



Living with Cystic Fibrosis

Cystic Fibrosis Trust Annual Review 2010



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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 8,500 children and adults in the UK.

Over two million people carry the faulty gene that causes Cystic Fibrosis - 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 two young lives are lost to Cystic Fibrosis.

Around half of people with Cystic Fibrosis will live over 38 years, although improvements in treatments mean 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.



Living with Cystic Fibrosis

The theme of this annual review is *Living with Cystic Fibrosis*, and within these pages, you will read about individuals and families doing just that.

In the past few years, we've witnessed encouraging developments in the management and treatment of Cystic Fibrosis, which have improved the prognosis for all those living with CF whether adults or newly diagnosed. Median predicted survival in the UK now stands at 38.8 years (meaning half of all people with CF will live to this age or older), and it is thought that babies born today with CF could live into their fifties or older.

But this is no time to rest on our laurels. Cystic Fibrosis is still a life-threatening illness, and sadly, still claims two young lives each week. For many, living with CF is a daily battle to stay well. There is no doubt that fantastic progress has been made, but we must all work together to keep up the momentum, to make life easier, and the future brighter, for all those living with Cystic Fibrosis.



A message from HRH Princess Alexandra

The theme of this year's annual review is *Living with Cystic Fibrosis* and I am pleased to learn that the outlook for those affected by this condition continues to improve. This is testament to both the work of the Cystic Fibrosis Trust and the enthusiastic support of the community at large.

The strength and positive outlook of so many people affected by Cystic Fibrosis continues to inspire. Despite the considerable burden that living with this condition entails, those affected remain determined to live their lives as fully as possible. I hope you will too be inspired.

Thank you to everyone who continues to support the Cystic Fibrosis Trust – you really do make a difference.



Highlights of the year

Data from the UK CF Registry showed that the median predicted survival for people with Cystic Fibrosis has increased from 35 to 38.8 years.

A record amount was raised by Team CF runners in the 2009 London Marathon, ten of whom had Cystic Fibrosis.

Based on encouraging data from the pilot study, approval was given for the toxicology study of our gene therapy trial.

A new fundraising event, the Forth Rail Bridge Abseil, raised over £42,000.

Excellent progress was made on the Payment by Results initiative to develop a more sustainable and appropriate method of funding Cystic Fibrosis care.

Our partnership with the Manchester United Foundation, which ended this year but raised much awareness and over £200,000.

A man with Cystic Fibrosis received a lung transplant in a revolutionary procedure using reconditioned lungs - made possible by Cystic Fibrosis Trust-funded research.

The Cystic Fibrosis Trust became the official charity of the Belfast City Marathon, whose events raised close to £131,000.

As of April 2010 approximately £18 million of additional funding had been pledged to CF Centres and Clinics in the UK as a direct result of the Cystic Fibrosis Trust's peer review program.

The Busy Bees Childcare partnership, which was highly successful both in generating valuable fundraising income and in encouraging support and volunteering too.



A message from Rosie Barnes

Cystic Fibrosis remains a very serious condition, but the prognosis is very much better than it was 14 years ago, when I became Chief Executive of the Cystic Fibrosis Trust. Then, it was not uncommon to hear of the death of a child with Cystic Fibrosis. Now it is a very rare event indeed. Then, the average life expectancy was barely 30. Now the median predicted survival is nearly 40 and for children born today, it is likely to be much older.

We did not have newborn screening in 1996, and after a long battle, it is now available throughout the UK. This means that babies with Cystic Fibrosis will be treated immediately to keep them well, and the misery of families with a sick young child but no idea of what is wrong with them will become a thing of the past.

The NHS care of many of those with Cystic Fibrosis has been chronically underfunded, but steps are in hand and plans well advanced to address this. The fear and hope that CF families live with still remain, but perhaps the fear has been dampened somewhat, and the hope of new treatments, including gene therapy, is giving greater optimism for a better future.

There is still a great deal to be done and I know the team at the Cystic Fibrosis Trust will continue to push back the frontiers of knowledge and treatment under the new leadership of Matthew Reed. Although by the time this report has been published I will have retired as Chief Executive, I will remain a loyal ambassador for those affected by Cystic Fibrosis.

I have been privileged to have worked to improve life for those with Cystic Fibrosis and their families, both in terms of their NHS care and in giving hope of significant advances in treatments for CF in the future. I am confident that whilst CF will remain a serious challenge, it is only a matter of time before those with CF can expect to have a much longer and better quality of life. I look forward to hearing that the Cystic Fibrosis Trust has been asked to produce one of our consensus documents entitled 'CF in old age'.

Rosie Barnes



A message from Dr James Littlewood OBE

Although this has been a difficult year financially, and the Cystic Fibrosis Trust has not been spared the effects of the recession, we have been able to continue with our two main initiatives - the gene therapy programme, and the very successful measures to improve the care of people with Cystic Fibrosis throughout the UK.

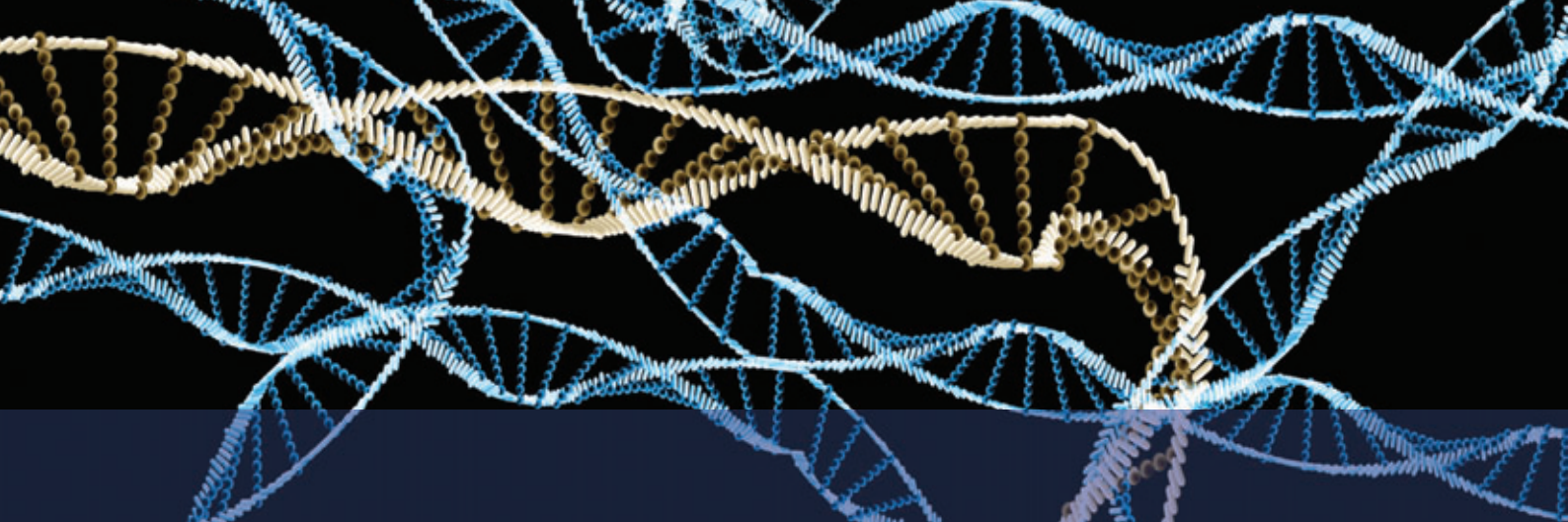
The Gene Therapy Consortium, formed at Rosie's initiative in 2001, has now started clinical trials with the product it has developed - the first major trial of gene therapy in the world. Congratulations to all involved.

With the increasing number of people with Cystic Fibrosis, and the greater proportion of adults, the provision of a high standard of care is a major requirement. The collaboration with the Department of Health and the very effective system of peer reviewing of CF Centres, initiated by the Cystic Fibrosis Trust and now popular with clinicians, is effective in achieving major improvements in many Centres.

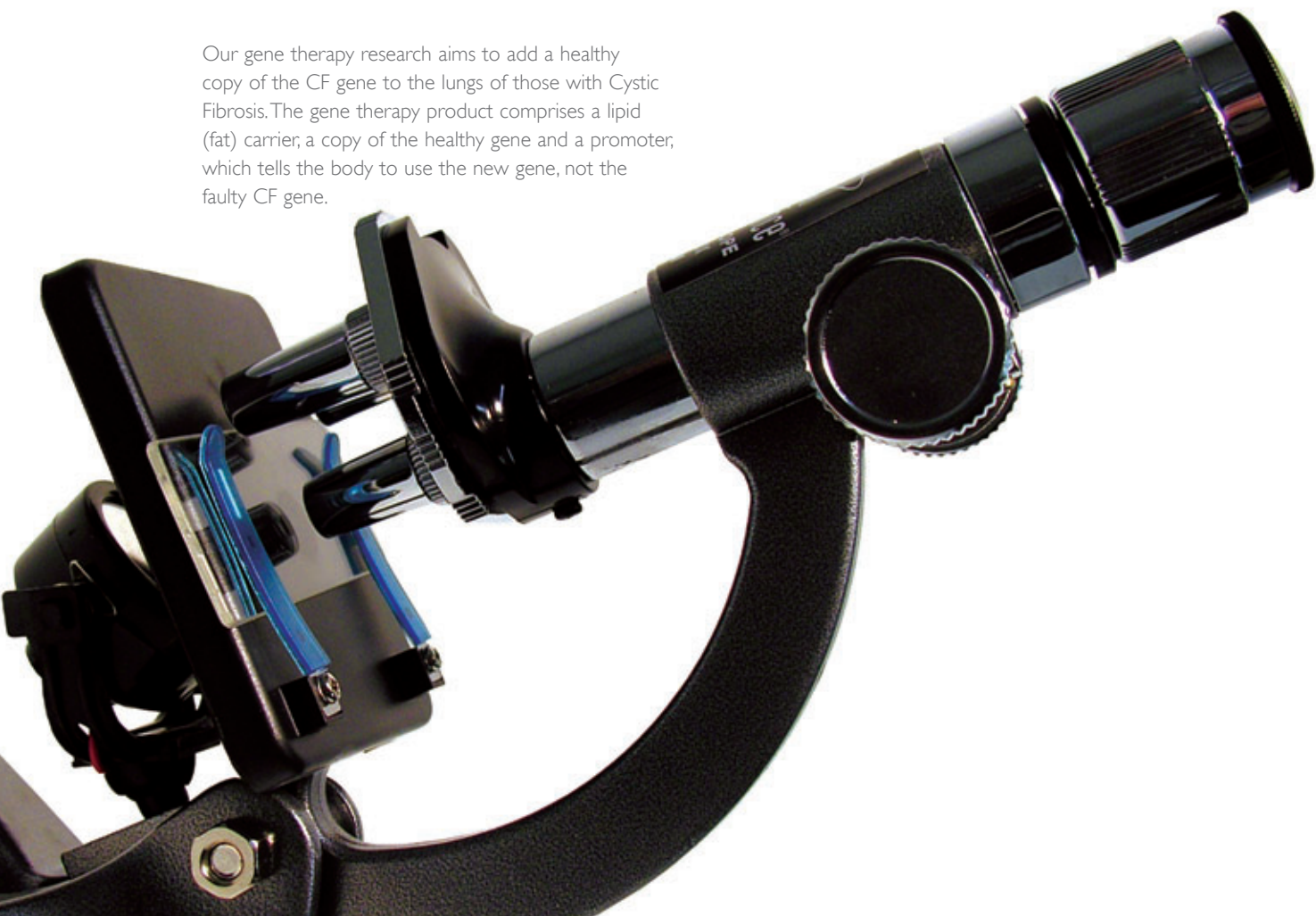
There will be major changes at the Cystic Fibrosis Trust in 2010. Rosie Barnes retired in August after 14 very successful years as Chief Executive. She is now known to and held in the highest regard and affection by all of us concerned with Cystic Fibrosis; her achievements are nationally and internationally appreciated. It is reassuring that we have been fortunate to appoint a worthy successor, Matthew Reed, from a wide field of applicants and we are confident that he will continue the steady progress that Rosie has achieved.

Survival continues to improve and the theme of this year, *Living with Cystic Fibrosis*, reflects the Cystic Fibrosis Trust's determination to ensure that despite the obvious problems still experienced by many people with CF, their quality of life is the very best that can be achieved.

Dr James Littlewood OBE, Chairman, Cystic Fibrosis Trust



Our gene therapy research aims to add a healthy copy of the CF gene to the lungs of those with Cystic Fibrosis. The gene therapy product comprises a lipid (fat) carrier, a copy of the healthy gene and a promoter, which tells the body to use the new gene, not the faulty CF gene.





gene therapy

In the last financial year, the Cystic Fibrosis Trust spent £2.8 million on its world-leading gene therapy research. Effective gene therapy would treat CF lung disease, irrespective of genetic mutation.



Living with CF: Katie's story



Name: Katie Holmes

Age: 13

Lives: Dumbarton, Scotland

I live with my mum, dad and five brothers and sisters. I'm in my third year of high school and have just started my options for my Standard Grades.

My younger sister of two, Lucy, also has Cystic Fibrosis. I want to set a good example for her future and this makes me try even harder to keep myself well. I hope that gene therapy works so I know her and all the other young people with CF, including me, have a bright future. It was an absolute privilege for me to take part in the gene therapy trials and I am so excited to see what the outcome is!

Living with Cystic Fibrosis, as anyone could guess and people with CF will know, isn't easy. But I always try and see the positive side of my life. No matter how difficult it may sometimes be, I wouldn't have it any other way.

Gene therapy

In the last financial year, we invested over £2.8 million in gene therapy research. It has been a year of good progress in which the single dose pilot study continued and work began to prepare for the multi-dose clinical trial planned for 2011.

The UK CF Gene Therapy Consortium comprises 80 dedicated scientists and clinicians working in Edinburgh, London and Oxford. This is the largest dedicated Cystic Fibrosis gene therapy team in the world.

The single dose pilot study is aimed at ensuring safety and gives an opportunity to measure molecular changes. It began early in 2009 and different doses of the gene therapy product were given to 16 people with Cystic Fibrosis. Each patient had a huge array of tests and measurements taken.

All of the patients who had a single dose, experienced a mild flu-like reaction. The symptoms were short lived and noticed more by the clinicians than the people with Cystic Fibrosis themselves and were relieved by normal painkillers. One patient felt tired for a few days following the dose whereas another went swimming early the following morning. The scientists believe this reaction is caused by being over efficient at delivering the gene - 75% greater delivery than in previous trials.

Encouragingly, in some of the patients on the pilot study, evidence of production of the CFTR protein (that controls the movement of salt through the cell lining and which is faulty in CF) was recorded at levels found in people without Cystic Fibrosis. These are the largest changes ever recorded using any therapy in CF, though this only happened in a few patients.

The Consortium is now working to refine the pilot study with a lower dosing level and pre-treating people with normal painkillers before the dose. The pilot will continue through 2010, but on the results so far, our Scientific Advisory Committee recommended the Trustees approve starting the toxicology study, which must happen before the multi-dose clinical trial. This is now underway.

Part of the planning for the multi-dose trial is the run-in. During the last year, over 150 people with Cystic Fibrosis have completed four visits to have an enormous range of clinical measurements. Of these, around 100 are now being selected to go through to the trial. The criteria for inclusion include the ability to deliver gene therapy and the ability to measure what effect it has had. Those chosen will continue to be tested every six months until the trial planned for the second half of 2011.

Although we are concentrating on wave 1, the Consortium has now selected a lead wave 2 product, which is a virus carrier for the CF gene. This modified virus looks able to be given repeatedly (most virus carriers are only effective once) and looks potentially more effective than the wave 1 product.

We remain committed to funding our world-leading gene therapy for Cystic Fibrosis.



Although we believe gene therapy will be an effective treatment for Cystic Fibrosis, we do not put all of our eggs in one basket. We continue to fund other areas of research aimed at both treating the symptoms of CF and exploring other ways of correcting the basic defect through drugs.





research

In the last financial year, the Cystic Fibrosis Trust spent £272,000 on non-gene therapy research and committed hundreds of thousands more for ongoing and future work in areas such as transplantation, inflammation, infection and drug treatments.



Living with CF: James's story



Name: James Finlayson
Age: 24
Lives: North Yorkshire

I was diagnosed with Cystic Fibrosis when I was about 18 months old. Last year, I received a double lung transplant using reconditioned lungs, in a procedure made possible by research funded by the Cystic Fibrosis Trust. Without these lungs, I may never have received a lung transplant. My transplant has transformed my life and enabled me to be part of the world again.

I have a degree in Transport and Product Design from Coventry University. Before I became too ill I did competitive kart racing. Now that I have had a lung transplant I am looking forward to getting a job, taking up my hobbies again and moving on to the next stage of my life.

Medical research

The Cystic Fibrosis Trust is committed to funding research that will have an important and/or imminent clinical benefit to those with Cystic Fibrosis. In the last financial year, we funded £272,000 of research across the UK in areas of clinical studies, infection, basic science and inflammation.

Currently around 70% of donated lungs are not used and sadly, many people with Cystic Fibrosis die whilst waiting on the transplant list. We funded Professor Fisher and the transplant team at Newcastle University and Freeman Hospital who are transforming currently unusable donated lungs into viable lungs for transplantation.

We funded a programme based at University College London to detect the earliest signs of lung damage in infants with Cystic Fibrosis. It is believed that lung function may be impaired even if there are no respiratory symptoms. Early detection means early treatment.

We also funded the UK part of an international study based at the Leeds Teaching Hospital into depression and anxiety in people with Cystic Fibrosis and their caregivers, which may have an impact on adherence to treatment and health outcomes.

Research funded by the Cystic Fibrosis Trust continued at Belfast City Hospital to assess the impact of infection with *Pseudomonas aeruginosa*, the most common cause of chronic infection in CF, on lung exacerbations in those with Cystic Fibrosis.

An important area of research in Cystic Fibrosis is the use of specific drugs or combinations of drugs to rescue the activity of CFTR - the protein that controls the movement of salts through the cell lining and which is faulty in CF (the basic defect). This class of drug is called a potentiator and we funded a project at the University of Bristol to test how different potentiators enhance the activity of CFTR and to test new combinations of drugs.

At the University of Cambridge, we funded tests on a drug that has been shown to increase secretions to explore whether the drug has potential to improve the levels of mucus in the CF airway.

The cycle of infection, inflammation and lung damage is central to Cystic Fibrosis, and we funded four projects investigating various aspects of this cycle: a grant was continued at Queen's University Belfast examining a receptor in the airways, which controls inflammation and which is stronger in the CF lung; our funding continued for the joint Medical Research Council project at Newcastle University investigating a chemical that drives inflammation in the CF airway; a project on inflammation at a molecular level was continued at the University of Dundee to explore findings made in previous CF Trust-funded work; and a grant was made to Belfast City Hospital to investigate inflammation in the airway caused by yeasts and fungi in the lungs of people with Cystic Fibrosis. Each of these projects is aimed at finding new ways of tackling the problem in the CF lung; essential, as lung disease is responsible for over 90% of deaths in Cystic Fibrosis.



A multidisciplinary team comprising doctors, specialist nurses and allied health professionals such as physiotherapists, dietitians, social workers and psychologists, is essential for effective and safe treatment of a complex, multi-system disease such as Cystic Fibrosis. We are working hard to ensure CF teams across the UK are adequately resourced.





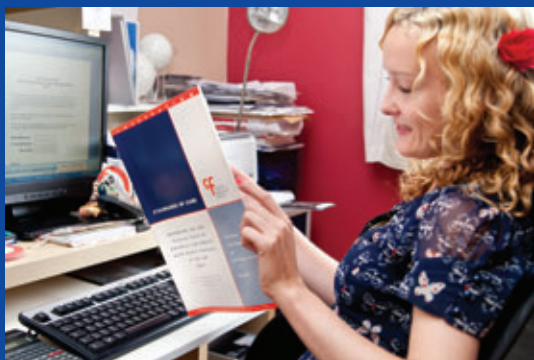
clinical care

In the last financial year, the Cystic Fibrosis Trust spent £1.3 million on improving clinical care. Our ultimate aim is that everyone with Cystic Fibrosis in the UK has a safe, equitable level of care, regardless of postcode.





Living with CF: Lynsey's story



Name: Lynsey Morton
Age: 27
Lives: York

I was diagnosed with Cystic Fibrosis at birth due to a blocked bowel (meconium ileus). I take up to 45 tablets a day and have daily physiotherapy and nebuliser treatments to help control my symptoms. I also have regular intravenous antibiotics via a drip to help fight off chest infections.

Despite my Cystic Fibrosis I am a keen runner which helps to clear mucus from my chest, keeping my lungs as healthy as possible and infection free.

I work for the Cystic Fibrosis Trust as an Expert Patient Adviser covering the Yorkshire, Humber and North West regions. There are seven of us based across the UK and we all have Cystic Fibrosis. Our role is to represent the views of the wider CF community and to help influence and improve CF clinical care locally and nationally.

Clinical care and campaigning

The Cystic Fibrosis Trust is committed to a robust clinical care programme, and in the past year has campaigned heavily for safe, appropriate and fair care for the 8,500 people with Cystic Fibrosis in the UK.

Work continued to develop a national annual banded tariff for Cystic Fibrosis, aimed at ensuring equitable and transparent funding for CF care. Data for over 2,000 people with CF from six paediatric and six adult Specialist CF Centres were collected and analysed to produce an annual cost for CF care based on level of resource required and severity of the disease. Work is continuing to refine this with a view to introducing the new payments across England from April 2011.

The Cystic Fibrosis clinical care pathway, a project initiated by the Cystic Fibrosis Trust at the request of specialist commissioners in the provision of CF care, is nearing completion. The pathway will make it easier for commissioners to understand exactly what care and treatment a person with CF needs and should expect at different points of their lives. A complex, multi-system disease such as Cystic Fibrosis also demands specialist treatment by expert clinicians. Last year the CF Trust provided two training grants to junior doctors, to train as specialist CF consultants. These grants help to safeguard CF care for future generations.

The UK CF Registry, a database of Cystic Fibrosis patients developed by the Cystic Fibrosis Trust, provides detailed information about CF care and outcomes across the UK enabling us to target help to where it is most needed. This year, data from the Registry showed the prognosis continues to improve for people with CF, as the median predicted survival has increased from 35 to 38.8 years.

As part of the Cystic Fibrosis Trust's highly-regarded peer review programme, eight Specialist CF Centres and 23 Networked Clinics were reviewed in 2009/10. As of April 2010 approximately £18 million of additional funding had been pledged to the Centres and Clinics visited - directly attributable to this intensive work which continues apace.

The Cystic Fibrosis Trust's well-attended annual Medical Conference is a chance for CF teams to converge and learn about recent advances and best practice in the clinical care of people with Cystic Fibrosis. The CF Trust also holds an annual meeting for the Directors of the UK's Specialist CF Centres, providing an invaluable opportunity for discussion and debate.

Our seven Expert Patient Advisers (EPAs), each of whom has Cystic Fibrosis, continued to work to improve clinical care across the UK, keeping abreast of clinical service developments and highlighting shortfalls in CF service provision. They work closely with people affected by CF and their families to ensure their views are heard and regularly represent patients on peer review panels. In the past year, the EPAs have worked hard to establish regional Patient Focus Groups to encourage discussion about topics of importance, such as management of cross-infection.

The EPAs have also been heavily involved in survey work we have carried out among specialist CF dietitians and physiotherapists to identify gaps in provision of these services, and we will use the results of this research to campaign for better services. Further research into psycho-social care provision is now planned.

Along with our policy adviser, who also has Cystic Fibrosis, we have submitted evidence to enquiries on hospital parking, benefits and prescription charges in the past year. All of these initiatives aim to improve clinical care, and we plan to keep up the pressure to ensure that everyone living with CF in the UK receives the care they need, and are entitled to.



We have expanded our online presence significantly in the last year, and our web forums and Facebook page in particular are extremely popular, providing a place for the CF community to chat and share news without the limitations of cross-infection.



support

In the last financial year, the Cystic Fibrosis Trust spent £912,000 providing information, advice and support to people affected by Cystic Fibrosis.

We listen to the CF community and ensure their needs are met in a practical and appropriate manner.



Living with CF: Chris's story



Name: Chris Benbow

Age: 22

Lives: Crewe

I am currently studying a photography degree and my main passion in life is night photography which I have invented my own word for - Noctography. Any work I sell I donate the money to the Cystic Fibrosis Trust and I am trying to use my work to help raise awareness of Cystic Fibrosis.

I was diagnosed with Cystic Fibrosis at four months and my first few years were quite a struggle, with overnight feeding and regular stays in hospital for intravenous antibiotics. I know it was hard back then but if I hadn't co-operated with the treatment I wouldn't be as well as I am today.

None of the advances in Cystic Fibrosis would have been made possible without the Cystic Fibrosis Trust and hopefully they will continue to be made. Money that the CF Trust awards to people living with CF can be a real life-saver. Recently, I received a start-up grant to help my wife and I furnish our new home, which we wouldn't have been able to afford to do without this financial support.

Information, advice and support

For people affected by Cystic Fibrosis, the Cystic Fibrosis Trust is often the first place they turn for information, advice and support. We take this responsibility very seriously and we work hard to ensure the information we provide is accessible, accurate and up to date.

We have an extensive range of factsheets and booklets to assist people living with Cystic Fibrosis, covering topics such as treatment options, physiotherapy guidance and general advice on day to day management. Last year, we were also pleased to add a new guideline on Antibiotic Treatment of Cystic Fibrosis to our series of highly regarded consensus documents for health professionals.

Our three helplines provide expert advice on benefits, welfare grants offered by the Cystic Fibrosis Trust, and a friendly, sympathetic ear for those who just want to chat. In 2009/10, the dedicated helpline staff responded to over 3,200 calls. In addition, our much-used *Ask the Expert* email service, manned by a panel of clinicians each specialising in different areas of Cystic Fibrosis, provides rapid responses to questions submitted by email. The experts respond to around 30 questions from the CF community each week.

Providing financial assistance is another way the Cystic Fibrosis Trust helps people with Cystic Fibrosis and their families. Last year we awarded over £100,000 in welfare grants, including start-up grants towards independent living for adults, pre-payment certificates for prescription charges, travel expenses for transplant assessments and also grants to assist with funeral expenses.

The Cystic Fibrosis Trust regularly holds conferences for parents of children and young adults with Cystic Fibrosis, to provide updates on care, treatment and disease management. In January 2010, we held a special meeting in London to update parents on the progress of the gene therapy trial, other research and clinical care. That over 700 people attended this event is testament to the demand for information about CF, and we intend to continue to hold parents' conferences in 2011 and beyond.

Keeping Cystic Fibrosis in the media is important, and we enjoyed good coverage throughout last year in national and local papers and on TV and radio. On Radio 4, CF doctors and researchers featured in a programme about clinical trials called *Trials for Life*, and there was also record coverage of Team CF runners in the London Marathon on BBC television.

As well as the wealth of information on our website about Cystic Fibrosis, our popular web forums enable people affected by CF to gain support from and share experiences with others; particularly pertinent as cross-infection risks restrict people with CF from meeting in person. Our Facebook group has grown to almost 24,000 members in the past year, and is a lively platform for the Cystic Fibrosis Trust to engage further with the CF community. Also on the web, we provide regular updates on the CF Trust's activities and highlight interesting and inspiring stories from the CF community on our Twitter page, YouTube channel and blog.

Find us online: www.facebook.com/cftrust www.twitter.com/cftrust www.youtube.com/cftrust





fundraising

In the last financial year, the Cystic Fibrosis Trust raised around £9 million. This is testament to the dedication and determination of the CF community in helping us raise vital funds. In tough financial times, our supporters are more important than ever.



Living with CF: Hannah's story



Name: Hannah Gorbey

Age: 3

Lives: Swansea

Hannah is very active and enjoys swimming and gymnastics. She takes all her medication without complaint, including inhalers and nebulisers when required. She is a very happy, delightful little girl who likes following in her big sister's footsteps. Her grandparents have nicknamed her 'Happy Hannah', as she is always smiling and loves to entertain others by singing and showing off her latest gymnastics moves.

Since Hannah was born she has had two hospital admissions, once with bronchiolitis and one for intravenous antibiotics following a long spell of antibiotics for a cough.

We fundraise to help the Cystic Fibrosis Trust pay for the research and development of new therapies, and especially the exciting gene therapy programme which is currently running.

Amanda Gorbey, Hannah's mum

Fundraising

Despite the continuing economic uncertainty, the Cystic Fibrosis community and the wider public helped us to raise £9 million in the last financial year, and we are extremely grateful for their efforts.

Community fundraising contributes to over half of our income. From coffee mornings to concerts, fashion shows to fun days, golf tournaments to garden parties, we are always inspired by the energy and enthusiasm of our supporters. People with Cystic Fibrosis and their families and friends, volunteers, and our hardworking Groups and Branches - the support of all of those in the CF community is invaluable.

For those who like to push themselves to the limit, running challenges remained hugely popular: Team CF runners in the 2009 London Marathon raised a record £387,000 and we also became the official charity of the Belfast City Marathon, which raised over £130,000 and considerable publicity for the Cystic Fibrosis Trust.

As well as old favourites, we are always on the lookout for new event opportunities. One of these, the inaugural Forth Rail Bridge Abseil held in September 2009, raised over £40,000.

And from China treks to London-Paris cycles, overseas challenge events raised over £327,000 last year. We are pleased that interest in these types of events is continuing to grow.

Our recycling partners, Precycle are now circulating approximately one million bags and generating in the region of £10,000 each month. Mobile phone, printer cartridge and clothing banks also continue to do well. We are very grateful to all who give so generously to these schemes. For more information on recycling visit www.cftrust.org.uk/help/recycling.

Along with a rewarding partnership with Busy Bees Childcare, our three-year partnership with the Manchester United Foundation and Football Club came to an end in 2010. This provided an invaluable opportunity to raise public awareness of Cystic Fibrosis, as well as almost £200,000.

We are also grateful for the continuing support of Next and BT, who have been involved with the Cystic Fibrosis Trust for many years. Without these and numerous other successful corporate partnerships, we couldn't have achieved all that we did throughout the year. However large or small a company, we endeavour to engage with all the staff and help them to achieve their Corporate Social Responsibilities with ease and enjoyment whilst supporting us.

With a vast choice of events, campaigns, partnerships and major fundraising initiatives there is something for everyone in fundraising and however our supporters choose to get involved they can be sure of our sincere appreciation and support in everything they do.

For details on how you can help, see page 31.



legacy giving



“Although I retired from the Cystic Fibrosis Trust in August this year, I plan to continue to work as an ambassador for the CF Trust and for people affected by Cystic Fibrosis. I hope the work I’ve helped to drive forward on gene therapy will be one lasting legacy I can leave; the other is the legacy that I’m leaving to the CF Trust in my will. This is a relatively simple way for me to support the CF Trust’s work in the future, whilst at the same time ensuring my family is cared for.”

Rosie Barnes

Making a difference today and tomorrow

In the last financial year, we received just over £950,000 in legacies. At nearly 10% of our income, this represents a significant source of funds and we would like to thank all those families and individuals who chose to support us in this way.

Many people may be put off leaving a legacy because they prefer to give financial support now in order to help those living with Cystic Fibrosis today. However, some projects we supported last year were funded with the help of legacies made many years ago. We would not have been able to undertake the same level of work if these individuals had not had the foresight to leave a gift in their wills.

In 2009 we received a legacy of £77,000 from the estate of Charles William Taylor. Mr Taylor had no next of kin and left his estate in the hands of solicitors Berry & Berry in Manchester. He requested that the proceeds of his estate - his two-bedroomed terraced house - be given to childrens' care organisations. Thanks to CF parents Angela and Patrick Regan raising awareness of Cystic Fibrosis, the work of the Cystic Fibrosis Trust was at the forefront of the solicitors' minds.

This legacy is helping to fund the training of a new Specialist CF Consultant at the CF Unit at Wythenshawe Hospital. It is difficult for doctors to gain enough experience of Cystic Fibrosis in the time allowed during standard training, so this grant will help give the specialist training necessary to ensure the best possible care for those with Cystic Fibrosis.

The training post was taken up by Dr Alex Horsley earlier this year and is enabling him to expand both his clinical and practical knowledge of Cystic Fibrosis. "The grant has enabled me to work in one of the largest units in the country, to be exposed to and participate in a wide range of different problems and issues, to meet and work with experts from other Centres, and to understand some of the practicalities and politics of CF care and funding," Dr Horsley said.

We recently ran a number of focus groups to find out what our supporters thought about legacies. As well as being more direct about asking for legacies, we identified that there's more we can do to provide information on issues such as inheritance tax, the low cost of a simple will and how the needs of family and friends can be protected while still including a gift to the Cystic Fibrosis Trust. To help our supporters make these decisions, we will this autumn be launching a campaign called Rosie's Lasting Legacy, to provide information about leaving a gift to the CF Trust via a will. It will be accompanied by a booklet detailing the benefits of legacy giving both to the CF Trust and to the individual preparing the will and their families. The campaign will be headed by our former Chief Executive Rosie Barnes, who explains in the booklet why she is choosing to help people with Cystic Fibrosis now, and in the future, by leaving a legacy.

If you would like to receive information about leaving a gift to the Cystic Fibrosis Trust in your will please email swhitehead@cfrtrust.org.uk.

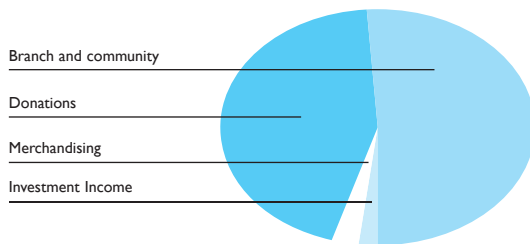
Summarised accounts

Year ended 31 March		2010	2009
Income and Expenditure Account		£,000	£,000
Where our money comes from			
	CF Trust branch and community	4,706	4,853
	Donations	4,058	3,828
	Merchandising	234	236
	Investment income	174	357
	Total Income	9,172	9,274
	Other (losses)	915	(531)
	Transfer from / (to) reserves	(1,907)	1,558
		8,180	10,301
Where our money goes			
	Research	3,107	5,278
	Clinical care	1,368	1,141
	Information, advice and support	912	1,073
	Fundraising	2,545	2,549
	Merchandising	170	193
	Governance	78	67
	Total Spending	8,180	10,301
Balance sheet			
	Fixed assets	1,132	1,282
	Investments	4,745	3,698
	Debtors	272	526
	Cash	3,211	5,614
	Grants payable	(8,204)	(11,866)
	Other creditors	(377)	(382)
	Net (liabilities) / assets	779	(1,128)
	Endowment funds	983	821
	Restricted funds		
	Gene Therapy Consortium	(7,515)	(9,479)
	Others	469	556
	Unrestricted funds	6,842	6,974
	Total Funds	779	(1,128)

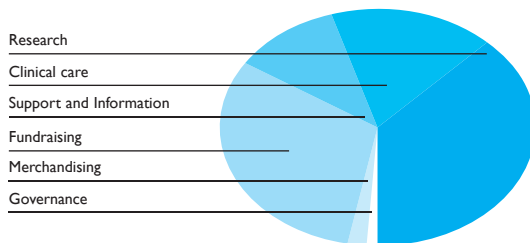


Report by the Trustees on the Summarised Financial Information

Total Income



Total Expenditure



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 28 September. The statutory financial statements, on which the auditors Horwath Clark Whitehill LLP gave an unqualified audit report on 28 September 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 2010.

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 FRCPCH DCH
Chairman
28 September 2010



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

A J N Steelstock Ltd
Graham and Pearl Aaronson
Apple Healthcare Group
BCR Global Textiles
BT Plc
The Balcombe Trust
David and Caroline Buchler
Busy Bees Nursery Ltd
Chelsea FC
The Childwick Trust
The Conneely Family
Darren and Sara Dein
David and Barbara Dein
Mark and Katrina Dujardin
The Eveson Charitable Trust
Forest Laboratories UK Ltd
Gilead Sciences Europe Ltd
Allan and Vera Gormly
Hills Prospect Plc
HSBC Communities
The Iliffe Family Charitable Trust
Jackpotcity Bingo.com
Tony and Lesley Khalastchi
The Knight Foundation
Charles and Sally Leggat
The Levy Foundation

Joseph Levy Memorial Fund
The Enid Linder Foundation
Lloyds Pharmacy Ltd
The Robert Luff Foundation
The MacRobert Trust
Harvey and Allison McGrath
Manchester United Foundation
The Myristica Trust
National Grid
Network Rail
Next Plc
Nigel Quinney
The Pears Foundation
Paul and Suzanne Pignatelli
Reading Textiles
The Sir Samuel Scott of Yews Trust
The Swire Charitable Trust
Simply Health
Solvay Healthcare Ltd
Josh Spooner
Star Cargo
Richard and Christine Stevens
Mark Stolkin
TT Electronics
The Gay and Keith Talbot Trust
Talkback Thames

Dennis Turner
The Waterloo Foundation
Peter and Sarah Wynter Bee
The Elizabeth & Prince Zaiger Trust
ZincOx Resources Plc
Zonzoo



how you can help

The Cystic Fibrosis Trust relies on the support of the CF community and the wider public. There are many ways in which you can help the CF Trust to help people living with Cystic Fibrosis.

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.

National events

Join in with our fun national campaigns such as the Big Cake Bake and Great Strides.

Visit www.cftrust.org.uk/help/nationalcampaigns for details.

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.

Corporate fundraising

Support from companies across the UK is invaluable to the Cystic Fibrosis Trust. There are many ways in which companies can support the CF Trust, from Charity of the Year partnerships to payroll giving. If you think your company may be able to help, please contact our Corporate Team on company@cftrust.org.uk.

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.

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 for further confidential information.

Your feedback is important to us. If you would like to comment on anything you have read in this year's annual review, please email publications@cftrust.org.uk.



Direct Debit Form

Title _____ Forename _____

Surname _____

Address _____

Postcode _____ Email* _____

	Instruction to your Bank or Building Society to pay by Direct Debit	
Please fill in the form and return it to the Cystic Fibrosis Trust at the address on the right		
This is not part of the instruction to your Bank or Building Society (please tick the appropriate boxes)		
I wish to give: £5 <input type="checkbox"/> £10 <input type="checkbox"/> £25 <input type="checkbox"/> £50 <input type="checkbox"/> my choice of £ <input type="text"/>		
on the 3rd <input type="checkbox"/> 17th <input type="checkbox"/> 28th <input type="checkbox"/> of each month		
Name and full postal address of your Bank or Building Society		
To: The Manager	Bank/Building Society	
Address		
Postcode		
Name(s) of Account Holder(s)		
Bank/Building Society account number		
Branch Sort Code		
Reference Number (Official use only)	Originator's Identification Number:	
	8 0 3 1 4 3	
Instruction to your Bank or Building Society		
Please pay Cystic Fibrosis Trust Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee.		
I understand that this instruction may remain with Cystic Fibrosis Trust and, if so, details will be passed electronically to my Bank/Building Society.		
Signature(s)		
Date		
Banks and Building Societies may not accept Direct Debit Instructions for some types of account		

giftaid it

Make your gift go further at no extra cost to you.

Tick if applicable:

I would like to Gift Aid this and all future donations until further notice.

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 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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KG GCVO

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(retired February 2010)

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FRCP FRCPE FRCPC DCH

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MD FRCP

Chair of Medical Advisory

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Dr Diana Bilton MD FRCP

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Professor Stuart Elborn
Mr Allan Gormly
Mr Brian Henderson
Mr Archie Norman
Mr Ed Owen
Mr Rupert Pearce Gould
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Mr Peter Sharp

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Mr Phil Smith FCCA

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www.cftrust.org.uk

Cystic Fibrosis Trust

11 London Road, Bromley, Kent BR1 1BY

Tel: 020 8464 7211

Fax: 020 8313 0472

enquiries@cftrust.org.uk

Cystic Fibrosis Helpline: 0300 373 1000

CF Benefits Helpline: 0300 373 1010

CF Welfare Grants Helpline: 0300 373 1020

Registered as a Charity Number 1079049 (England and Wales)
and SC40196 (Scotland).

A company limited by guarantee registered in

England and Wales Number 3880213.

Registered office: 11 London Road, Bromley, Kent BR1 1BY

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Pages 4 and 26 Howard Sayer, Page 8 Iain McLean,

Page 10 Graham Shirley, Page 12 Bethany Clarke, Pages 14 and 16 Matt Grum,

Page 20 Chris Benbow, Page 24 Gareth Danks

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