



**pulling together**

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## The Facts

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

Cystic Fibrosis affects over 8,000 children and adults 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.

Around half of people with Cystic Fibrosis will live over 35 years, although a baby born today can expect to live longer.

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



## **Pulling together in the fight against Cystic Fibrosis**

The last financial year has proved challenging for the Cystic Fibrosis Trust, who, like many other charities, organisations and companies, has seen a decline in income due to the recession. This is despite a very exciting year on the research front, along with many encouraging developments spanning all of our charitable objectives. As our income for the year fell by around £2 million, we have had to look very closely at our expenditure to ensure that we can continue to fund our most important work and safeguard our research commitments.

At times like this, it is important for everyone to pull together, and the CF community is no exception. What has been very encouraging is the unwavering determination of our supporters and fundraisers to do all they can to help us raise funds and awareness of Cystic Fibrosis, despite the gloomy economy. We are immensely grateful for their continuing support, along with the commitment and dedication of the clinical teams, researchers and scientists, who work so hard to provide excellent clinical care and improved treatments for those with Cystic Fibrosis.

The most welcome news this year that the median predicted survival (formerly called average life expectancy) for those with Cystic Fibrosis has increased has given considerable encouragement, but it is still far from good enough and this is no time for complacency. Too many young lives are still lost to CF, and we still have a long way to go to change this. It is the strength and determination of families and individuals affected by CF that will help us to weather this recession and emerge stronger than ever before, hopefully, one step closer to an effective treatment for Cystic Fibrosis.

We're all in this together.



HRH Princess Alexandra KG GCVO

## **A message from HRH Princess Alexandra**

### **pulling together**

I am delighted to see the progress that has been made over the last year at the Cystic Fibrosis Trust and I offer my thanks for the dedication and hard work of everyone who has made this possible.

It is heartening to learn that medical advances have made it possible to extend the life expectancy of those with Cystic Fibrosis. Good news indeed. News which strengthens our resolve to continue the fight against Cystic Fibrosis.

The commitment of families living with Cystic Fibrosis is a constant inspiration to me and I sincerely hope that you will remain strong through these difficult times as work continues to improve the length and quality of life for those with Cystic Fibrosis.

## Highlights of the year

The launch of the pilot study into gene therapy for Cystic Fibrosis - page 9

Over £470,000 in research grants awarded to institutions across the UK - page 13

The success of the UK CF Registry, which has revealed that people with Cystic Fibrosis are living longer than ever before - page 17

29 Specialist CF Centres and Clinics peer reviewed - page 17

Steady progress on our Payment by Results initiative - page 17

Our well-attended regional conferences, parents conferences and medical conferences - page 21

The 5,000 fans who joined our Facebook page, and the launch of the CF Trust blog and e-newsletter - page 21

Record-breaking challenge events including the Great North Run with 520 runners and over £180,000 raised - page 25

The Sparkle Ball in London which raised £150,000 towards a new adult CF unit in Sheffield - page 25

Over £94,000 raised from Big Brother eviction votes - page 25



Rosie Barnes, Chief Executive and Dr James Littlewood OBE MD FRCP FRCPE FRCPC DCH, Chairman

## pulling together

It has been business as usual for the Cystic Fibrosis Trust this year, and we will continue to do all we can to serve the needs of people with Cystic Fibrosis in the UK.

## **A message from our Chairman and Chief Executive**

In spite of the volatile economic climate, it has been business as usual for the Cystic Fibrosis Trust this year in addressing the pressing needs of those with Cystic Fibrosis. We have made significant progress in terms of both research and improving clinical care.

Our Gene Therapy Consortium, comprised of over 70 scientists and other health professionals, continues to work apace to bring this potentially life-saving treatment closer. Our first product, wave 1, is now being tested for safety in 27 patients with Cystic Fibrosis. If this pilot study indicates it is safe and appropriate to proceed, the gene therapy will then be subject to further toxicology tests to ensure it is safe to give repeat doses of the treatment. We will then be ready to start the multi-dose trial, in which 100 people aged 12 and over will receive the nebulised drug once a month for a year. Half will receive a placebo and half the gene therapy product.

Whilst we wait for these important results, we are not resting on our laurels. We are researching further delivery systems for gene therapy which early results indicate may be considerably more effective than our wave 1 product. With this wave 2 initiative we are embracing new technology as it becomes available, to give those affected by CF, now and in the future, the best chance of a longer and better quality of life.

Our work to improve the clinical care of those with CF throughout the UK has been productive. Our programme of peer reviewing CF Centres and Clinics, combined with the vital clinical data from the UK CF Registry, has given us invaluable tools to drive up the standard of clinical care. As a direct result of this, over £14 million of additional NHS funding has been pledged to improve the staffing levels, equipment and facilities for those cared for in CF Centres and Clinics throughout the UK.

Our programme is demanding and challenging, but we are determined to succeed. The adults who have lived with CF for many years, the teenagers who are railing against it and the very young who cannot yet say the words Cystic Fibrosis, are all depending on us.





Our world-leading research into  
gene therapy for Cystic Fibrosis is  
at a crucial stage.

# Gene Therapy

## **Dr Deborah Gill and Dr Steve Hyde of the UK CF Gene Therapy Consortium**

Dr Gill and Dr Hyde head up the Oxford-based research group of the UK CF Gene Therapy Consortium (the Consortium is split between London, Oxford and Edinburgh). Their work has been concentrating on refining the plasmid DNA (healthy copy of the CF gene) for the pilot study. The plasmid approved for the pilot was the 169th version, which has been carefully designed to ensure its suitability for the trial.



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It has been a long time in preparation, but the gene therapy product is now being tested in a pilot study in people with Cystic Fibrosis.

## Gene therapy

Since we brought together the UK's leading CF gene therapy teams in 2002 to form the UK CF Gene Therapy Consortium, we have spent a great deal of time and effort to get gene therapy from the lab concept into the clinic. Last year, we invested £4.5 million in gene therapy research.

The first dose in the much anticipated pilot study was given in February 2009. The pilot study involves up to 27 young adults with CF who will each be given one dose of the gene therapy product using a lipid-based carrier (pictured left).

Once the results of the pilot study have been analysed, a further round of safety tests in small and large animal models is necessary before the multi-dose clinical trial can begin. These toxicology studies also have to undergo analysis by the government's medicines approval board before we can continue.

During the last year, the Consortium completed recruiting young people with CF for the run-in to the clinical trial. It is a tribute to the enthusiasm and co-operation of families affected by CF that the participants were recruited so quickly and just under 200 people are now undergoing tests to take key measurements, which can be compared with similar tests during the multi-dose trial. Using these, scientists will be able to detect the effect and potential benefit of gene therapy.

It was also decided that the manufacture of the multi-dose product will only begin after the results of the single dose clinical trial are known. This is because it is very expensive (several millions of pounds), which we cannot afford to waste if there are changes to be made. Although this means the timescale for gene therapy research has been extended, it is not worth the financial risk to go ahead with production until the final, optimum formulation is known.

If all is well in the pilot study, safety studies and the product is passed by the regulatory authorities, the multi-dose clinical trial should begin in 2011 with results 18 months or so later. This groundbreaking work has not been undertaken anywhere in the world before, so we constantly have to review timescales. We are all keen for a result, but we have to ensure that safety is our priority.

Work also continued last year on wave 2 gene therapy products, including using a new type of virus carrier which can be given repeatedly, and some further lipid-based carriers, which could improve on the wave 1 product currently being piloted.

This world-leading work remains on track, but we all need to pull together to ensure its continued funding.

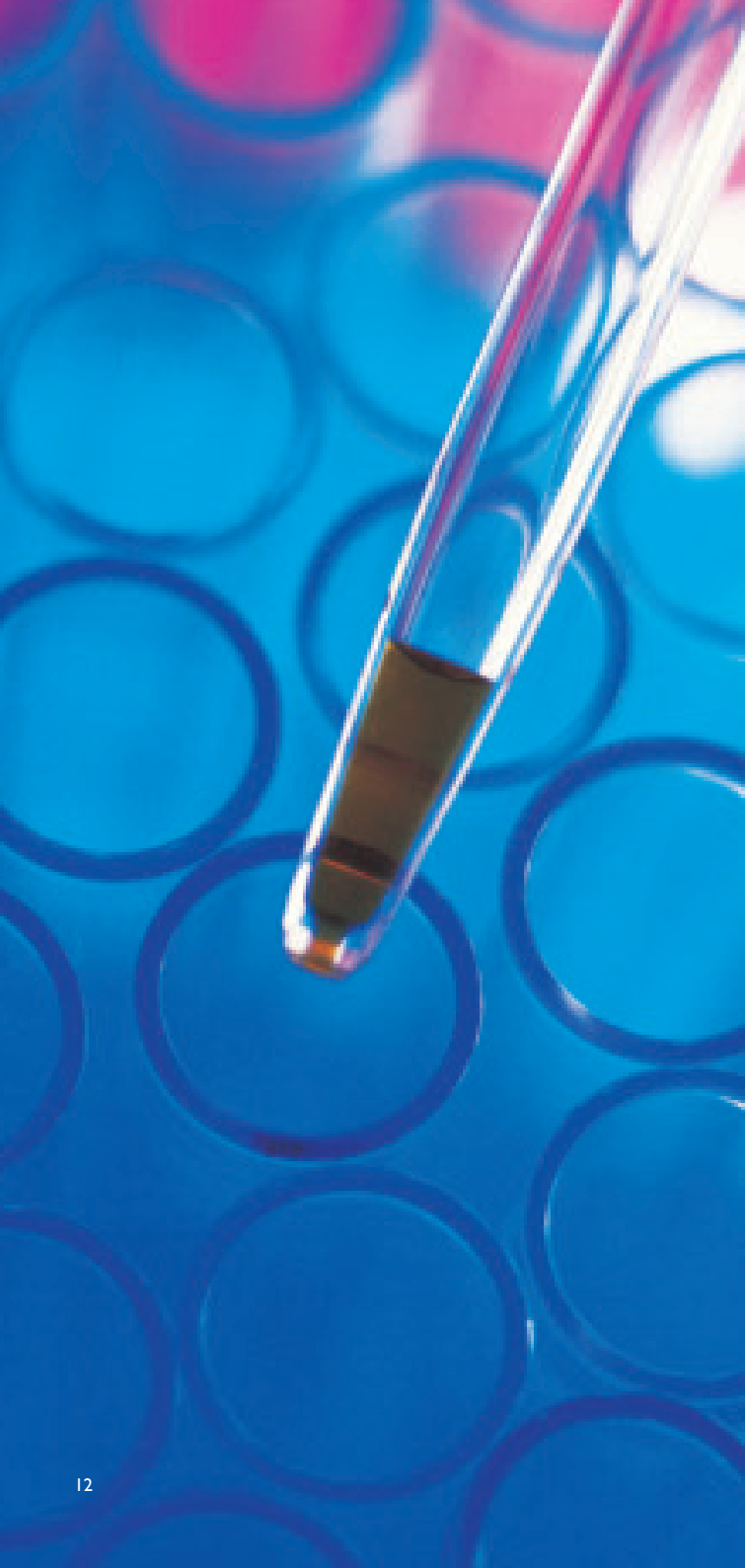


We fund research into many aspects  
of CF, to improve the length and quality  
of life for people with Cystic Fibrosis.

# Research

## **Dr David Sheppard, University of Bristol**

Dr Sheppard has been involved in research into new treatments for Cystic Fibrosis for over fifteen years. Along with his team at the University of Bristol, he is carrying out leading research into the structure and function of CFTR. Mutation of the CFTR gene is the root cause of all the problems in Cystic Fibrosis. Dr Sheppard is particularly interested in substances called potentiators, which increase CFTR activity and which are showing considerable promise as future drug treatments for Cystic Fibrosis.



## pulling together

From basic science to clinical trials, the community of CF scientists, researchers and clinicians is pulling together to find new and improved treatments for Cystic Fibrosis.

## Medical research

The Cystic Fibrosis Trust is committed to supporting research which will have an important and/or immediate clinical benefit for those with Cystic Fibrosis, and we spent £775,000 on non-gene therapy research in the last financial year. This included funding projects into various aspects of CF such as inflammation, infections and different approaches to treating the underlying cause of Cystic Fibrosis.

In 2008/9, the Lottery-funded work of the UK CF Microbiology Consortium drew to a close. This project investigated various aspects of the CF infections *Pseudomonas* and *Burkholderia cepacia* such as transmissibility and virulence. It has led to new ways of detecting infection and opened new areas of research into treating these dangerous pathogens. Four of the young researchers involved have also continued to work in CF research.

Along with this work on infection, the Trust funded Professor Elborn in Belfast who is investigating the link between infection and exacerbations in the lungs. This complemented the work by Dr Kenna in Edinburgh who was researching the genetics of highly virulent strains of *Pseudomonas*, and we continued to provide financial support to the Microbiology Lab in Edinburgh, where many CF Centres send their samples for testing.

The CFTrust worked with the Medical Research Council to create a joint training fellowship in Newcastle, using the lungs of those with CF who have had a transplant to determine new treatments for the cycle of inflammation and lung damage in Cystic Fibrosis.

As this cycle is such a problem, the Trust also funded two further projects into inflammation. Dr Schock in Belfast is investigating a protein that controls the body's inflammatory response to infection and which is only produced in low amounts in people with Cystic Fibrosis. In Dundee, Dr Mehta is researching a different protein that his team has discovered links CFTR (the protein that controls the movement of sodium and chloride through the cell lining and which in CF either doesn't, or only partially, works) and inflammation.

The fault in CFTR is the underlying cause of the problems in CF and Professor Cuthbert in Cambridge is researching the use of an existing drug to open other channels in the cell walls to allow the movement of sodium and chloride.

Dr Sheppard (see pages 10-11) continued his work into potentiators, which are drugs that bind to the CFTR and help it to do its job properly. Many possible potentiators have been discovered and this project will assess them for their effect on CFTR function for specific mutations of the CF gene.

Finally, we funded Dr Fisher in Newcastle who is using a modified bypass machine to increase the number of lungs that are suitable to be transplanted (currently around 75% of available donor lungs are unusable) and a natural anti-inflammatory protein to protect the lungs following transplant.





Along with scientific research, improving the clinical care for people with CF in the UK, both now and in the future, is an integral part of our remit.

# Clinical Care

## **Emma Lake, Expert Patient Advisor, Cystic Fibrosis Trust**

Emma Lake, 27, has been working at the Cystic Fibrosis Trust as an Expert Patient Advisor for over six years. Emma was diagnosed with CF at birth, and her role at the Trust involves using her knowledge of living with Cystic Fibrosis to influence those involved with the commissioning and provision of CF care and services.

Along with the CF Trust's six other Expert Patient Advisers, Emma also liaises with the CF community at large to ensure their voice is heard.



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Access to good CF care is of the utmost importance for people with Cystic Fibrosis, and the CF Trust works hard to ensure a high standard of care is available to all, wherever they live in the UK.

## **Clinical care and campaigning**

Last year the CF Trust spent £1.1 million on campaigning and clinical care to improve the outlook for people with Cystic Fibrosis in the UK.

Comprehensive assessments of 29 CF Centres and Clinics were conducted as part of our peer review programme to improve the level of care that hospitals can offer their CF patients. As a direct result of these visits, which are conducted by a panel of experts in CF care in conjunction with the CF Trust, over £14 million additional funding has been pledged to two-thirds of the CF services reviewed for new facilities and increased staffing. Work will continue to address identified shortfalls.

The CF Trust works hard to address inequalities in patient care. When our peer reviews revealed a lack of dietetic support to be a common theme, we surveyed dietitians, families and adults on our database to ask for their views, which gave us a strong case to present to funding bodies. This resulted in some significant pledges to improve the situation, but there is still a lot more to do in this area. We are currently repeating this survey for physiotherapy and next year hope to address psycho-social services, which have also been identified as lacking or inadequate in some Centres and Clinics. Having the relevant information will enable us to make an effective case to NHS managers for improvements.

Ensuring good CF care in the future is also very important. The CF Trust allocates training grants to encourage trainee consultants to become adult CF consultants. The success of this scheme is encouraging – four specialist CF consultants have been appointed since it began in 2005 – and last year we were able to offer two more grants for this purpose. We also continued to offer our development grants for CF services in response to specific needs.

Our work on Payment by Results, an initiative with the Department of Health to agree the proper cost of good CF care and ensure that CF clinical teams are properly resourced, continued to make steady progress. A detailed costing/banding document was submitted to the Department of Health for analysis in March 2009, and it is hoped that a mandatory national tariff based on an annual/banded package of care will be implemented by the start of the financial period in 2011-2012.

The UK CF Registry, a database of all those with CF in the UK, continued to provide invaluable data about CF, enabling us to identify patterns and anomalies in CF care and outcomes across the UK, and tailor our campaigning and clinical care programmes more effectively. This year, the Registry revealed the very encouraging news that the median predicted survival for people with CF in the UK now stands at 35.2 years, compared to 31, and we expect it to rise further year on year.

Work continued on our Clinical Care Pathway, a comprehensive online resource detailing the care that people with CF should expect from birth onwards. This pathway will be launched in 2010. Finally our team of seven Expert Patient Advisers, all of whom have CF, continued to work with health authorities across the UK to ensure CF remains a priority on healthcare agendas.



The diverse needs of people with CF and their families, as well as the wider CF community, are met in a personal, focussed and practical manner.

# Support

## **Anne Hayler, Helpline Officer, Cystic Fibrosis Trust**

Anne Hayler has worked at the CF Trust for over 15 years. Her first role was as a regional coordinator for the support service, and for the last seven years, Anne has provided a sympathetic ear as well as practical, expert advice to those who call the CF Trust helplines.



pulling together

From medical literature to conferences to welfare grants, we strive to ensure information about all aspects of life with Cystic Fibrosis is readily available and easily accessible by all.

## Information, advice and support

As well as improving standards of clinical care for those with Cystic Fibrosis, last year we spent £1.1 million providing information, advice and support to those affected by CF, as well as health professionals, the media and any other interested parties.

Our experienced helpline staff provide sensitive, expert advice to anyone affected by Cystic Fibrosis. There are three confidential helplines for general issues, benefits and welfare grants, which last year responded to over 3,000 calls.

Complementing the helplines, our email Q&A service *Ask the Expert* provided information and in many cases reassurance to the hundreds of people who emailed questions last year; a panel of over 100 experts ensuring a timely response to queries. We also added new factsheets and documents to our extensive catalogue of publications, most of which can be downloaded online free of charge.

Our programme of conferences went from strength to strength, with excellent turnouts at our annual parents' and medical conferences (pictured left). We also held a series of smaller, regional conferences to keep families up to date with our activities and region-specific clinical care issues. And our annual meeting for the Directors of Specialist CF Centres in the UK continued to provide a unique forum for the discussion of key issues in CF care, also helping to promote equality of care across the UK.

Living with a chronic, lifelong condition such as Cystic Fibrosis can be challenging financially as well as physically and emotionally. Last year we allocated over £206,000 in welfare grants to help make life a little easier.

*Stars in the Sky*, our online memorial to those with CF who have died, has been running for three years now, and many bereaved families take comfort from this opportunity to remember a loved one.

Regular communication with the CF community is of great importance, especially as infection risks prevent regular, face to face contact between people with Cystic Fibrosis. Last year we joined *Twitter*, started a blog, and launched our e-newsletter *CF Now*, a *You Tube* channel, a *Flickr* and a *Facebook* page, the latter which had over 5,000 followers after 12 months. Making use of these social media opportunities has enabled us to communicate with and update the CF community about our activities and CF-related news with far greater regularity, and has also increased the opportunities for discussion between people affected by Cystic Fibrosis.

Although keeping CF in the spotlight can be difficult sometimes, we do all we can to ensure that our profile doesn't dip, and in the past year, we received numerous mentions in print media as well as on the radio and television, including a detailed article on our gene therapy trial in *The Observer* magazine.





Despite the gloomy economic outlook, the CF community remains as strong as ever, pulling together to help raise funds and help us improve the outlook for all those affected by Cystic Fibrosis.

# Fundraising

## **Nikki Samsa, CF Trust Senior Regional Fundraising Manager, and her daughter Beth**

Nikki Samsa has worked at the CF Trust for over five years. In her role as Senior Regional Fundraising manager Nikki leads the Trust's team of seven fundraisers for the south of the UK, who provide a support network for the thousands of individuals who fundraise tirelessly for the Trust throughout the year. Nikki is inspired every day in her work by her nine-year-old daughter Beth, who was diagnosed with Cystic Fibrosis at six weeks old.



pulling together

Our fundraisers ran, walked, danced and bounced, pulling together with our branches, groups and corporate partners in the fight against Cystic Fibrosis.

## Fundraising

It has been a turbulent year financially with the credit crunch and recession, but despite this, through the great efforts of the CF community, we still raised £9.3 million. Although this is not as high as we had hoped, we will continue to pull together to fund our important work.

The CF community is at the heart of what we do, and once again a magnificent effort by people with CF, their parents, partners, siblings, grandparents, other family members and friends has formed the core of our income. From cycling to recycling, and from Big Brother to the Big Apple, there was something for everyone.

There are so many amazing stories and events - as many as there are fundraisers - such as the Big Apple Ball in Scotland raising £25,000, the Swansea skydive raising £9,000, Santa Runs in Northern Ireland bringing in £8,000 and the second Sparkle Ball in London raising £150,000 towards a new adult CF unit in Sheffield.

Guests at the Sparkle Ball were entertained by gifted musician Alex Stobbs, a documentary about whom was shown on Channel 4 raising a lot of interest in Cystic Fibrosis from the public. Also on Channel 4 last year, we were delighted to receive over £94,000 from phone votes on Big Brother.

For those who like an active life, the Cat & Fiddle 55-mile cycle ride had another record year with almost 1,500 cyclists raising over £55,000 and braving the infamous seven-mile climb. Team CF runners raised impressive amounts in the London Marathon, the Great North Run and New York City Marathon to name but three. For details of how to get involved, visit [www.cftrust.org.uk/help/events](http://www.cftrust.org.uk/help/events). We also held a fundraising match at the home of English rugby in Twickenham with singer Josh Jones who has CF playing alongside professional (and some not-so professional!) team-mates.

The introduction of our *Dance for CF* campaign saw a huge rise in popularity of dance-based fundraising events - almost £450,000 has been raised so far through discos, balls and danceathons.

Our recycling fundraising also began to raise good money last year and now around £7,000 each month is brought in this way. Another important source of income is legacies. In the last financial year, we received nearly £700,000 from gifts supporters left in their wills. We are extremely grateful to everyone who chooses to support our work in this way. It doesn't matter how large or small the gift is, every gift in a will makes a difference.

Whether you donate to an appeal, run a marathon, organise a ball, leave a legacy or abseil from a building, every penny helps us continue our work for those with Cystic Fibrosis. Thank you to all of our magnificent fundraisers past and present, our branches and groups and our corporate friends. Please keep going as we could not do it without you.



**Ben Shephard, CF Trust patron, with his wife Annie**

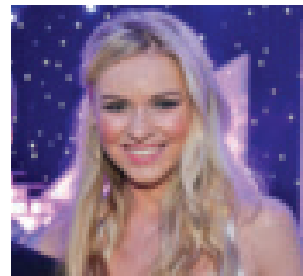
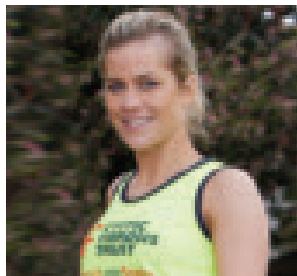
"I have been supporting the CF Trust for five years, and this year I ran my second marathon for the charity on the island of Tresco. Since my association with the Trust I have met many incredible people, and I am always moved and amazed by the determination of those with Cystic Fibrosis to live life to the full. Although there is still some way to go in the fight against the disease, people with CF are living longer than ever and I have great confidence for the future, providing we all continue to support the Trust in whatever way we can."

## Celebrity support

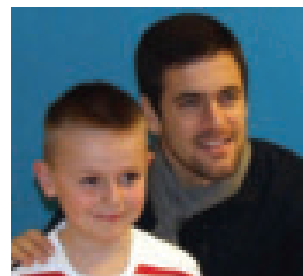
### pulling together

Our celebrity patrons and supporters are invaluable in helping us raise the profile of Cystic Fibrosis and the work of the CF Trust, both in the media and in the public at large. They give us their time, support and encouragement with great generosity. We are immensely grateful to all of those pictured on these pages and to the many others, who do so much to keep CF in the spotlight.

Ben Fogle  
Kate Lawler  
Zoe Salmon



Gus Poyet &  
David Baddiel  
Darren Campbell  
Joe Cole & Luke Phair\*



David Bull  
Jenny Agutter  
Natalie Imbruglia &  
Kate Smith\*



David Seaman  
Gail Porter  
Bill Bryson



\*person with CF

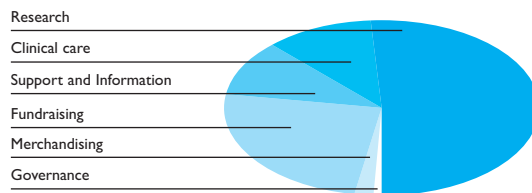
## Summarised accounts

Year ended 31 March		2009	2008
Income and Expenditure Account		£,000	£,000
<b>Where our money comes from</b>	CF Trust branch and community	4,853	6,109
	Donations	3,828	4,796
	Merchandising	236	205
	Investment income	357	420
	<b>Total Income</b>	<b>9,274</b>	<b>11,530</b>
	Other (losses)	(531)	(350)
	Transfer from / (to) reserves	1,558	(1,499)
		<b>10,301</b>	<b>9,681</b>
<b>Where our money goes</b>	Research	5,278	4,982
	Clinical care	1,141	1,121
	Information, advice and support	1,073	957
	Fundraising	2,549	2,385
	Merchandising	193	161
	Governance	67	75
	<b>Total Spending</b>	<b>10,301</b>	<b>9,681</b>
<b>Balance sheet</b>	Fixed assets	1,282	1,145
	Investments	3,698	4,071
	Debtors	526	964
	Cash	5,614	5,067
	Grants payable	(11,866)	(10,502)
	Other creditors	(382)	(315)
	<b>Net (liabilities) / assets</b>	<b>(1,128)</b>	<b>430</b>
	Endowment funds	821	920
	Restricted funds		
	Gene Therapy Consortium	(9,479)	(5,725)
	Others	556	419
	Unrestricted funds	6,974	4,816
	<b>Total Funds</b>	<b>(1,128)</b>	<b>430</b>

### Total Income



### Total Expenditure



## Report by the Trustees on the Summarised Financial Information

This 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 6 October 2009. The statutory financial statements, on which the auditors Horwath Clark Whitehill LLP gave an unqualified audit report on 6 October 2009, 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 2009.

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.

**Dr James Littlewood** OBE MD FRCP FRCPE FRCPC DCH  
Chairman  
6 October 2009

## Organisation

### Patron

HRH Princess Alexandra  
KG GCVO

### President

Mr Duncan Bluck CBE

### Vice President

Mr Peter Levy OBE FRICS

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Dr James Littlewood OBE MD  
FRCP FRCPE FRCPCD DCH

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Mr Allan Gormly CMG CBE

### Hon Treasurer

Mrs Alison Halsey FCA

### Chair of Research

#### Advisory Committee

Professor Stuart Elborn  
MD FRCP

#### Chair of Medical Advisory Committee

Dr Diana Bilton MD FRCP

### Chief Executive

Mrs Rosie Barnes

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Mrs Giorgia Arnold  
Mr Duncan Bluck  
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Professor Stuart Elborn  
Mr Allan Gormly  
Mrs Alison Halsey  
Mr Brian Henderson  
Sir Robert Johnson  
Mr Archie Norman  
Mr Ed Owen  
Mr Martyn Rose  
Mr Peter Sharp

### Company Secretary

Mr Alan Larsen ACA

### Research Advisory Committee

Professor Stuart Elborn *Chair, 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*  
Mrs Giorgia Arnold *Parent Representative*  
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*  
Dr Andy Jones *Adult Physician, Wythenshawe Hospital, Manchester*  
Dr Daniel Peckham *Adult Physician, St James's University Hospital, Leeds*  
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*  
Dr Craig Winstanley *Microbiologist, University of Liverpool*

### Medical Advisory Committee

Dr Diana Bilton *Chair, Adult Physician, Royal Brompton Hospital, London*  
Dr Iolo Doull *Deputy Chair, Consultant Paediatrician, Children's Hospital for Wales, Cardiff*  
Ms Maxine Bedford *Parent Representative*  
Dr Mandy Bryon *Consultant Clinical Psychologist, Great Ormond Street Hospital, London*  
Dr Gary Connett *Consultant Paediatrician, Southampton General Hospital*  
Ms Clare Cox *Pharmacist, Papworth Hospital, Cambridge*  
Ms Katie Ferguson *Paediatric Physiotherapist, King's College Hospital, London*  
Dr David Honeybourne *Adult Physician, Heartlands Hospital, Birmingham*  
Dr Alastair Innes *Adult Physician, Western General Hospital, Edinburgh*  
Mrs Alison Morton *Specialist CF Adult Dietitian, St James' University Hospital, Leeds*  
Mrs Lynsey Morton *Patient Representative*  
Dr Rosie Rayner *Consultant Paediatrician, New Cross Hospital, Wolverhampton*  
Ms Kathy Wedlock *CF Nurse Specialist, Bristol Children's Hospital*  
Mrs Sue Wolfe *Specialist CF Paediatric Dietitian, St James' University Hospital, Leeds*

### UK CF Gene Therapy Consortium Scientific Advisory Committee

Professor Stuart Elborn *Chair, Adult Physician, School of Medicine, Queen's University of Belfast and Belfast City Hospital*  
Mr Aaron Brown *Patient Representative*  
Professor Pierre Lehn *Laboratoire de Biogenetique et HLA, INSERM, France*  
Professor Gerry McElvaney *Department of Medicine, Royal College of Surgeons in Ireland*  
Mrs Nikki Samsa *Parent Representative*  
Professor Brandon Wainwright *Institute for Molecular Bioscience, The University of Queensland, Australia*  
Dr James Littlewood *Chair, Cystic Fibrosis Trust*  
Mr Allan Gormly *Deputy Chair, Cystic Fibrosis Trust*  
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. We must all pull together to ensure that our work in research, support and care can continue.

There are many ways you can help the CF Trust.

### **Local fundraising**

We have many active branches and groups across the UK. Visit [www.cftrust.org.uk/help/whatsoninyourarea](http://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](http://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](http://www.cftrust.org.uk/help/nationalcampaigns) for details.

### **Making a donation**

You can make a donation by using the form overleaf, by calling 020 8464 7211 or online at [www.cftrust.org.uk/help/howtodonate](http://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.

### **Leaving a gift in your will**

You can leave a lasting legacy to those with Cystic Fibrosis by remembering us in your will. Email [legacies@cftrust.org.uk](mailto:legacies@cftrust.org.uk) for further confidential information.

**Thank you for your support.**

**Donation Form**

**Your Details**

Title	Forename
Surname	
Address	
Email*	Postcode

**Your Gift**

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

£10 ☐ £25 ☐ £50 ☐ £100 ☐ other

☐ **I enclose:** Cheque/Postal Order/CAF Voucher Please make cheques payable to *Cystic Fibrosis Trust* OR

Please debit my:

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

Card No

Start date  /  /  Expiry date  /  /

Issue No (Switch/Maestro)  Security No\*  \*Last three digits on signature strip on back of card (four on Amex)

Signature	Date
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**Make your gift go further at no extra cost to you.** Tick all that apply:

- ☐ I would like to Gift Aid this donation.
- ☐ I would like to Gift Aid all future donations until further notice.
- ☐ I would like to Gift Aid all previous donations for the charity's current financial period and the previous four:

*giftaid it*

To qualify for Gift Aid, you must pay an amount of UK Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (currently 25p for each £1 given).

Please return the completed form to: Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY

**Data Protection / Privacy Policy** The Cystic Fibrosis Trust does not sell or rent your personal details to any other organisations. The details you provide on this form may be used to contact you about our work. Please see [www.cftrust.org.uk](http://www.cftrust.org.uk) for details of our Privacy Policy.  
**\*Email consent:** By giving us your email address, you are giving us consent to send emails to you with information about our work and events.

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## Trust & Corporate supporters

The Cystic Fibrosis Trust is grateful to all the individuals, companies and trusts who support our work. We would particularly like to thank:

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[www.cftrust.org.uk](http://www.cftrust.org.uk)

**Cystic Fibrosis Trust**

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**Cystic Fibrosis Helpline: 0845 859 1000**

**CF Benefits Helpline: 0845 859 1010**

**CF Welfare Grants Helpline: 0845 859 1020**

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