

# **Cystic Fibrosis Trust**

## **Annual Review 2012**



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# A message from our Patron

The Cystic Fibrosis Trust is working hard to improve the lives of people affected by cystic fibrosis and is at the forefront of research and care in the UK. The past year has seen significant advances in the treatment and understanding of cystic fibrosis, providing hope for an even brighter future for those living with the condition.

Without the dedication and enthusiasm of the Trust's many supporters, this progress would not be possible. Thank you for lending your support, which ensures that the outlook for everyone with cystic fibrosis continues to improve.



A handwritten signature in black ink, which appears to read 'Alexandra'.

HRH Princess Alexandra

# A message from our Chief Executive

It is almost half a century since the Cystic Fibrosis Trust began its work. In that time, survival rates and life chances for people with cystic fibrosis have changed dramatically. Where once babies born with CF were lucky to survive beyond childhood, there are now more adults with the condition in the UK than under 18s.

The Trust has played a crucial part in creating this changed picture. By mobilising the efforts of patients, families, clinicians, researchers and others we have helped raise money and awareness to facilitate improved standards of clinical care, better treatments and far greater understanding and support for people with cystic fibrosis.

This vital work continues today with as much passion and commitment as ever, and progress is being made all the time to ensure people with CF live longer, better lives. But our job is far from done. Too many lives are still being cut short by the condition, and the imposing burden of daily medication and care robs people with cystic fibrosis of the freedoms and opportunities others take for granted.

In 2013 we will be redoubling our efforts to maximise our impact for all those affected by cystic fibrosis. We will be unveiling a new brand to reach new audiences and increase our influence and funds. We will be rolling out a new Quality Improvement Programme to drive up standards in CF care and we will be looking at how we can help improve transplant rates and the often difficult transition from childhood to adulthood for people with cystic fibrosis.

Perhaps most significantly, our renewed mission will also include the publication of an ambitious new research strategy to identify and invest in innovative research into new treatments to beat CF for good and make a long-term difference to the lives and life chances of all.

The prospects of finding such transformational therapies and treatments have rarely looked more promising. Kalydeco, a revolutionary new “small molecule” treatment developed in the US for those with the G551D CF mutation is the first licensed treatment that deals with the basic genetic defect of cystic fibrosis, and is now being prescribed to NHS patients in England and Scotland. At time of going to press, we are still awaiting decisions in both Wales and Northern Ireland. In 2012, the UK CF Gene Therapy Consortium began a Phase 2b clinical trial into its Wave 1 product after many years of investment from the CF Trust.

Research was at the heart of what the Trust stood for when we were established in 1964, and this commitment is still as strong today.



Ed Owen, Chief Executive,  
Cystic Fibrosis Trust

# What is cystic fibrosis?

Cystic fibrosis (CF) is a life-shortening genetic condition that causes the lungs, digestive system and other organs to become clogged with sticky mucus. Over time, the organs become increasingly damaged, and a lung transplant may be the only option to prolong life. Around half of people with CF won't live to celebrate their 40th birthdays.

People with cystic fibrosis can look healthy, but they may have to take up to 100 tablets a day, inhaled and injected drugs, follow a special diet and undergo hours of physiotherapy, just to stay well.

Over 9,000 people are living with cystic fibrosis in the UK. The faulty gene that causes CF is carried by more than two million people, most of whom have no idea. If two carriers have a baby, there's a one in four chance their child will have cystic fibrosis.

Each week in the UK, five babies are born with cystic fibrosis and two lives are lost to the condition.

We're here to beat cystic fibrosis and make a daily difference to the lives of people with the condition, and those who care for them.

We do this by:

funding research to develop improved treatments and, ultimately, a cure for cystic fibrosis

driving up standards of clinical care

providing information, advice and support where needed

raising awareness, campaigning and lobbying on behalf of those with cystic fibrosis



## Success stories

### New plan to help us deliver more

In early 2012, after extensive consultation with our stakeholders, we launched an ambitious and important plan to help guide our work over the next few years. *Living Longer, Living Better: Our vision to 2016* will ensure we're directing our efforts where they are most needed to deliver maximum impact on the lives of those affected by cystic fibrosis. You can view *Living Longer, Living Better* online at [www.cftrust.org.uk](http://www.cftrust.org.uk).



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#### Gene therapy trial gets green light

A Phase 2b multi-dose clinical trial of gene therapy for cystic fibrosis began in the summer of 2012 following a major appeal by the CF Trust to raise funds in 2011. Over ten years, we have invested more than £30million in this world-leading research to get it to this exciting stage, which is the first time in history that effectiveness of CF gene therapy will be evaluated over a long time period.

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#### National funding tariff agreed

For four years, the Cystic Fibrosis Trust has worked with clinical teams and the Department of Health to develop fairer funding for CF services. A new national tariff for CF clinical care (called Payment by Results) will be mandatory from April 2013 and will see Specialist CF Centres paid according to the needs of the patients that they treat.

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#### CF Trust evolves

This year we carried out a major project to examine how the CF Trust is perceived and how we present ourselves. The work will help us to continue to evolve and make sure we're communicating as fully and as effectively as possible about what we do, so we're even better equipped to respond to the needs of people affected by CF and raise awareness in the wider community. We're very excited about revealing the outcomes of this project in 2013.



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#### Shouting louder in CF Week

May 2011 saw supporters up and down the country helping us shout louder about cystic fibrosis as part of our revitalised CF Week. In line with our new direction of work, the theme was 'Living longer, living better' and over £232,000 was raised – a huge boost to our work.



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### Recognition for major donors

2012 saw the launch of the 65 Roses Club, which enables us to recognise and thank those who support our work at a higher level, and encourage new donors who may be able to pledge the major gifts which help us plan our work going forward.

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### London Marathon runners set new record

Our runners in the 2011 Virgin London Marathon set a new income record. The 230 CF Trust participants raised over £460,000, an amount that would cover the costs of the four new research grants we awarded last financial year. We are hugely grateful to everyone who took on this incredible challenge.

### Investing in us

“The Cystic Fibrosis Trust has contributed hugely to the incredible progress made in understanding and treatment of CF in recent years – thanks in no small part to our fundraisers, supporters and our staff team. And we’re still moving forward. The past year has seen a period of change within the Trust, as we develop the organisation so we’re better equipped to achieve some key aims as set out in a new vision for the next four years – Living Longer, Living Better. We’re investing in the right skills and expertise, improving our internal and external communications and increasing consultation and engagement with our many stakeholders. Our staff team is one of our most valuable assets, and we have recently appointed a Head of Human Resources and Organisational Development to ensure we’re working together as effectively and efficiently as possible. Our ultimate aim? To ensure how we work achieves the greatest impact in extending and improving the lives of everyone affected by cystic fibrosis.”

George Jenkins OBE, Chairman,  
Cystic Fibrosis Trust



# Investing in research

## We invested £968,000 in research last financial year to improve understanding of cystic fibrosis and speed up the development of better treatments

Throughout our history we've funded research that has increased understanding of cystic fibrosis, and contributed to better treatments and care. Today, the outlook for those with the condition is brighter than ever before.

But cystic fibrosis still claims two lives each week, and the median age of death is just 29. And while length of life is improving, the burden of treatment remains high – inhaled and injected drugs, up to 100 tablets, a special diet and hours of physiotherapy can be required daily to prevent a dangerous decline in health.

The CF Trust is currently funding 12 research projects across the UK. We fund a diverse range of studies, but each has the same goal in mind – finding ways to significantly improve the quality and length of life of people with cystic fibrosis and, one day, beat CF for good. Last financial year **we invested over £360,000 in four exciting new research projects.**

We funded researchers at Great Ormond Street Hospital and the Institute of Child Health, University College London investigating the **best time to begin treatment in infants** with cystic fibrosis. This means that babies will be able to benefit from new treatments before lung damage has developed. The study will also establish ways of determining whether treatment is benefiting young children during these crucial stages in lung development.

We funded a research group at the Universities of Bristol and Bath to develop new **drugs to treat the root cause of cystic fibrosis** rather than the symptoms. Current drugs tackling the faulty CF gene either target a protein called CFTR, which the gene prevents from working properly, or repair defects in salt transport for

### How we fund research

The CF Trust invites applications for funding of research projects and studentships through both our website and contact with eligible institutions. All research applications are peer reviewed by external referees and then internally by our Research Advisory Committee to ensure that only those that have the most potential to deliver real clinical benefits to people with cystic fibrosis are approved for funding.

which it is responsible. However the group previously identified 'double action' molecules that fulfil both of these roles and show promise as new CF drugs; it now aims to pinpoint how they work and improve their design.

We awarded a grant to the University of Sheffield, where scientists are looking at new techniques to **detect the earliest signs of lung disease** in cystic fibrosis. Prompt treatment of lung disease has a major impact on length and quality of life in CF, but spotting the early warning signs can be hard. The researchers are investigating two cutting-edge techniques to identify early lung damage in order to prevent lasting harm to the lungs. The techniques could also be used to better assess response to new treatments.

We're also funding researchers at the University of Liverpool to study the **ways antibiotics can cause an allergic response**. Antibiotics are the most important medical therapy available to people with cystic fibrosis, but unfortunately many people develop allergies to these vital drugs due to the way that they activate the immune system. This research will lead to the



Dr David Sheppard at the University of Bristol is researching drug therapies for CF



development of diagnostic tests to help guide the management of patients with allergic responses to antibiotics, making their treatment safer and more sustainable.

In 2011/12 we also **helped secure the future of CF gene therapy research**. Since 2001 the CF Trust has invested over £30million in the research of the UK CF Gene Therapy Consortium (GTC), which seeks to halt or prevent the lung damage that causes 90% of deaths in cystic fibrosis by replacing the faulty CF gene with a healthy copy.

In 2011 we launched a Gene Therapy Appeal that elicited a fantastic response from our supporters, which, together with funds awarded from the Medical Research Council and National Institute for Health Research meant the research could continue.

The GTC began a Phase 2b clinical trial to measure clinical effectiveness of its Wave 1 gene therapy product in June 2012. This historic trial is the first time in the world that gene therapy in the CF lung has been studied in this long-term way; results are expected in 2014.



Professor Andrew Fisher, Chief Investigator of DEVELOP-UK

We're also continuing to **improve access to lung transplants**. For people with CF whose lungs are very damaged, a transplant can be their last hope; sadly, not everyone who needs a transplant will receive one. We are determined to change this, and since 2009 have been supporting a major study to increase the quantity of lungs available for transplant.

DEVELOP-UK uses a revolutionary technique called ex-vivo lung perfusion (EVLP) to improve the condition of lungs deemed unsuitable for transplant due to doubts over their quality. The CF Trust was able to fund the pilot study of this important research thanks to restricted funding from the Robert Luff Foundation, which last year also helped us fund the expansion of the study to all five adult lung transplant centres in the UK. Results are expected early 2016, and scientists believe DEVELOP-UK could boost lung transplant rates by 30%.

Around 80% of donated lungs are not used in transplants, yet many people with CF on the waiting list for new lungs won't receive them due to a shortage of suitable donor organs. We're working to change this by funding research to improve the quality and quantity of lungs for transplant, and by advocating organ donation in the wider community.

### **What next?**

The past year has seen a number of encouraging developments in the pipeline of new CF treatments, and we're committed to doing all we can to further advance CF research in the UK and abroad. We're stepping up our efforts to ensure maximum impact from our investment in research.

Our new Director of Research, Dr Janet Allen, is **developing an ambitious, highly focused research strategy** which aims to deliver greater impact on the lives of people with cystic fibrosis. We have also put in place some key measures to boost our research programme right now.

Much CF research takes place in Specialist CF Centres. We hope to joint-fund with the NHS **up to six new research co-ordinators**, who will increase capacity for research in these centres by helping clinicians carry out research alongside their daily care.

We have a long history of funding **new CF training fellows** to support those involved in cystic fibrosis care, treatment and research. This programme, which improves care and treatment of people with CF today and safeguards care for future generations, will be relaunched shortly.

In addition to the grants awarded last financial year, we're funding three exciting new projects researching **drug development and preventing lung decline in teenagers**. This brings the number of research projects we're currently funding to twelve.

And in 2013, we will hold the **first ever UK cystic fibrosis research conference** to launch our new research strategy and bring together CF researchers from across the UK.

With several promising new drugs and therapies in development, this is an exciting time for CF research. We will continue to do all we can to build on this momentum and ensure a constantly improving prognosis for everyone with cystic fibrosis.

You can find out more about the research we fund at **[www.cftrust.org.uk/research](http://www.cftrust.org.uk/research)**.

**“The past year has seen some key advances in the pipeline of CF drugs in development, with a number of promising treatments moving a step closer to becoming available to people with cystic fibrosis. As one of the UK’s biggest investors in CF research, the CF Trust is committed to funding work that could deliver real clinical benefits to patients. We believe that the new projects funded last financial year, together with our continued funding of vital studies such as a national study to improve availability of lungs for transplant, will further improve the outlook for everyone living cystic fibrosis.”**

Dr Janet Allen, Director of Research,  
Cystic Fibrosis Trust

## Angharad Truelove

**“The CF Trust is helping make my hopes for Aanya’s future a reality.”**

**The Cystic Fibrosis Trust supports people affected by cystic fibrosis from the time of diagnosis and throughout their lives. Angharad Truelove, mum to Aanya, explains what this support has meant to her family.**

“My name’s Angharad Truelove, I’m 31 years old and work as a Project Manager in the NHS. I’ve been married to my husband Chris for 12 years and we have a beautiful little girl, Aanya, who was born in summer 2011. Oh, and Aanya has cystic fibrosis.

Aanya was diagnosed via the heel prick test that is administered when babies are five days new and the diagnosis was given to us when she was two and a half weeks old by a CF Nurse Specialist from the team at Leeds General Infirmary and our local Health Visitor. Our initial reaction was one of grief as the child you think you have, and the life you have planned with them, is taken away and something entirely different is put in their place. Both sides of our family suffered losses to CF during the 1950s and 60s – one cousin in mid-childhood but the other had been only 11 months old and, as my knowledge of CF was so limited, I assumed that that was what lay ahead for Aanya. I now know that this is no longer the norm. The information pack provided by the CF Trust when Aanya was first diagnosed helped us to realise just how much the outlook for CF sufferers has improved and that with the right treatment and support, she could live a longer and more fulfilling life than we initially expected.

That said, Aanya’s treatment regime is hard work. Even though her treatment is as basic as it can currently get, Aanya has to have prophylactic

antibiotics twice a day along with additional vitamins and an enzyme supplement with any food she eats that contains fat. She has to have at least two physiotherapy sessions and, at 15 months old, we still sterilise everything she uses to eat, drink and take her medicines. It is also important to avoid people who have coughs and colds which can be difficult at the best of times but near impossible when placing Aanya with a childminder so that I could return to work part-time.

While I may have sounded blasé when I added at the start that Aanya has CF, my hope is that through sticking with her treatment regime and the ongoing developments into more effective treatments, e.g. the ongoing research into drugs to treat the root cause of CF rather than just managing the symptoms, we can keep CF as just a small part of who Aanya is and allow her to get on with growing up and living a long, happy and healthy life. The CF Trust’s ongoing research into a variety of projects that aim to improve the length and quality of life for all CF sufferers will help to make my hope for Aanya’s future become a reality.”







# Making care better

## We spent over £1million on our clinical care programme last financial year to help CF services deliver improved patient care

Cystic fibrosis is a complex condition that requires specialist clinical care, and there is a strong link between standards of care and the length and quality of life of people with cystic fibrosis. Driving up standards of care is therefore a fundamental aspect of our work.

There are currently significant variations in the quality, consistency and responsiveness of clinical care throughout the UK leading to a postcode-lottery effect in commissioning CF services and treatments. We work in tandem with clinicians, health professionals, international organisations and the wider CF community to improve standards of care. Last financial year we helped make care better for people with cystic fibrosis in a number of ways.

We helped **develop fairer, sustainable funding for CF services** by continuing to work with clinical teams and the Department of Health to develop a Payment by Results system for care funding. The new national tariff, which will be mandatory from April 2013, is based on severity of illness, level of resource and treatment required, meaning Specialist CF Centres will be paid according to the needs of the patients that they treat. We have lobbied hard to ensure that cystic fibrosis is one of the first services that will move across to the new commissioning arrangements so that people with CF benefit as soon as possible.

The Cystic Fibrosis Trust is also represented on the Cystic Fibrosis Clinical Reference Group, one of 60 such groups set up to help guide the changes to specialised commissioning over this period of transition in the NHS. They are made up of hundreds of clinicians, medical staff, patient



Our clinical care programme punches above its weight; our peer reviews alone have secured almost £20million in NHS funding for CF services across the UK that otherwise may not have been available.

representatives and commissioners with the sole purpose of **making specialised services work better for patients.**

We published **revised national guidelines for clinical care.** Our Standards of Care document is a consensus of opinion on best practice in CF care against which CF services are measured as part of a peer review. The nationally-recognised guidelines are widely used in Specialist CF Centres and Clinics in the UK to make sure that all patients have access to the highest level of multidisciplinary specialist care, which is adequately resourced and based on the latest evidence. The standards have been instrumental in improving the understanding, management and treatment of CF and as a consequence increasing longer-term survival.

**“The CF Trust Standards of Care document sets out the recommended clinical care and treatment someone with CF should expect throughout their lives. It guides CF services in delivering optimal care to their patients, and is also the basis for service specifications, peer review and designation of CF services.”**

Dr Ian Balfour-Lynn, Consultant Respiratory Paediatrician, Royal Brompton Hospital, London

Our peer review programme assesses specialist CF services against the Standards of Care to ensure a high and safe level of care provision. We **helped CF services deliver sustainable improvements** by strengthening the review process to ensure that CF centres can deliver ongoing service improvements following a review. Three pilot reviews have already taken place at the Liverpool Heart and Chest Hospital, Great Ormond Street Hospital and James Cook University Hospital in Middlesbrough and a programme has been developed to fully implement the new process.

Last financial year we also **increased access to specialist care** by continuing to fund a dietetic post at the Great North Children's Hospital in Newcastle, which has led to improved nutritional care of the 180 children the unit sees (see pages 16-19). The shortfall in the dietetic service at the hospital was identified as a result of our peer review programme.

We further **promoted best practice in clinical care** at our annual medical conference. Attended by over 100 clinicians and researchers from across the UK the event facilitates the sharing of knowledge and experience in CF treatment and care, and provides valuable networking opportunities. We also held a meeting for lead clinicians from the UK's 50 Specialist CF Centres, establishing a unique forum for discussion and debate around patient care and managing a specialist CF service.

We **aided research into care and treatment** by continuing to fund and facilitate the UK CF Registry. Containing detailed clinical information about CF patients, this database allows comparison of clinical outcomes between centres, guiding commissioning of CF services and highlighting effective care and treatment. In collaboration with the US CF Foundation and Imperial College Hospital we embarked upon a project to compare several key clinical outcomes measures between the UK and the US patient populations which will further guide best practice. We have also continued to publish annual Registry reports online, enabling patients to examine outcomes from their own CF service.

The UK CF Registry was established with the overall aim of improving standards of care and therefore improving outcomes for people with CF in the UK. By recording clinical data from everyone with CF on a national database, we would be able to look at how people were doing over time and measure the effectiveness of particular treatments or models of care. Over the last five years the Registry team, supported by a Steering Committee, has worked steadfastly to make sure that as many people with CF as possible are recorded – the Registry now boasts one of the most complete sets of patient data in the world and is having a major impact on clinical care and research in the UK.

## **What next?**

Our clinical care programme has made great strides in improving the care that is available to people with CF across the UK, but there is still some way to go in ensuring safe, fair care for all and there are a number of challenges that if left unmanaged, could put standards of care at risk. We will continue to work with people affected by CF, clinicians and NHS commissioners to further drive up standards of care and bring about positive change for people with cystic fibrosis.

In 2013 we will **launch a new Quality Improvement Programme**, designed to deliver major improvements in clinical care standards throughout the UK by introducing a highly-structured and rigorous approach to:

- measuring how well each CF service conforms to agreed standards of care and taking action to drive improvements
- using data sources such as self-assessment results, international benchmarking and the UK CF Registry to analyse and drive improvements to prevailing care standards
- creating and documenting a highly effective best practice process that clearly identifies, disseminates and encourages CF clinics to adopt agreed best practice

Transition from paediatric to adult clinical care can be a challenging time for people with CF and their clinical teams, and lung function can suffer as a result. A key priority is to work with key stakeholders to develop and deploy an agreed set of clinical care standards to **support the successful transition from pediatric to adult care.**

To complement the medical research we fund into lung transplants, we will implement a lung transplant policy to ensure that **everyone with CF assessed as suitable for a transplant receives one**. The policy will address wider issues around the entire process of organ donation, as increasing the number of people on the organ donor register is only one piece of the puzzle.

Current comparisons of clinical data from Specialist CF Centres do not tell us whether there are meaningful differences between centres, or potential reasons for these differences. We plan to work with statisticians at Imperial College London to determine whether there are meaningful differences in key health outcomes between CF centres in the UK and, if so, to pinpoint what is driving them, helping us identify and promote practices to maintain good health. The development of national specialist commissioning for CF in England with an associated mandated tariff from April 2013 means that this project is critically timed to **inform future service specification and development**.

We also plan to reinstate our training fellowship grants, to **attract clinicians and healthcare professionals to a career in CF** and ensure that the needs of a growing and ageing CF population are met.

Driving up standards and ensuring that everyone with cystic fibrosis has access to the best possible specialist care and treatment remains an utmost priority. We will continue to push for better care through our work in clinical care and campaigning.



**“Good CF care gives people with CF the best chance of staying well enough to benefit from new treatments when they become available. The CF Trust’s new Quality Improvement Programme will ensure quality, consistency and longevity of CF care across the UK.”**

Jo Osmond, Director of Clinical Care and Commissioning, Cystic Fibrosis Trust

# Helen McCabe

“Feedback from families has been overwhelmingly positive.”

**Due to the impact of cystic fibrosis on the digestive system, which can make it hard to maintain a healthy weight, specialist dietetic input is an essential part of CF care. For the past three years, through funding from a charitable trust, the Cystic Fibrosis Trust has supported a dietetic post in the Regional Paediatric CF Services at the Great North Children's Hospital in Newcastle. Specialist CF Dietitian Helen McCabe explains the difference this has made.**

“It is well recognised that good nutrition plays a vital role in improving the health of people with cystic fibrosis. From diagnosis, the dietitian works closely with the parents and with other members of the clinical team to ensure that care is optimised and the building blocks for good long-term nutritional care are laid. At the Great North Children's Hospital in Newcastle we care for around 180 children with CF across the North of England, including children we see at smaller outreach clinics and other hospitals.

This volume of patients, coupled with the complexity of cases and the wide geographical area covered made it an ongoing challenge to deliver a consistent specialist dietetic care for all. In particular, we recognised the benefits of delivering some of the follow-up care in the patients' own homes; however, resource constraints meant this was usually not possible.

The CF Trust funding has been fantastic for the service. It has allowed for the recruitment of a dietitian into a three-year training post to “grow” a dietitian with the knowledge base and practical expertise required to treat paediatric CF patients at a highly specialist level. The Hospital Trust

agreed to continue funding this training post at the end of the three-year period, a commitment that it has fulfilled. Importantly, the training aspects of the post were planned out at an early stage with the creation of a competency framework that set out the objectives of the training, how they were to be achieved and measured the accomplishments throughout the period.

The funding meant we could also carry out research to ensure that our nutritional care was addressing the needs of our patients and families. I looked at the findings from ‘Food for Thought’ – a detailed research project carried out by the CF Trust and specialist dietitians about nutritional care in CF – and also talked to the patients and families we care for.

Many families simply wanted improved access to a dietitian so developing a home visiting service was a key priority and feedback from families has been overwhelmingly positive. The home environment is so important for many parents, not just for convenience but because it represents their real life setting. Parents have told me that the home visiting service makes them feel the dietitian can better understand their home life. As one parent said: “The clinic appointments are often hectic and rushed... at home, I was able to show the portion sizes of the food my child eats and therefore explain and discuss more, this is important to me.” There is also a huge benefit to being free from the constant interruption of hospital phones!

We have also improved education for the children by devising age-appropriate literature and quizzes, and developed literature for specific patient groups including the under ones and



CF Trust funding has led to improved dietetic support at the Regional Paediatric CF Centre in Newcastle.



weaning advice; we are also able to provide more info on the fat content of foods, meals, snacks, eating out, schools etc.

Having the additional post has freed up some of my time to work in collaboration with Leeds Metropolitan University to set up and successfully deliver a Masters course specifically for dietitians specialising in cystic fibrosis; the module commenced on for the first time in March of 2012. This has been the first formal qualification of its kind and has become a recognised qualification for specialist CF dietitians.”

**Heidi Finlay’s four-year-old son Joel is one of many children with CF to have benefited from the improved dietetic support available at the Great North Children’s Hospital.**

“Having the support of the specialist dietitians is invaluable. When Joel was a baby one of our main worries was how to ensure he got the right nutrition. He had a very poorly chest for a while, but knowing that we could call the dietitian whenever we had a query or a concern and that they were there whenever we needed them was very reassuring.

Joel’s weight is good at the moment, but managing nutrition in CF is complicated – there are so many different factors to consider. We see the dietitian at every clinic visit – about every six weeks.

Joel has recently contracted a lung infection called *Pseudomonas aeruginosa*, which has been a worry for the family and means getting the right

nutrition is even more important. *Pseudomonas* can cause serious damage to the lungs, but ensuring an optimal diet means the body is better able to fight the damaging bugs that can infect the lungs of people with cystic fibrosis.

Situations where it’s difficult to control food intake, such as parties, can cause some anxiety – it’s hard to keep an eye on what’s being eaten and as such getting the right amount of enzymes can be hard – difficult when you’re trying to socialise and be normal!

Joel has to take between 30 and 40 tablets every day, half of which are usually the digestive tablets Creon, which are essential to help digest any food. Joel is a strong-willed character – if he doesn’t like something he doesn’t eat it – but thankfully he doesn’t have any problems taking his tablets – in fact he happily swallows four or five at a time!

As we have another child without CF, the dietitians have given us nutritional advice regarding the whole family. This has been really important in learning how to manage meal times and snacks to ensure both children have healthy diets.”

*You can read about why a charitable trust chose to fund dietetic support in the north east on page 35.*





# Summarised accounts

**“In part due to the extraordinary response to our Gene Therapy Appeal, our income for the year increased by 18.9% to £10.4million. Income from individuals, branches and groups showed the biggest increases due to the Appeal response, including £1.1million in major gift pledges over future financial years. Corporate donations did fall, as businesses have less to give in the current climate.**

**Investment in fundraising has also resulted in a considerable increase in particular streams of income. Spend on direct marketing campaigns to increase the income from committed givers are also part our investment to diversify our fundraising.**

**Well over 90% of our income continues to arise from voluntary income, with over 50% from community fundraising and branches and groups, reflecting the commitment and enthusiasm shown by our volunteers and supporters. The Cystic Fibrosis Trust greatly appreciates this support, without which we would not be able to continue our work.**

**An increase in reserves in 2012 means that the charity is in a position to make a significant investment in clinical research in line with an ambitious new research strategy to be launched in 2013.**

**Overall expenditure increased from £5.05 million to £5.63 million.”**

**Ed Owen, Chief Executive, Cystic Fibrosis Trust**

## **Report by the Trustees on the Summarised Accounts**

The summarised financial information is extracted from the full Annual Report and Financial Statements for the year ended 31 March 2012 which were approved by the Trustees and signed on their behalf on 16 October. The statutory financial statements, on which the auditors Crowe Clark Whitehill LLP gave an unqualified report on 16 October, will be submitted to the Registrar of Companies and the relevant charity regulators 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 2012.

The 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 auditor’s report may be obtained from the Company Secretary.

**George Jenkins OBE, Chairman**  
**16 October 2012**

Year ended 31 March 2012	2012	2011
	£,000	£,000

## Income and expenditure account

### Where our money came from

CF Trust branch and community	5,226	4,499
Donations and other income	4,894	3,898
Trading and merchandising	154	221
Investment and interest income	152	149
<b>Total income</b>	<b>10,426</b>	<b>8,767</b>
Transfer (to) reserves	(4,793)	(3,719)
	<b>5,633</b>	<b>5,048</b>

### Where our money was spent

Research	968	263
Clinical care	1,012	1,008
Information, advice and support	666	899
Governance	95	90
Generating voluntary income	2,799	2,648
Trading and merchandising	93	140
<b>Total expenditure</b>	<b>5,633</b>	<b>5,048</b>

## Balance sheet

Tangible assets	845	985
Investments	4,962	4,839
Debtors	536	364
Cash	5,524	4,267
Grants payable	(1,047)	(2,402)
Other creditors	(1,527)	(3,553)
<b>Net assets</b>	<b>9,293</b>	<b>4,500</b>
Endowment funds	985	976
Restricted funds	975	688
Gene therapy Consortium	(6,031)	(7,144)
Designated funds	3,604	2,984
Unrestricted funds	9,760	6,996
<b>Total funds</b>	<b>9,293</b>	<b>4,500</b>



## Providing the right support

**Last financial year we spent over £660,000 providing essential information, advice and support to people with CF, families, carers and the wider public**

Making sure people affected by cystic fibrosis have the information and support they need to live well with CF, deal with the challenges it can bring and make informed decisions about their care and treatment, is one of our core objectives.

Last financial year we **awarded over £100,000 in welfare grants** to assist individuals and families living with cystic fibrosis. From helping with the purchase of essential household items when setting up home for the first time, to paying the first year of prescription charges, our grants help lessen the financial burden of CF where it is often most felt. This included over £27,000 in funeral grants that **supported 58 families who had lost a loved one to cystic fibrosis.**

We **assisted over 3,000 people seeking advice and support through our national helpline.** Whether specific information is sought or just a sympathetic ear, we're on hand to help. We also **helped over 100 families come to terms with a CF diagnosis** by providing new parent packs full of information about CF and our services.

We **provided areas for people affected by CF to chat to and support each other** on our website forums, which have almost 7,000 users. With dedicated forums for teenagers and adults with CF, parents, partners and fundraisers there are plenty of opportunities for virtual interaction among the CF community, which is often prevented in person due to the risks of passing on harmful bugs between individuals with cystic fibrosis.

**“The CF Trust forums are so helpful. I cannot talk directly to someone with CF but the forums were a great source of advice when I was considering whether to have a portacath inserted for my intravenous antibiotics.”**

Teenager with CF

We **increased engagement with our stakeholders using social media.** Our 46,000 Facebook fans and 8,500 Twitter followers illustrate the importance of digital communication with the CF community and wider public. We use our pages to promote events and campaigns, seek feedback and share CF news and developments.

We **kept parents and carers up to date** at our national conference held in Manchester in November 2011. Over 400 people travelled from across the UK to hear updates on research, care and the work of the Trust, and were treated to an inspirational closing talk by a young entrepreneur with CF Rob Law.

**“I’ve had a really informative, positive and inspiring day.”**

Quote from a parent who attended our 2011 parents conference

We also **continued to provide information on cystic fibrosis and on our work** through our factsheets, clinical guidelines, regular magazine *CF Today*, website and e-newsletters.

## What next?

A number of exciting initiatives are planned and underway to improve the support and information we provide.

We will continue to **develop our online and printed resources** for people affected by cystic fibrosis, including information packs to assist individuals and families during key life stages such as diagnosis and lung transplant.

We will **show the public that our information is reliable and trustworthy** by applying for certification with the Information Standard, a scheme that assesses the processes organisations use to produce health information. We aim to achieve certification in 2013.

We will **reach out to young people with cystic fibrosis** by producing a short film for teenagers with the condition. Following our hugely successful animated kids film *Getting Nosed about CF*, our teens film will explore some of the issues young people with CF tell us are important, and will help raise awareness.

We will also publish a **more modern and engaging CF Today** magazine, informed by what the readers tell us they'd like to see in our flagship publication.

Providing information and support remains at the very heart of what we do, and we will continue to expand and improve upon these vital services to ensure we're fully equipped to address the diverse needs of people affected by cystic fibrosis.

**“A major project is underway to review and revamp our brand and website, and their reveal in 2013 will be a big moment for the CF Trust. We sought feedback from hundreds of people affected by cystic fibrosis, and the wider community, to inform this work, and believe we will be far better equipped to respond to the needs of our supporters and stakeholders as a result. A key aim is to raise awareness of CF in the general public, to increase our income and therefore our impact through the work we do. The costs of this kind of work can be high, however we have worked hard to ensure this has been done as competitively as possible. For the charity to compete in an increasingly crowded charity marketplace it's important that people know exactly who we are and what we stand for, and the impact that CF has on people's lives. Our brand and website are key to helping us achieve this.”**

Tamsyn Clark, Director of Marketing,  
Cystic Fibrosis Trust

## Dominic Kavanagh

“Advances in treatment, as well as better understanding of CF, have undoubtedly helped prolong my life.”

**Dominic Kavanagh is a Clinical Care Patient Adviser at the Cystic Fibrosis Trust. Maintaining his health hasn't always been easy, but with the support of his family and friends, and spurred on by continuing advances in CF, he remains positive about the future.**

“I joined the Cystic Fibrosis Trust in 2008, as a Clinical Care Patient Adviser in the Midlands. I work with CF teams at Specialist CF Centres and Clinics, to help ensure safe and appropriate care. I provide the patient voice on a local and national level and use my knowledge of cystic fibrosis to advise the CF Trust. I help raise awareness of the condition too. My role has its challenges but influencing change and also reassuring parents or CF adults can be very rewarding.

I'm 45 and was diagnosed at birth, the fourth child in my family to be born with cystic fibrosis. Advances in treatment, as well as better understanding of CF, have undoubtedly helped prolong my life. My siblings were all diagnosed in the 1960s when understanding of CF and its treatment was far more limited than today. I'm the sole CF survivor in my family.

The support of my wife, family and friends has also helped me keep going. I follow the CF Trust's advice on attending a Specialist CF Centre, although it does mean travelling a distance. The commitment and expertise at my Specialist CF Centre has been instrumental in helping me keep well enough to work part-time and enjoy quite physical hobbies – wildlife photography, motorcycling and swimming. I always consider my CF care as two-way, or teamwork between the CF team and me. Sport has been an integral part of my life, and helped me stay fit.

I always try to remain optimistic and positive about CF and my future. I set myself challenges, but I'm realistic in accepting the natural progression of the disease – my declining lung function, increased tiredness and arthritis remind me of this. I do get frustrated by the time that physiotherapy and nebulising various drugs requires. I find it increasingly difficult to plan ahead, what with more frequent hospital check-ups and inevitable chest infections and resultant inpatient intravenous antibiotics.

But I know how lucky I have been to get this far, and to be able to maintain a quality of life that I didn't think I would have at 45.

Developments in research, treatments and CF expertise do not happen by chance. The CF Trust should take great credit for funding research, organising educational conferences for specialists to share their knowledge, facilitating peer reviews to audit CF services around the UK, maintaining the CF Registry and actually employing people with CF who can reflect the patient voice, talk from personal experience at all levels and influence key stakeholders.

So where now for CF? Like all, I'd like to see survival continue to improve and a significant treatment come to the market, to ease the lives of all with cystic fibrosis. We still live in hope of gene therapy, or another treatment to prevent or halt the lung damage that causes over 90% of deaths in people with cystic fibrosis. In the meantime, I'd like to see uniformity in standards of CF care across all of the UK and am proud that my work as a Clinical Care Patient Adviser is helping the CF Trust move closer to this goal.”



# Campaigning, awareness and influencing

Many people don't know what cystic fibrosis is, or understand its effects. To bring about positive change for people affected, we work hard to raise awareness of CF and influence policy and decisions in the interests of those with the condition.

Last financial year we **campaigned against NHS cuts to specialist posts** with our influencing campaign 'Don't turn back the clock'. Despite the Coalition Government's reassurance that there would be no cuts to frontline NHS services, we discovered that specialist CF services were experiencing cuts. We wrote to every MP in England and Wales to make them aware of the issues, and many offered their support to our campaign. We continue to monitor and respond to challenges and threats to CF care in the NHS.

**“Cuts to NHS frontline services manifest in a number of ways – from specialist posts remaining vacant or being disestablished, to dedicated CF time being reduced – the result is the same: specialist CF services are shrinking and, as a result, length and quality of life are being jeopardised. We are actively campaigning against this.”**

Claire Francis, Policy and Public Affairs Manager, CF Trust

We **campaigned against closure of children's cardiac services** at the Royal Brompton Hospital, which could impact the level of care provided to over 330 children treated by the hospital's paediatric CF service, as well as its world class research facility. The independent

Vaughn Gething AM performing a lung function test during CF Week in Wales



Safe and Sustainable Review last year decided that the cardiac service at the Brompton would close, however a further review has since been launched, and we continue to fight to safeguard the hospital's vital CF service.

Our Clinical Care Patient Advisers (CCPAs) **fostered relationships with clinicians and the CF community** through Virtual Patient Focus Groups and Regional Network Meetings. The CCPAs use their and others' experience of living with CF to influence policy at a regional and national level. They represented patient views at new treatment appraisals for the National Institute for Health and Clinical Excellence and regional service redesign meetings, and met politicians and ministers to press for better services.

We also raised the profile of CF by securing coverage in a range of printed and broadcast media, helping bring CF to a wider public. Our Gene Therapy Appeal led to 89 news items across BBC radio alone, reaching seven million listeners, as well as a feature in the *Observer*. In May 2011 CF Week was covered extensively after research we commissioned into the importance of social media was covered by the





# Supporting the Cystic Fibrosis Trust

We could not carry out our vital work without the dedication and determination of our fundraisers and supporters, and we are grateful for every penny raised

Last year community and branch fundraising raised over £5.2million – over half our income.

There are many ways in which you can lend your support to the CF Trust. In turn we do our utmost to support our fundraisers in their endeavours – whether holding a fundraising event, training for a challenge, considering leaving a gift to the CF Trust in their will or simply making a donation.

## Community and branch fundraising

Community fundraising – carried out by volunteers often directly affected by CF and members of our 100 fundraising branches, groups and committees – is at the core of our income.

Last year thousands of people across the UK organised their own fundraisers or took part in our regionally-organised events. We continue to be amazed at the dedication of our supporters and the inventive and often brave ways they choose to fundraise, from sponsored head-shaves to skydives and many more in between.

Our long-running campaigns the Big Cake Bake, the Big Bounce and Great Strides continued to prove popular as simple and fun ways for all the family to fundraise and over £82,000 was raised from these events last year.



**“Around half of the Cystic Fibrosis Trust’s income comes from the CF community – people affected by cystic fibrosis and their friends, families and colleagues. This dedicated group are themselves the CF Trust’s lifeline; without them, we would not be able to carry out our work.”**

Andrew Sinclair, Senior Regional Fundraising Manager

## Challenge events

Runs, walks, cycles, swims and other sporty fundraising events continue to contribute significantly to income raising over £2.2million last year – enough to fund two years of our clinical care programme. Our biggest event, the London Marathon, saw a record £460,000 raised by our 230 runners; other runs such as the Cardiff Bay 5 (sponsored by Tata Steel) with over 1,000 runners raised more than £33,000 and brought the overall running income to over £1.3million. Swims raised over £45,000 and cycling income jumped 31% to £235,000. An inaugural event, the Beetham Tower Run in Manchester, raised over £29,000 – a repeat event was promptly set for October 2012 and we aim to expand to other cities in 2012/13.

Our challenge event participants raised enough to run our clinical care programme for two years. That hard work really does pay off!

Big Bounce remains one of our most popular fundraising campaigns



### Overseas events

Overseas events can present an exhilarating and even life-changing fundraising opportunity and last year over 50 people took on an epic adventure such as climbing Mount Kilimanjaro, trekking in Peru or competing in an international marathon raising a total of £309,000.

Find out about our challenge and overseas events at [www.cftrust.org.uk/events](http://www.cftrust.org.uk/events)

We enjoyed huge success in CF Week. In May 2011, supporters from across the UK pulled together in an extraordinary effort to raise over £232,000 in just seven days! Almost 1,000 new followers joined us on Twitter and almost 4,000 on Facebook, helping us shout even louder about cystic fibrosis and taking part in fantastic and fun events all week to raise funds. Cystic Fibrosis Trust staff get involved too with awareness stalls, cake bakes and sponsored silences. The week is a huge boost to our work and we're very grateful to our supporters who help us achieve so much during CF Week and throughout the year.

## Sophie Holt

**“My placement with the CF Trust provided me with fantastic experience.”**

**The CF Trust relies on the support of volunteers so we can support people with cystic fibrosis. Volunteering can be a hugely rewarding experience as well as a great boost to your career. Sophie Holt, who worked at the CF Trust for a year as part of a sandwich placement during her marketing degree course, describes what she gained from the experience.**



“I study Business Studies with Marketing at Brighton University, which encourages students to find a placement to gain valuable knowledge in the business industry, and my placement with the Trust did provide me with fantastic experience. At my interview, I was impressed by the welcoming environment and the organisation’s clear role – to help those with and connected to cystic fibrosis. This was a real pull for me.

My placement was in the Fundraising Support team where my main role involved promoting fundraising events online and in publications, however I was encouraged to get involved with different tasks such as helping with PR. The job had flexibility and I could contribute to the cause directly. Together with a colleague I organised the ‘Big Bromley Cake Bake’ during CF Week, which raised over £1,000. It was such a rewarding feeling to achieve this amount and to drive an event from beginning to end. I felt very valued as a member of staff.

My placement with the CF Trust provided me with fantastic experience. I attended several fundraising events for the Trust and found them to be inspiring and enjoyable. I’ve gained an understanding of the goals that the charity is striving towards and the routes they are implementing to achieve these. Another huge advantage to attending fundraising events is meeting people from the CF community. They have remarkable enthusiasm for the cause and remind you of the urgency for future funding. I would recommend to anyone to consider gaining work experience at the CF Trust.”

If you’re interested in work experience or volunteering at the CF Trust, we’d love to hear from you.

Please contact [enquiries@cftrust.org.uk](mailto:enquiries@cftrust.org.uk).







**“We are proud to support the CF Trust – as our charity partner we have been able to work with them to share information about the range of work the Trust does to support people with cystic fibrosis and raise awareness of the condition, as well as allowing our staff opportunities to raise funds. As the UK organ donation and transplantation organisation we share a common goal with the CF Trust – to increase the number of organs available for patients who need a lifesaving transplant. We look forward to continuing to work together towards this goal and supporting the excellent work of the Trust as it moves forward.”**

Lynda Hamlyn, Chief Executive,  
NHS Blood and Transplant

### **Working in partnership**

Relationships with companies, organisations and businesses across the UK play a vital role in enabling us to fund and plan our work, and can bring real benefits to the workplace too. Last year we were delighted to be selected as charity partner of NHS Blood and Transplant, and the partnership has recently been increased from two to five years.

### **Gifts in kind**

We are very appreciative for the many supporters who donate Gifts in kind, which can generate significant further funds. GlaxoSmithKline is just one which has secured auction and raffle prizes in excess of £10,000 that have been put to excellent use over the last year.

### **Pro bono support**

Pro bono support from companies has been a huge boost to the CF Trust’s research, clinical care and support programmes this year. Deloitte provided consultancy with CF Trust staff members to review some of our existing supporter care processes and made recommendations to improve efficiencies, some of which were taken forward and helped save us processing time and enabled costs savings to be made.

Also last year, PWC provided pro-bono consultative support carrying out detailed research to help with our strategy development, which involved surveying our many stakeholders to get a better understanding of they want from us as an organisation. A detailed online survey and one-to-one interviews were used to produce a comprehensive report, the feedback from which provided an invaluable insight into the needs of people affected by CF

and those involved in their care, research and treatment. This informed the development of our new corporate strategy, helping us guide and focus our work and identify key priority areas that we are already addressing. The research also improved our understanding of how the different areas of our work, such as fundraising, communications and lobbying, can help us achieve our objectives.

**“We are delighted to have been able to support the Cystic Fibrosis Trust by giving our people the opportunity to share their skills developing this important piece of work for the Trust. Those involved have found it truly inspiring and have brought new perspectives to other clients as a result.”**

Alastair Rimmer, Partner and Global Strategy Leader, PwC

We are extremely grateful to PwC for their support, the benefits of which will continue to be felt as we implement our corporate strategy to ensure we're delivering the very best for our stakeholders.

To find out more about how your company or business could support the CF Trust, and how such a partnership could benefit your workplace, email [company@cftrust.org.uk](mailto:company@cftrust.org.uk).

## Major gifts

We are very grateful to those who support our work at a higher level, and offer a number of options for supporting the CF Trust in this way. Our dedicated team works with supporters giving £5,000 and above who wish to support specific areas of our work.

Many of our key projects would not have been possible without support from these major donors, for example the Gene Therapy Appeal in 2011 that raised £1.1million in donations and pledges to ensure this important research could continue.

2012 saw the launch of the 65 Roses Club, designed for a small group of donors who support us with gifts of between £1,000 and £5,000 annually. Members can direct their gift to one of our broad areas of work – clinical care, research or support – and receive personalised updates on their chosen area, as well as an invitation to an annual lecture to update them on the full breadth of our work.

Many supporters arrange gala dinners for the Trust. Most recently, Tony and Lesley Khalastchi hosted a dinner at Quaglino's, which raised over £90,000. Events such as these are a great way of introducing new contacts to our work in an informal and fun setting.

## Share the giving

Gordon and Johanna Branston have two daughters who have a milder form of CF, so mainly stay quite well. But this hasn't stopped Gordon and Johanna fundraising, from Johanna whistling in support of the CF Trust to promoting legacy giving.

Gordon used to work in finance and is also familiar with the benefits of donating to charity through a gift of shares, which he has done in support of the CF Trust on a number of occasions most recently to support the Gene Therapy Appeal. For those who receive shares as a part of their remuneration this provides a highly effective way of charity giving at a significant level. About £100million is given in shares to charities in the UK each year.

Gordon says:

**“Although our daughters have CF, we are fortunate that each has an unusually mild form, and we therefore feel we want to do what we can to support the Trust and those CF families who are more burdened by daily treatment regimes and frequent hospital visits. I find share giving a tax-effective way of making donations to the Trust, which then additionally benefits from Gift Aid.”**

A gift of shares to charity is tax effective because the donor can claim income tax relief. The amount of relief depends on whether the donor is a basic or higher rate taxpayer. A basic rate taxpayer could save up to 20% income tax, in which case a gift of shares worth £1,000 would only cost the donor £800. A higher rate taxpayer could save up to 40% income tax, in which case a gift of shares worth £1,000 would only cost £600. In addition Capital Gains Tax does not apply to charitable gifts of shares\*. Whilst the CF Trust cannot offer financial advice, gifting shares is a relatively straightforward process and is something that the CF Trust can help with via its investment managers, Schroder's.

If you are interested in finding out more about supporting the CF Trust through major giving please email Claire Burrage at [cburrage@cftrust.org.uk](mailto:cburrage@cftrust.org.uk) or call 020 8290 8040.

## Support received from charitable trusts and foundations

We have been generously supported by a number of Trusts and Foundations in the past year, with over £500,000 being donated towards our work. It is only through such support that we can continue to ensure that people with CF receive the best possible care and support in all aspects for their lives.

The Robert Luff Foundation agreed to continue supporting pioneering research at Newcastle's

\*If you are unsure of the tax consequences of your gift to charity, you may wish to contact HM Revenue and Customs ([www.hmrc.gov.uk](http://www.hmrc.gov.uk)) or a tax adviser for further guidance.



Funding from a charitable trust has helped Helen McCabe deliver an improved dietetic service in Newcastle

Freeman Hospital into lung “reconditioning” (see page six). The Childwick Trust has been supporting the CF Trust since 1993 and donated a further £10,000 towards our welfare grants, so we can provide financial support where it is most needed. And another charitable trust, which wishes to remain anonymous, continued to fund vital dietetic support at the Regional Paediatric CF Service in Newcastle, ensuring more children have access to dietetic and nutritional support that helps them ward off infection and stay well – you can read about the difference this has made on page 16.

“On the whole our trust has shied away from supporting health-related projects, which receive the vast majority of philanthropic donations in the UK (and elsewhere) whilst other vulnerable groups, especially those on the margins of society, can struggle to get their voice heard. However, we had made small grants to the Cystic Fibrosis Trust in the past and having met the Trust for a pitch, were persuaded that as with other projects we’d funded, a relatively small project could make a big difference. So, we met the CF Trust for the pitch and were persuaded that a relatively small project could make a big difference. We agreed to fund the appointment for three years of a dietitian whose sole focus would be on children (and their families) with cystic fibrosis. It was subject to the hospital

agreeing that it would continue the post once our funding stopped. We have been thrilled by the outcome. It could not have happened without the quality of the Principle Dietitian Helen McCabe and the new appointee. Their passion for their patients and their commitment to learning has ensured that the knowledge gained is going to be accessible by way of a module at Leeds Met so that others can further their understanding. We look for grants that can help people and have the potential for a broader impact. Our congratulations go to all involved.”

Charitable trust (anonymous)

We also received support from donors new to the CF Trust. The John and Lucille Van Geest Charitable Trust supported Dr Alan Brown’s research into the impact of diabetes in cystic fibrosis, which 30% of adults with CF will develop. The research is investigating the link between diabetes and a damaging infection of the CF lung and the results will help guide the most effective management of this additional complication in cystic fibrosis.

And in January 2012, Jeans for Genes Day kindly agreed to support development of a contemporary short film about cystic fibrosis in the teenage years, which will help us engage with the 2,000 teenagers with CF in the UK.

We are very grateful to all the Trusts and Foundations that have supported us over the years. If you have a charitable trust, or if you sit on a trustee board and would like further information on the work of the CF Trust, please email Philip McCarthy at

**[pmccarthy@cftrust.org.uk](mailto:pmccarthy@cftrust.org.uk)** or call  
**020 8290 8047.**



Legacy income helps us drive up standards of clinical care across the UK

### **The importance of legacy income**

This year the Cystic Fibrosis Trust received over £912,000 from legacies and we would like to thank all our supporters who left a gift to the Trust in their will. The money people leave us in their wills makes a big difference, amounting to around 9% of our total income.

Last year we reached more supporters with our legacy marketing campaign Rosie's Lasting Legacy. Thank you to those who took part in focus groups to give your views on legacy giving, and to those who responded to our direct mail appeals. In CF Week we trialled our first will promotion scheme, working with solicitors in the Bromley area and the North West of England.

During the summer we visited branch meetings in Kent and Sussex to talk about legacy giving. Over 268 supporters have let us know that they will be leaving a legacy to the CF Trust in their will since the campaign began in October 2010.

### **How changes in Inheritance Tax could affect legacies in the future**

If your estate is worth over £325,000 when you die Inheritance Tax may be due. From 6 April 2012, if you leave 10 per cent of your estate to charity the tax due may be paid at a reduced rate of 36 per cent instead of 40 per cent. The chancellor announced this change in his 2011 budget to encourage gifts to charity. As a result, donors can leave more of their estate to charity and their family could save money overall. There is further information on the HM Revenue and Customs website with examples of how this works in practice.



The value of legacies for all charities has been affected by the current economic environment in the short term, particularly given the uncertainty around property and share prices. However we are confident that legacies will continue to be an important source of funding in future, which is why we are continuing to develop our legacy programme.

If you would like to receive information about leaving a legacy to the Cystic Fibrosis Trust or further details about Inheritance Tax changes, please email Sue Whitehead on [swhitehead@cftrust.org.uk](mailto:swhitehead@cftrust.org.uk) or call 020 8290 8051.

#### **Why we left a legacy to the CF Trust**

In July we received a legacy of £20,000 from a grandmother to someone with cystic fibrosis. Her daughter tells us what led to this generous gift:

**“My mother was a regular supporter of the CF Trust, by making donations and through fundraising efforts such as selling garden produce outside her house, and passing on to the Trust the fees she received for some professional work in her retirement. She also gave lots of practical support to my daughter and to us as parents around the time of our daughter’s transplant.**

**We are all so proud of my daughter’s achievements in her all-too-short life. She got through university, including a year spent abroad as part of her course, and gained a good degree.**

**She had a variety of jobs after uni, in which she impressed her employers with her great dedication and capability. She took and passed her driving test while she was an inpatient at our local hospital during a period when she was quite unwell as a result of an infection and her declining lung function.**

**My mother’s admiration for my daughter’s positive outlook on life, plus her gratitude for the help and support which the CF Trust gave to our daughter and our family, led her to leave a legacy to the Trust in her will.”**

# How you can help

There are many different ways in which you can help us continue the work you've read about in this review.

## **Make a donation or set up a regular gift by Direct Debit**

Support our work by making a donation or setting up a Direct Debit to make a regular gift every month. Please fill in the form overleaf and return to Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY. To find out more visit our website or email [supportercare@cftrust.org.uk](mailto:supportercare@cftrust.org.uk).

## **Leave a legacy**

After providing for those you care for, please consider leaving a gift in your will to the CF Trust. This will help ensure we can continue our work for future generations. To find out more about leaving the legacy pages on our website or email [swhitehead@cftrust.org.uk](mailto:swhitehead@cftrust.org.uk).

## **Get your company involved**

As well as benefiting the CF Trust, corporate fundraising can bring huge benefits to the workplace. Visit the corporate fundraising pages on our website to find out more or email [company@cftrust.org.uk](mailto:company@cftrust.org.uk).

## **Offer your skills or services**

Could you help us make cost-savings so we can spend more on our crucial care, research and support programmes? If you feel that you could offer your skills or business services to help in any areas of our work, we would love to hear from you. Email [enquiries@cftrust.org.uk](mailto:enquiries@cftrust.org.uk).

## **Recycle your unwanted items**

Recycling is a simple but effective way of raising funds. Unwanted clothes or gifts, old mobile phones or even used printer cartridges – we can put them all to use!

Contact [company@cftrust.org.uk](mailto:company@cftrust.org.uk) or visit the recycling page on our website to find out more.

## **Take part in a fundraising event**

We offer a diverse range of fundraising challenges and events throughout the year – there truly is something for everyone. Visit the events pages on our website to find out what's happening near you and as well as national and overseas challenges and campaigns, or email [events@cftrust.org.uk](mailto:events@cftrust.org.uk).

## **Organise a fundraising event of your own**

From coffee mornings to cake bakes, fashion shows to fancy dress parties, if you're thinking of organising your own fundraising event, we'll support you every step of the way. Visit the fundraising pages on our website for tips and ideas.

## **Volunteer with us**

Volunteering can be a great way to gain experience in the charity sector, and can be very rewarding on a personal level too. If you'd like to find out more about volunteering and work experience placements with us, email [enquiries@cftrust.org.uk](mailto:enquiries@cftrust.org.uk).

## **Help us raise awareness**

Raising awareness of CF and its impact is a major challenge. Real life stories really help us to do this. If you'd like to help us promote greater understanding by sharing your experiences of living with cystic fibrosis in the media, please email [enquiries@cftrust.org.uk](mailto:enquiries@cftrust.org.uk).

## **Help us campaign**

We shout loud on the issues that matter, and we often need others to add their voices too. If you'd like to get involved in our next campaign, sign up for our e-newsletters so we can reach you when we need your support.

Email [supportercare@cftrust.org.uk](mailto:supportercare@cftrust.org.uk) with your contact details.

Visit our website [www.cftrust.org.uk](http://www.cftrust.org.uk) for details on all of the ways you can help the Cystic Fibrosis Trust.

# Donation form

**1. If you would like to make a donation to the Cystic Fibrosis Trust please fill in this form and return your donation to the Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY. Thank you.**  
Alternatively you can donate online at [www.cftrust.org.uk](http://www.cftrust.org.uk) or by calling 0300 373 1040.

Please fill in your name and address – IN CAPITALS

Title \_\_\_\_\_ Full name \_\_\_\_\_

Home address \_\_\_\_\_

Postcode \_\_\_\_\_

Telephone number \_\_\_\_\_ Email \_\_\_\_\_

Please tick the relevant box if you are happy for us to contact you by email ☐ or by text message ☐

By telling us your date of birth we can save valuable funds by contacting you about the most relevant products and services.

/   /

**2. I'd like to make a regular donation of: £2 ☐ £5 ☐ £10 ☐ Other £**

## Instruction to your bank or building society to pay by Direct Debit

Please fill in the whole form using a ball point pen and send to:  
Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY

### 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

-   -

Service user number



Reference

### FOR CYSTIC FIBROSIS TRUST OFFICIAL USE ONLY

This is not part of the instruction to your bank or building society.

I'd like to make a regular donation of: £  
**monthly/quarterly/annually\*** starting on the 3rd/17th/28th\* of

\*Please delete as applicable

### 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 the Cystic Fibrosis Trust and if so, details will be passed electronically to my bank/building society.

Signature(s) \_\_\_\_\_

Date \_\_\_\_\_

**3. I'd like to make a one-off donation of: £5 ☐ £10 ☐ £50 ☐ Other £**

Please debit my: Visa ☐ MasterCard ☐ Maestro ☐ Amex ☐ CAF Charity card ☐

Card number

Start date

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**4. Increase your donations by 25% at no extra cost to you.**

☐ (Please tick if applicable) I am a UK taxpayer\* and I would like the Cystic Fibrosis Trust to treat all donations I have made in the last four years and all donations I make in the future, as Gift Aid donations until I notify you otherwise. Gift Aid is gratefully received and used to support the Cystic Fibrosis Trust where it is needed most.

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**Protecting your personal information.** We promise that any information you give us will be used by the Cystic Fibrosis Trust only. We'd like to keep in touch (including telephone) to let you know about the Cystic Fibrosis Trust's activities, including fundraising, and how your support is making a difference. If you would rather not hear from us then please let us know. Please see [www.cftrust.org.uk/privacy-policy](http://www.cftrust.org.uk/privacy-policy) for details of our Privacy Policy.

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