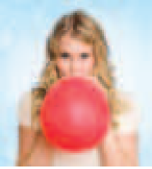
MEDICAL RESEARCH FAMILY SUPPORT FUNDRAISING CAMPAIGNING INFORMATION GENE THERAPY EDUCATION CARE

2007 review

CYSTIC FIBROSIS TRUST

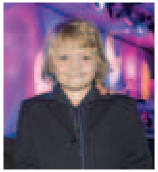
CONTENTS

CF AND ME



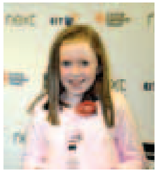
“CF doesn’t mean I can’t do what my friends all do, but I just have to take good care of myself. I’m hoping that we can raise enough money for the CF Trust to fund gene therapy research to stop Cystic Fibrosis lung damage and to continue their great support for people with CF.”

Sophie Longton page 8



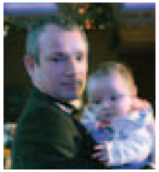
“CF means I have to get up early and do my physio and medicine before breakfast. When I am poorly, I need IVs and I hate having the line put in. Sometimes CF is annoying. The CF Trust is where we send the money we raise because they are trying to find a cure - I hope it comes soon.”

Oliver Dillon page 12



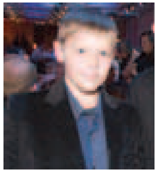
“CF is like a commander telling me and my body what I can do, but I don’t let it. Through the CF Trust, we all unite to try to raise funds and beat this awful ruler, so the more we can do for the Trust, the better for me and for others.”

Elena Byrne page 16



“CF means lots of things: quality of life, doing daily treatments, adapting to change and having fun. The CF Trust shows relentless pursuit towards combating symptoms and complications through research and by working with individuals and collectively at a local level within clinics.”

Tom McLoughlin-Yip page 20



“CF means I have to take lots of medicines, but I don’t let it stop me playing my hockey matches. The CF Trust is working hard to find a treatment for my Cystic Fibrosis.”

Jack Perkins page 24

“CF has been a cause close to my heart ever since I met a young boy with CF who wanted to be a professional footballer. I am delighted to work with the CF Trust so they can continue funding important research.”

David Seaman page 30

HRH Princess Alexandra KG GCVO

As Patron of the Cystic Fibrosis Trust, it gives me great pleasure to continue my support of its work for those with Cystic Fibrosis and their families.

Every year, I draw inspiration from the stories of those with Cystic Fibrosis and the efforts that you all put into raising funds for medical research.

I continue to hope that there will soon be a treatment for this condition and my thanks go to everyone involved in the work of the Trust, from the families to the hospital staff and scientists.

Alexandra

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 31 years, although with improved treatments, a baby born today is expected to live longer.

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

CHAIRMAN'S STATEMENT

Dr James Littlewood
OBE MD FRCP FRCPE FRCPCH DCH
Chairman

It has been another busy and exciting year for the CF Trust in all areas of our work, from research to care and support.

Having looked after children with Cystic Fibrosis for many years in Leeds, I saw first hand the importance of best possible care. Children who receive expert CF care usually do very much better than those receiving sub-optimal care. The problem for many families is how to know whether they are getting first class care or not.

Ensuring that everyone in the UK with CF gets the best possible NHS care is an ongoing priority for the CF Trust. With new structures in place to address the commissioning and provision of care in every CF specialist centre and clinic, we are determined to work with the NHS to ensure that those with CF are offered the best possible care by an expert CF team irrespective of where they live.

The work we are doing to respond to this challenge is demanding and pressing, but its importance cannot be overstated. We still come across those with CF who have not been well looked after. Although they are the exception rather than the rule, everyone with CF is entitled to the best care that modern medicine can offer and we are determined to ensure they get it.

Through the Medical Advisory Committee, our medical conferences and *CF Today*, we try to keep the CF community up to date with advances in treatments for the condition and as soon as there is news, we let you know. We are committed to continuing to do all we can for those with CF and their families.

CHIEF EXECUTIVE'S STATEMENT

Rosie Barnes
Chief Executive

One very busy and productive year for the Cystic Fibrosis Trust is now spilling over into the next one.

Our gene therapy research programme is moving steadily forward. The 70 scientists working flat out on this initiative are determined and relentless, with the firm goal of taking the 'life-threatening' out of Cystic Fibrosis.

They have addressed and overcome one obstacle after another including scientific challenges, mountains of bureaucracy and practical challenges. There have been few 'Eureka!' moments, but plenty of hard work. Under the wise and focussed leadership of Professor Eric Alton, they are justifying our commitment to this project.

Sometimes the CF community feels that it is taking on huge burdens and responsibilities without any help, which for the 8,000 families in the UK affected by CF seems overwhelming.

Every now and again, we get special help from individuals or organisations, which lifts not only the burden, but also the spirits. Recently, a Liechtenstein charitable foundation named Medicor recognised the enormous struggle our families face to raise the millions necessary for our gene therapy research. They gave an amazing £3.4 million, representing around half of the cost of the gene therapy product, which is about to go into clinical trials.

More recently, we were bowled over to learn that we had been chosen as one of Manchester United's two chosen national charities for the next three years. The excitement and gratitude felt by those affected by CF to know that a football club of the stature of Manchester United cares about CF and is now on our side has put a new bounce in our step.

Tackling CF together has always been our approach, and whilst never easy, it seems much more possible with such generous and influential supporters.

Sophie Longton

Sophie was a bubbly teenager when she first approached the CF Trust to see if she could help us. Her health had been good with relatively few complications and she was soon representing the Trust in a warm, articulate and amusing way.

Since then, Sophie's health has presented her with problems, but she still has immense zest for life and juggles her university work, hectic social life and her commitment to helping others with Cystic Fibrosis - she always sparkles and is a wonderful ambassador for the CF Trust.

consortium

gene THERAPY

CLINICAL TRIALS

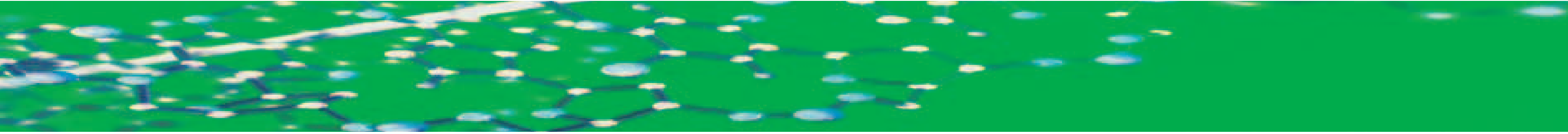
GENE THERAPY

It has been another very busy year for the UK CF Gene Therapy Consortium as it continues in its search for an effective treatment for Cystic Fibrosis lung disease through gene therapy.

In the last financial year, the CF Trust invested £7,726,000 in gene therapy. This money was used to fund the 70 dedicated scientists working in the Consortium as well as essential laboratory equipment and chemicals.

As the build up to the pilot study of the gene therapy product continues, the teams in Edinburgh, London and Oxford continue to make improvements - for example, the healthy copy of the DNA, the copy without CF, is now in its 69th version. The pilot study is planned to begin in early 2008.

Although the scientists wanted to carry out the multi-dose clinical trial for a year, this was going to be too expensive, even for the fantastic



efforts of the CF community, so we thought we were going to have to settle for six months. Fortunately, a very generous donation has been pledged to fund an extra six months of the clinical trial so it will run for 12 months, planned to begin late in 2008. We are in an unusual position of being able to fund the second six months whilst still needing to secure full funding for the first six months.

It is through the extraordinary efforts of our supporters that we have been able to come this far - the multi-dose clinical trial involving up to 100 people with CF will be the first time anywhere in the world that CF gene therapy will have been studied in this extensive way.

Although gene therapy will not be a complete cure, it will be the nearest thing available in the foreseeable future.

Oliver Dillon

Oliver has a great love of performing and enrolled in drama school where he quickly landed a great role in *Guys and Dolls* despite all the other main parts going to over twelves.

He is now the voice of Lumpy the Heffalump in Disney's *My Friends Tigger and Pooh*. He is unaware of the size of his success and he remains naturally innocent. As Oli says: "When I am Lumpy, I don't have to think about my CF or my meds. I just think about being a four year old Heffalump!"

research

SYMPTOM CONTROL INFECTION INFLAMMATION DRUG THERAPY LUNG FUNCTION

length of life ›››››› 31 YEARS

MEDICAL RESEARCH

Along with investing in gene therapy, the Cystic Fibrosis Trust remains committed to funding high quality research that could have important and/or imminent benefit for those with Cystic Fibrosis.

In the last financial year, £742,000 was spent on medical research on projects recommended to the Trustees by the Research Advisory Committee - our body of eminent scientists and clinicians and representatives of the adult CF community and parents.

Amongst the 13 projects funded were three studies into various aspects of CFTR, which is the protein made by the gene that in CF prevents the proper movement of salts and water through the body. There were also two projects investigating inflammation in the lungs and another studying new ways of clearing the airways of mucus.

We funded four projects looking at infections in CF such as *Pseudomonas* and *Cepacia* and the UK CF Microbiology Consortium

continued its lottery funded work in this area. These related programmes will help to provide early identification and treatment regimes for CF ‘bugs’.

Other areas of funding included drug treatments for specific CF mutations, lung function studies and the Cochrane Library that assesses the evidence for various treatments.

In collaboration with CF centres and clinics, the CF Trust began work to create a new clinical database of people with Cystic Fibrosis. This valuable resource will allow clinicians access to information about the health of their patients with CF nationally and help promote best practice in NHS care.

The CF Trust continues to invite further applications for research grants from across the UK.
For further information, visit www.cftrust.org.uk/research

Elena Byrne

Elena has many outstanding achievements in school, swimming, golf and music. She is very caring and looked after her family when they were ill and she loves her little brother Connor who lifts her spirits when she doesn't feel well.

Elena has raised over £2,000 by organising her school fundraising quizzes, raffles and a Big Bounce. Along with these qualities, Elena loves reading and has been published in a Young Writers' anthology of poems.

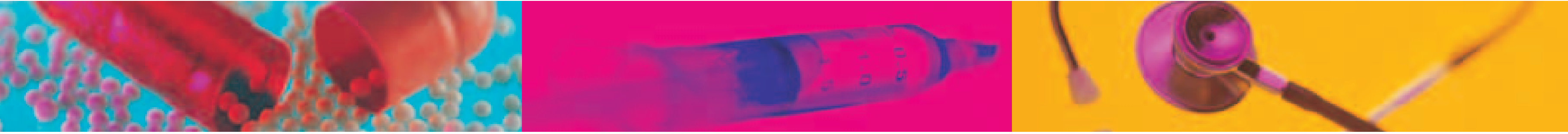

campaigning
TRAINING GRANTS DEVELOPMENT TRANSPLANTATION PRESCRIPTION CHARGES FAIR CARE FOR ALL PEER REVIEW
treatment
care
INSULIN BP 40

CARE AND CAMPAIGNING

The Cystic Fibrosis Trust believes everyone with CF should have access to a high level of healthcare, wherever they live in the UK. Last year, the CF Trust spent £567,000 on working for better care for those with Cystic Fibrosis.

We implemented a peer review process for specialist CF Centres, identifying where improvements can be made and pre-empting possible problems. We hope that in time this will mean everyone attending a CF Centre in the UK will receive a standard 'gold level' of CF care. Since the process began in 2006, there have already been significant improvements in several units visited.

We also run a scheme to encourage general doctors to become specialist CF consultants. Over £200,000 was allocated for these training grants in 2006-7, and it is planned to offer two more grants per year for the next few years. In addition, the Cystic Fibrosis Trust contin-



ues to offer smaller development grants to fund other health professionals involved in CF care.

Securing a better future for people with Cystic Fibrosis does not just mean improving care and investing in research - the Cystic Fibrosis Trust actively campaigns to raise awareness and influence government policy on a range of subjects, such as prescription charges, home oxygen and transplantation. We aim to improve the outlook for people with CF awaiting lung transplants as currently, only 50% of those with CF on the active transplant list will receive the organs they desperately need.

We recognise that there are many reasons behind this, and we are actively trying to influence transplantation policy both in the government and in hospitals across the UK.

Tom McLoughlin-Yip

Tom worked for the CF Trust for a long time as a CF Advocate then as an Expert Patient Adviser. Over the last two years, Tom's life changed dramatically as he met Li who was working as a paediatric nurse and married her 14 months later.

Tom and Li took part in Robert Winston's TV program, *Against All Odds* about fertility treatment, and happily Tom's son Ki-Yan was born in February 2007. Tom's courage in being part of the series won great praise, particularly from the CF community.


database
cf today
CYSTIC FIBROSIS TRUST
HELPLINES INFORMATION SUPPORT ASK THE EXPERT WELFARE GRANTS PUBLICATIONS
e Facts
oduction to Cystic Fibrosis
for a brighter tomorrow
CYSTIC FIBROSIS TRUST
support
Caring
www.cftrust.org.uk

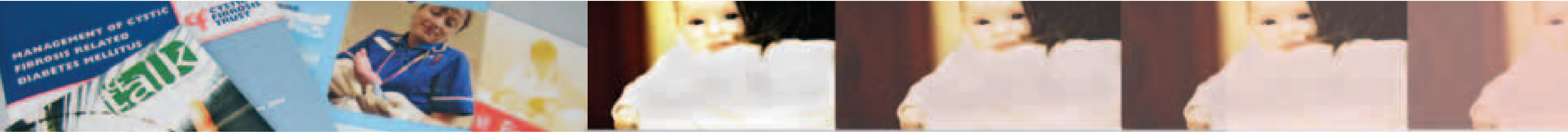
SUPPORT AND EDUCATION

Supporting those affected by Cystic Fibrosis is one of our most important roles. Last year the CF Trust spent £672,000 on support and education.

Whether by being a sympathetic ear, or giving in-depth advice, the CF Trust helplines, manned by understanding, experienced staff, are an invaluable resource for people with CF, their families, friends and carers, and also for employers and teachers.

Our welfare scheme can be a lifeline and over £111,000 was given in small grants to people with CF last year.

We also offer an *Ask the Expert* facility, where anyone with a medical question about CF can email their query to asktheexpert@cftrust.org.uk and receive a reply from a professional in that area. Access to information is also vital in helping people to manage better as complex a condition as Cystic Fibrosis. We produce a wide range of booklets and factsheets aimed at all ages and covering all aspects of life with Cystic Fibrosis.



Our regular publications include the popular youth magazine *CF Talk*, written entirely by the CF community, and our informative magazine *CF Today*. For the medical community, we produce a series of detailed consensus guidelines covering key topics in CF care. These are also available to people with CF who request them.

The Cystic Fibrosis Trust website was re-launched in January 2007, and the new, modern look has received excellent feedback. Our message boards are a very popular feature, providing a forum for people to share their experiences with one another. The website also contains a wealth of information about living with CF, and fundraising activities. Most of our publications can be downloaded free of charge.

To help health professionals stay up to date in CF care, we hold an annual medical conference featuring many topics, from emerging treatments to working with funders.

Jack Perkins

Jack had a liver transplant at just ten months, but despite this and the treatments for this and his CF, he is a very active boy who copes with everything through enthusiasm and a sense of fun.

Although he excelled at both, Jack had to choose between football and hockey. Hockey won out and he now represents his local under 11s and under 13s teams.

He tells all his friends that his transplant scar is where he was bitten by a shark!


COMMUNITY CHALLENGE EVENTS COMPANY CHARITY OF THE YEAR LEGACIES BREATHING LIFE AWARDS
CYSTIC FIBROSIS TRUST
HELP US TO HELP THE CYSTIC FIBROSIS TRUST
celebrity
giving
community
corporate

FUNDRAISING

Once again the CF community pulled out all the stops in their fundraising throughout the last year. All across the UK, and even across the world, families and friends ran, swam, bounced, baked, danced, walked, biked and sold to raise money for the Cystic Fibrosis Trust. Through our branches and the CF community, over £4,680,000 was raised last year. Amazing!

Adding in the money raised by donations, companies, charitable trusts, Christmas cards and other schemes, a total of £9,615,000 was received last year. Thanks everyone!

Our challenge events went from strength to strength with income up by nearly 25%! 175 brave people pounded the streets of London for the marathon raising a staggering £330,000. The Great Run series was hot on its heels though with £130,000 raised at the Great North Run and £56,000 at the Great South Run. We are introducing more

exciting opportunities to run, cycle and trek the world, so check out www.cftrust.org.uk for more great events.

In Manchester, Fred the Red and around 400 daring souls abseiled into Old Trafford football ground roping in £100,000 for the Trust.

On two wheels, we were a part of the great Capital to Coast bike ride from London to Hove and the annual Cat & Fiddle 55 mile challenge with cycling legend Shaun Kelly has now raised over £137,000 in its first five years.

It's not all action though; there is always the opportunity for fancy frocks and fancy dress. Across the central region, spooky Fright Nights in haunted buildings raised the hairs on our necks and £32,000 for our work, whilst in Scotland, a 65 Roses Ball and a Big Apple Ball were glamorous ways to help See Off CF. Not to be outdone in the

glamour stakes, we were left stirred, not shaken, by a *Licence to Cure* James Bond theme Ball in Ipswich.

In Northern Ireland, Anglo Beef Processors held a summer barbecue making a sizzling £28,000 and old favourites like the Slieve Donard Dander continued to raise much needed funds.

Our friends in the corporate world were also active on our behalf. The Trust once again benefited from the Lawyer Awards where top legal firms make donations with their nominations and take part in a raffle raising over £36,000.

NEXT and BT once again generously sponsored the *Breathing Life Awards*, which are our opportunity to celebrate the spirit and achievements of people with Cystic Fibrosis with family, celebrities and our corporate friends.

In November 2006, law firm SJ Berwin adopted the CF Trust as their official charity and through a series of raffles, auctions and events are on course to raise well over £100,000 when the partnership ends in late 2007.

The Jaguar Enthusiasts club sold raffle tickets to win a Jaguar car. The draw took place at the NEC in October and over £25,000 was raised.

We would like to thank all of the people who work so hard fundraising for us, only some of whom are mentioned here. We are very grateful for all of your support.

If you would like any further information on fundraising, or to find out what help we can give to your events, contact our head office and we will be delighted to talk to you.

David Seaman

Former Arsenal and England international goalkeeper, David Seaman has been supporting the Cystic Fibrosis Trust ever since he was introduced to a young boy with CF, whose dream was to be a professional footballer. Since then he has been a regular supporter and attended many events on our behalf.

David became an official patron of the Trust in 2005 and has been overwhelmed by the bravery and determination of people with CF he has met along the way - many of whom have become friends.

1 Holly Brisley and Ben Shephard
2 Matthew Wright
3 Charlie Dimmock
4 Mark Bright and David Baddiel
5 Rio Ferdinand
6 Janet Ellis and Konnie Huq
7 Kate Lawler
8 Mark Richardson
9 Cleo Rocos
10 Chico
11 Kirsty Young
12 Mel C
13 Amanda Lamb
14 Caroline Feraday
15 Claire Sweeney and David Bull
16 Jenny Agutter
17 Bill Bryson
18 Joe Cole
19 Bruno Tonioli and CeCe Sammy
20 Alan Hinkes

CELEBRITY SUPPORT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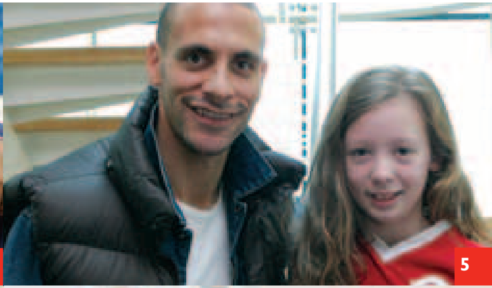
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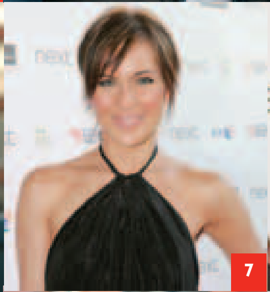
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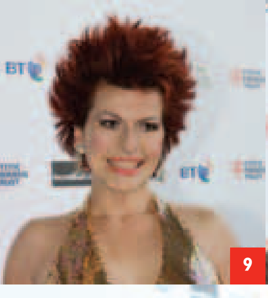
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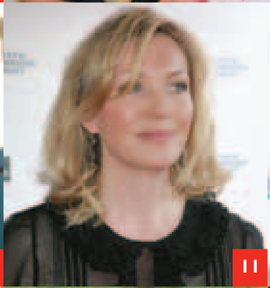
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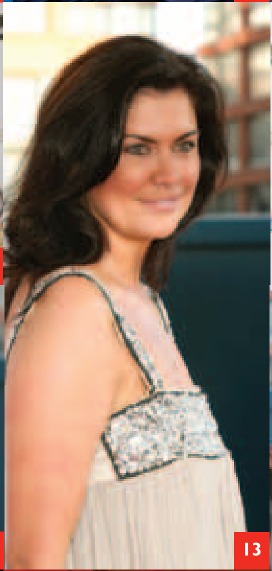
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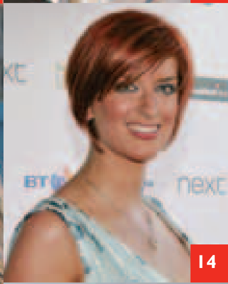
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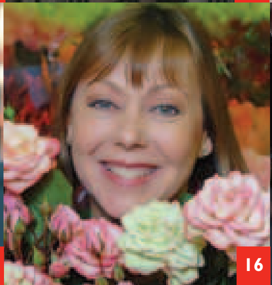
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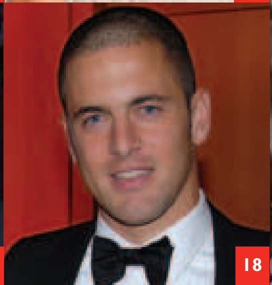
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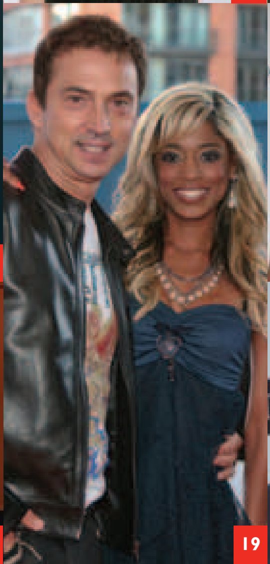
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SUMMARISED ACCOUNTS

Where our money comes from

	2006-7 £000	2005-6 £000
CF Trust branch and community	4,682	4,198
Donations	4,691	3,389
Merchandising	242	299
Investment income	356	287
Total income	**9,971**	**8,173**
Other gains	99	416
Transfer from/(to) Reserves	3,058	(266)
	13,128	**8,323**

Where our money goes

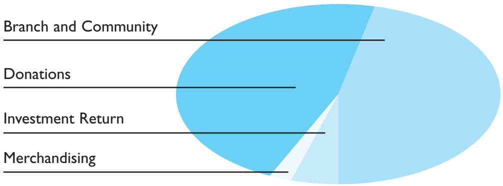
	£000	£000
Research	8,777	4,042
Clinical care	752	708
Information, advice and support	785	660
Fundraising	2,524	2,585
Merchandising	226	266
Governance	64	62
Total spending	**13,128**	**8,323**

Balance Sheet

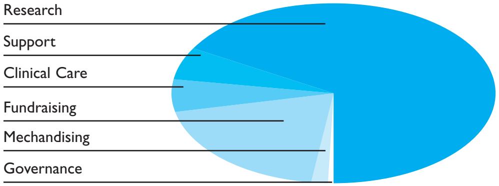
31 March 2007

	£000	£000
Fixed assets	1,096	1,104
Investments	4,139	3,905
Current assets	5,639	4,841
Grants payable	(11,610)	(7,543)
Other creditors	(333)	(318)
Net (liabilities)/assets	**(1,069)**	**1,989**
Endowment funds	990	987
Restricted funds		
Gene Therapy Consortium	(7,145)	(4,000)
Others	76	244
Unrestricted funds	5,010	4,758
Total funds	**(1,069)**	**1,989**

Total Income



Total Expenditure



Report by the Trustees on the Summarised Financial Information

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 17 July 2007. The statutory financial statements, on which the auditors Horwath Clark Whitehill LLP gave an unqualified audit report on 17 July 2007, have been submitted to the Registrar of Companies and the Charity Commission on 15 August 2007.

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 2007.

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.

Jim Littlewood

Dr James Littlewood **OBE MD FRCP FRCPE FRCPCH DCH** Chairman
15 August 2007

ORGANISATION

Patron
HRH Princess Alexandra KG GCVO
President
Mr Duncan Bluck CBE
Vice President
Mr Peter Levy OBE FRICS
Chairman
Dr James Littlewood OBE MD FRCP
FRCPE FRCPH DCH
Deputy Chairman
Sir Robert Johnson
Hon Treasurer
Mrs Alison Halsey FCA *from October 06*
Chairman of Research and Medical Advisory Committees
Professor Stuart Elborn MD FRCP
Chief Executive
Mrs Rosie Barnes
Trustees
Dr James Littlewood
Mr Anthony Angel *stood down September 06*
Mr Duncan Bluck
Sir Peter Cresswell
Professor Stuart Elborn
Mr Allan Gormly *from September 07*
Mrs Alison Halsey *from October 06*
Mr Brian Henderson
Sir Robert Johnson
Mr Adrian Llewellyn-Jones
Mr Ed Owen
Mr Martyn Rose
Mr Peter Sharp
Company Secretary
Mr Alan Larsen ACA

Research Advisory Committee
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Adult Physician, School of Medicine, Queen's University of Belfast
and Belfast City Hospital
Dr Michael Gray *Deputy Chair*
School of Cell and Molecular Biosciences
University of Newcastle upon Tyne
Professor Margarida Amaral
Department of Chemistry and Biochemistry
University of Lisboa, Portugal
Dr Chris Boyd
Centre for Molecular Medicine
University of Edinburgh
Ms Judy Bradley
Physiotherapist, Belfast City Hospital
Professor John Govan
Department of Medical Microbiology
University of Edinburgh
Mrs Donna Harcombe
Parent representative
Dr Andy Jones
Adult Physician, Wythenshawe Hospital, Manchester
Mr Peter Sharp
Patient representative
Dr Janis Shute
School of Pharmacy and Biomedical Sciences
University of Portsmouth
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

Medical Advisory Committee
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Adult Physician, School of Medicine, Queen's University of Belfast
and Belfast City Hospital
Dr Diana Bilton
Adult Physician
Papworth Hospital, Cambridge
Mrs Mary Dodd
Consultant Physiotherapist
Wythenshawe Hospital, Manchester
Dr Alistair Duff
Clinical Psychologist
St James's University Hospital, Leeds
Mr Kevin Goody
Parent representative
Ms Valerie Hall
CF Nurse Specialist
Belfast City Hospital
Dr Nabil Jarad
Adult Physician
Bristol Royal Infirmary
Ms Jacqui Lowdon
Dietitian
University Hospital of Wales, Cardiff
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Professor Chris Higgins
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Laboratoire de Biogenetique et HLA
INSERM, France
Professor Brandon Wainwright
Institute for Molecular Bioscience
The University of Queensland, Australia
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Imperial College School of Medicine, London
Professor Gerry McElvaney
Department of Medicine
Royal College of Surgeons in Ireland

HOW YOU CAN HELP

There are lots of ways you can help the Cystic Fibrosis Trust fund vital research, family support and develop care:

Local fundraising

Visit www.cftrust.org.uk/help/whatsoninyourarea to meet our friendly team of regional fundraisers who can tell you what is happening near you and how you can get involved.

National events

Have you every fancied running a marathon, climbing a mountain or joining thousands of walkers to See Off CF? For a list of events for the fit and not-so-fit, visit www.cftrust.org.uk/help/events

Setting up a regular gift

You can download a direct debit form from our website or email enquiries@cftrust.org.uk and help us plan our work ahead by making a monthly donation.

Leaving a gift in your will

Leave a lasting gift to those with CF by remembering us in your will so your support will continue in the future. Email legacies@cftrust.org.uk for more, confidential information.

Making a donation

There is a donation form on the back of this page if you would like to donate now, or you can donate online or via our donation line 0845 859 2040

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I wish to donate: (please tick the appropriate box)

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Visa ☐ Mastercard ☐ Switch/Maestro ☐ Amex ☐ CAF Charity Card ☐

Card No. ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

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The Cystic Fibrosis Trust does not sell or rent your personal details to any other organisations.
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Gift Aid

There has never been a better time to give to the Cystic Fibrosis Trust.

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Please authorise Cystic Fibrosis Trust to reclaim tax on all your donations made for the six years prior to this year, (but no earlier than 6/4/2001) and all donations you make from the date of this declaration by ticking here. ☐

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Cystic Fibrosis Trust
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Bromley Kent BR1 1BY

Signature

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CF Welfare Grants Helpline: 0845 859 1020

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