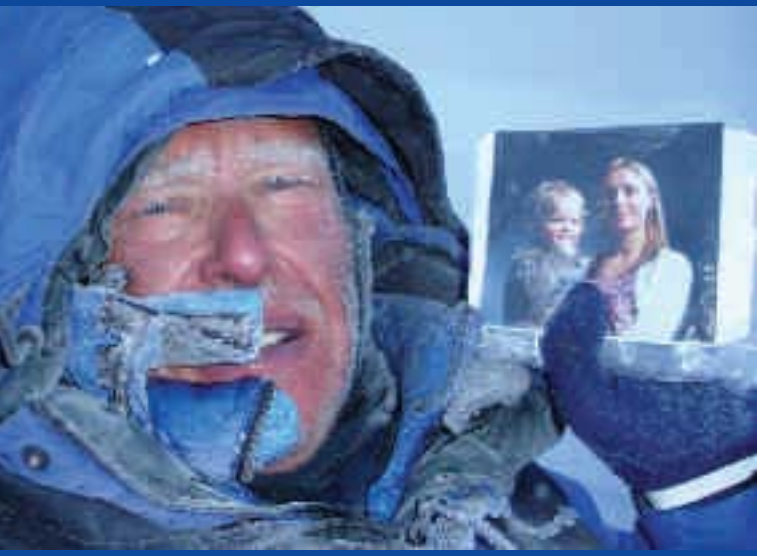
Our first season with Manchester United FC kicked off well with around £48,000 raised through auctioned signed memorabilia, corporate hospitality and our now famous Santa Run round Old Trafford. We look forward to the next two years of this partnership.

In the corporate world, we were delighted to be chosen as one of B&Q's charities of the year. Over four weekends of collections, 500 supporters raised an amazing £104,000 from shoppers at over 350 stores across the country.

City law firm SJ Berwin also adopted us as their charity and through a series of events raised £125,000, whilst Samsung organised a 5k run in Battersea Park and a gala dinner raising over £50,000.

Alan Hinkes OBE
Mountaineer and Fundraiser

"I have been supporting the Cystic Fibrosis Trust for 15 years. As a mountaineer, I am all too aware of how uncomfortable it is not to be able to breathe properly - at high altitudes, it can feel like all of the breath has been sucked from your body. But for many with CF, they have to deal with this feeling on a daily basis. I have an enormous amount of respect for all those living with this devastating condition, but continue to be inspired by those I have met during my association with the Cystic Fibrosis Trust, who tackle life with such vigour. We can all learn from their determination and positive, can-do attitudes."



Alan Hinkes OBE the first Briton to scale all 14 summits over 8,000 metres.

Fundraising

We are very grateful to all the companies and charitable Trusts who give their support - for a fuller list, please see the back pages.

Our Great Strides campaign supported by Solvay to get people walking across the country was a tremendous success in its first year, raising over £160,000 from around 40 walks organised by volunteers and our regional team. In the last year, we also expanded our range of overseas treks and climbs and for those who like a faster pace, the Great Run series and Marathons proved increasingly popular.

Whether it is hurtling through the air before floating gently to the ground in a tandem skydive, abseiling from famous stadiums and landmarks or white-knuckle white water rides, the Trust's Event Team has something for everyone. Visit www.cftrust.org.uk/help to find out more.

Coffee mornings, fetes, school fundraising, Christmas fairs and so many other events add up to an incredible amount of money for the Trust. We could not carry out our work detailed in this annual review without your ongoing support. Whether you take part in an event, organise a ball, donate to an appeal or support us in some other way, please accept our thanks and please continue to help us *See off CF.*

Ben Shephard

Elton John

Natalie Imbruglia

Mark Richardson

Bill Bryson

Joe Cole

David Seaman

Jenny Agutter

Christopher Biggins

Amanda Lamb

David Bull

Carole Smillie

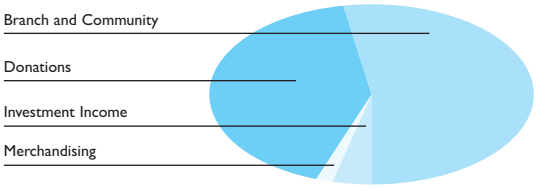
Roger Black

Summarised Accounts

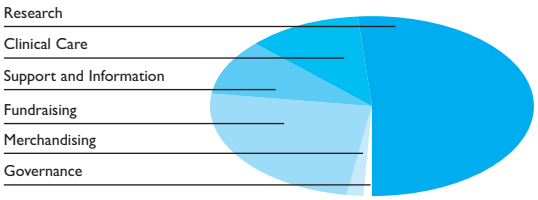
Year ended 31 March		2008	2007
Income and Expenditure Account		£,000	£,000
Where our money comes from	CF Trust branch and community	6,109	4,682
	Donations	4,796	4,691
	Merchandising	205	242
	Investment Income	420	356
	Total Income	**11,530**	**9,971**
	Other (losses)/gains	(350)	99
	Transfer (to)/from Reserves	(1,499)	3,058
		9,681	**13,128**
Where our money goes	Research	4,982	8,777
	Clinical Care	1,121	752
	Information, advice and support	957	785
	Fundraising	2,385	2,524
	Merchandising	161	226
	Governance	75	64
	Total Spending	**9,681**	**13,128**
Balance Sheet	Fixed Assets	1,145	1,096
	Investments	4,071	4,139
	Debtors	964	713
	Cash	5,067	4,926
	Grants payable	(10,502)	(11,610)
	Other creditors	(315)	(333)
	Net assets/(liabilities)	**430**	**(1,069)**
	Endowment funds	920	990
	Restricted funds		
	Gene Therapy Consortium	(5,725)	(7,145)
	Other restricted funds	419	76
	Unrestricted funds	4,816	5,010
	Total Funds	**430**	**(1,069)**

Report by the Trustees on the Summarised Financial Information

Total Income



Total Expenditure



The above summarised financial information is extracted from the full trustees' annual report and statutory financial statements, which were approved by the trustees and signed on their behalf on 7 October 2008. The statutory financial statements, on which the auditors Horwath Clark Whitehill LLP gave an unqualified audit report on 7 October 2008, will be submitted to the Registrar of Companies and the Charity Commission within the appropriate timescale.

The auditors have confirmed to the trustees that the summarised financial information is consistent with the statutory financial statements for the year ended 31 March 2008.

This summarised financial information may not contain sufficient information to gain a complete understanding of the financial affairs of the charity. The full trustees report, statutory financial statements and auditors' report may be obtained from the Company Secretary, or they can be downloaded from the CF Trust website.

Dr James Littlewood OBE MD FRCP FRCPE FRCPCH DCH
Chairman
7 October 2008

Organisation

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Dr Andy Jones *Adult Physician, Wythenshawe Hospital, Manchester*
Dr Daniel Peckham *Adult Physician, St James's University Hospital, Leeds*
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Professor Rosalind Smyth *School of Reproductive and Developmental Medicine, University of Liverpool and Alder Hey Children's Hospital*
Dr Colin Wallis *Consultant Paediatrician Great Ormond Street Hospital, London*
Dr Craig Winstanley *Microbiologist, University of Liverpool*

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Dr Steve Conway *Deputy Chair Consultant Paediatrician, St James's & Seacroft Hospital, Leeds*
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Dr Alistair Duff *Clinical Psychologist, St James's University Hospital, Leeds*
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Mrs Rosie Barnes *Chief Executive, Cystic Fibrosis Trust*
Mr Alan Larsen *Director of Research and Finance, Cystic Fibrosis Trust*

How you can help

The Cystic Fibrosis Trust relies on the support of the CF community and the public. Without the efforts of the CF community, we would not be able to fund our research, care and support work.

You can help in many ways:

Local Fundraising

We have many active branches and groups across the UK. Visit www.cftrust.org.uk/help/whatsoninyourarea to meet our team of friendly regional fundraisers who will be happy to help you.

Challenge Events

We have a huge range of challenges on offer, from running a marathon to climbing Kilimanjaro. You will receive great support from our events team on the way. Visit www.cftrust.org.uk/help/events for a full list.

National Events

Join in with our fun national campaigns such as Dance for CF and Great Strides.
Visit www.cftrust.org.uk/help/nationalcampaigns for details.

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You can make a donation by using the form overleaf, by calling 020 8464 7211or online at www.cftrust.org.uk/help/howtodonate. You can also set up a Direct Debit to give us a regular amount each month, which helps us to plan our work.

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