

Cystic Fibrosis Trust
Annual Review 2011



Be inspired

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Message from our Patron



People with Cystic Fibrosis and those involved in their support, care and treatment are an inspiration to us all. It is encouraging to know that, although Cystic Fibrosis continues to cut short young lives, significant advances, particularly in research, have been made in recent years and continue to be made. As you will read in this report, the Cystic Fibrosis Trust is doing all it can to build on this momentum and there is real hope for the future.

Thank you to all those who do so much to support the vital work of the Trust and it is hoped that this Review will be a further source of inspiration.

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

HRH Princess Alexandra

Four-year-old Eva Higgins (pictured cover) was diagnosed with Cystic Fibrosis when she was three months old. Last year, Eva became a 'hero' for the BBC's Big Splash campaign to inspire people to swim in the run up to the 2012 Olympics.

Welcome to the Cystic Fibrosis Trust Annual Review 2011

The purpose of this Review is to provide an overview of the Cystic Fibrosis Trust's activities in the last financial year (ending March 31 2011), and to demonstrate their impact on the lives of people living with and affected by Cystic Fibrosis.

The theme this year is 'Be Inspired'.

Inspiration is a theme we return to frequently in Cystic Fibrosis; not only because we are continually inspired by those battling CF and by those involved in CF care, treatment and research, but also because 'inspire' also means 'to breathe', something most of us take for granted but that for people with CF too often sadly becomes a luxury.

In this review you will read about people with and affected by Cystic Fibrosis living their lives as fully as possible despite the limitations that a chronic, complex condition such as CF can impose – and how the CF Trust helps them to do this. You will read how researchers, scientists and clinicians are working to improve care and treatments for people with Cystic Fibrosis, and how the CF Trust supports this

essential work. You will read about ways in which the CF Trust helps people with CF in times of need or going about their day to day lives. And you will also read about people who support the Cystic Fibrosis Trust in a variety of ways, helping us achieve our goal of improving the length and quality of life for everyone living with Cystic Fibrosis – and how you too can help.

You can also view this Annual Review, or download a separate document containing the financial summary, online at www.cftrust.org.uk/aboutcf/publications/.

About the Cystic Fibrosis Trust

The Cystic Fibrosis Trust, founded in 1964, is the UK's only national charity dedicated to all aspects of Cystic Fibrosis (CF).

Our objectives are:

- To fund medical and scientific research to find effective treatments for Cystic Fibrosis.
- To ensure appropriate clinical care for those with Cystic Fibrosis.
- To provide information, advice and support to anyone affected by Cystic Fibrosis.

Our head office is in Bromley, Kent, but we employ Expert Patient Advisers (each of whom has CF) and Regional Fundraisers who are based throughout the UK. We also have a strong network of dedicated volunteers and fundraisers in our Branches, Groups and Committees.

The Facts

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

Cystic Fibrosis affects over 9,000 people in the UK.

Over 95% of the UK CF population is Caucasian, but CF affects many ethnic groups.

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

If two carriers have a child, the 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 lives are lost to Cystic Fibrosis.

Half of those with Cystic Fibrosis can expect to live past 41 years of age, although improvements in treatments mean a baby born today could expect to live for longer.

A message from our Chief Executive

Dear friends

The Cystic Fibrosis Trust has a tenacious vision of a world where the length and quality of life is not disrupted by Cystic Fibrosis. That is why throughout the last year we have continued to support a range of research and clinical care programmes, and of course provide information, advice and support where needed.

The number of new Cystic Fibrosis therapies in development around the world should give us all strong confidence that future treatment in CF will be even better than it is today. In the meantime, though, it is essential to ensure that the best possible care is available today for all 9,000 people in the UK living with Cystic Fibrosis.

Over the past twelve months, external factors have challenged our ability to champion both the best research and excellent clinical care. Changes and restrictions on funding in the NHS have presented real concerns as to how Cystic Fibrosis care is delivered now and in the future. We have been battling on many fronts to ensure that the gains of the last few years are not lost, and that capacity for a growing CF population is expanded for the future. We feel that we are though making progress against the headwind.

In our research programme, the challenging fundraising environment and rising costs of research also meant that during 2010–11 we had to significantly revise our commitments to the gene therapy research; at the time of writing a range of new funding options were

“We are making progress against the headwind.”



being vigorously pursued and the outlook for the future of the research looked positive.

We remain confident though that the new treatments and better care will continue to be offered into the future, not least because of the commitment and drive of so many people working in Cystic Fibrosis research and care. Thank you.

Thank you also for all that you and your families and friends have done over this past year to support this work through the CF Trust. We are immensely grateful for the generosity and time so many people give to enable the Trust's work to happen and for progress to be made. Thank you very much indeed.

With kind regards,

Matthew

Matthew Reed
Chief Executive

Success stories



10,000 views

Our animated film for children with Cystic Fibrosis – Getting nosey about CF – proved a hit with children and parents alike, attracting almost 10,000 views during its first month on YouTube and garnering international acclaim.

Thanks to a successful campaign by the Cystic Fibrosis Trust and parents in Northern Ireland, plans to close a vital CF unit in Belfast providing inpatient care to over 50 teenagers with Cystic Fibrosis were axed.

The launch of our legacy campaign Rosie's Lasting Legacy saw 129 pledges in its first six months, and later won a prestigious Institute of Fundraising award for best legacy marketing campaign.

The Department of Health agreed to work towards implementation of a mandatory tariff for funding CF care based on severity of condition, meaning that from 2012 people with Cystic Fibrosis should receive a level of care appropriate to their individual needs.

£250,000

An explosion of interest in overseas treks and cycles saw our income from these types of events increase by 200% from £80k to almost £250k.

£45,000

The introduction of The Big Cake Bake campaign saw our income from coffee mornings more than double to over £45k.





£18m

The first round of peer reviews of Specialist CF Centres in the UK has now been completed as part of the CF Trust's peer review programme, which has leveraged over £18million in NHS funding for the CF services visited.

Average age of diagnosis with Cystic Fibrosis is now three months old – the lowest ever thanks to a prolonged campaign by the CF Trust to see nationwide newborn screening for CF, finally implemented in 2007. The earlier CF is diagnosed, the sooner treatment can begin and the better the prognosis.

The conclusion of the Pilot Study into gene therapy for Cystic Fibrosis, funded by the Cystic Fibrosis Trust, which identified the safe dose for the Multi-dose trial. The UK CF Gene Therapy Consortium is now at a crucial stage in its world-leading gene therapy research.

All patients at CF Centres in the UK are now registered on the CF Trust-funded UK CF Registry. Complete data has been entered for 82% of this population – one of the most complete sets of CF data worldwide – which will enable us to monitor outcomes and target help to where it is most needed.



Improving and maintaining standards of care

People with Cystic Fibrosis should receive the best possible care to ensure they have the best possible length and quality of life. The Cystic Fibrosis Trust is committed to achieving excellent, equitable care for everyone living with Cystic Fibrosis in the UK, and in the past year work has continued on several initiatives aimed at achieving this.

Reviewing specialist CF services

There are 48 Specialist CF Centres and 120 Networked Clinics in the UK, providing expert care to children and adults with Cystic Fibrosis. Unfortunately, not all are adequately resourced. The CF Trust peer review programme assesses services against national Standards of Care, identifies shortfalls and helps CF services to improve the care they provide.

Peer reviews of eight Specialist CF Centres and 23 Networked Clinics were conducted in the last financial year, but 2011 saw the first break in the peer review programme to evaluate the current system and to ensure that CF Centres can deliver ongoing service improvements following a review. A revised programme for 2012 will see peer review reports being made available to the public for the first time, providing comprehensive, independently verified information about individual CF services.

Every £1 the CF Trust spends on its peer review programme leverages £20 of NHS funding for CF services that would otherwise not have been available. To date, over £18million has been made available to CF services as a direct result of peer reviews, and used to recruit specialist staff where there were shortfalls, provide essential equipment and improve facilities from inpatient rooms to exercise equipment.

Ensuring appropriate funding

Cystic Fibrosis can affect people very differently. As such, it is imperative that people with CF receive a level of care that is appropriately funded according to their individual, changing needs.

For the past few years, the Cystic Fibrosis Trust has been working with clinical teams and commissioners of CF services to develop an improved strategy for funding of CF care that takes this into account. In 2010, we were delighted that the Department of Health agreed to work with the CF Trust to develop fairer funding of CF care, through a newly proposed national tariff based on severity of illness and treatment required. This is due to be implemented in 2012.

Monitoring outcomes

The UK CF Registry, which contains clinical information about CF patients, now contains data for almost all of the UK CF population (full data for 82%), making it one of the most complete set of CF clinical data worldwide. This enables us to target resources to where they are most needed and drive up standards of care, and assist commissioners in the planning of future CF services, increasingly important as the CF population continues to grow. The Registry is also helping aid research into potential new treatments and clinical practice.

Last year we published Registry reports online for the first time, enabling people with Cystic Fibrosis to examine outcomes from their



In 2010–11 the CF Trust spent over £1million on its clinical care programme.

own CF Centre or Clinic and make informed decisions about their healthcare.

Promoting best practice

Work began in 2011 to update our Standards of Care, which provide guidelines in best practice in CF care and treatment against which CF services are measured during a peer review. Last year we also published new guidelines on processing microbiological samples from people with Cystic Fibrosis – of critical importance given that timely identification and treatment of infections in CF is crucial in combating health decline.

We run an annual medical conference for CF clinicians, providing invaluable opportunities to share and promote best practice in Cystic Fibrosis care and treatment.

In 2011 we also completed the CF Clinical Care Pathway (www.cfcarepathway.org.uk), an easily accessible online guide to CF care for commissioners and others involved in CF care provision.

Patient advocacy

Seven expert patient advisers (EPAs) are employed by the Cystic Fibrosis Trust to use their knowledge of living with Cystic Fibrosis to influence those involved in commissioning or provision of CF care and services. Last year the EPAs worked on a range of projects including focus groups, patient surveys and the peer review programme, ensuring the views and

needs of CF patients are represented at a regional and national level.

Safeguarding vital services

The Cystic Fibrosis Trust stands up for patients where CF services are at threat of cuts or closure. Thanks to a successful campaign by the CF Trust and parents in Northern Ireland, plans to close a vital CF unit in Belfast providing care for 50 teenagers with CF were axed. We added our voice to the campaign against frontline NHS cuts and began working on a more in depth project to address potential future threats. We also campaigned against the closure of children's cardiac services at the Brompton Hospital in London which would place its CF service at risk of closure.



“There is no such thing as a day off from Cystic Fibrosis.”

Penny Higgins, mum to Eva, four, and Abel, six.

We didn't really know what Cystic Fibrosis was or what it meant for Eva when she was diagnosed at three months. Hearing that Eva's life expectancy could be less than my age at her birth horrified us – everything seemed so uncertain and we were terrified of the future.

The CF Trust's web forum is a real source of support – hearing positive stories about other children and adults with CF, celebrating Eva's achievements, as a speedy way to reach out to the CF community and to offer our support to others. Without it, we would have felt very lost at times.

Last year I was invited to be the parent representative for a peer review of Alder Hey Children's Hospital. Initially I hadn't a clue what a peer review was, but I left Liverpool that day with a completely different outlook on what the CF Trust does. To know they visit every CF Centre was a welcome eye-opener, and to see Centres embracing this support so that they can improve the care they provide to children like Eva was immensely reassuring. It was truly refreshing to have a sense of how money being raised for the CF Trust by us and others was impacting on our Eva right here and now.

Eva is our inspiration for living life as fully as possible – she has achieved so much in spite of Cystic Fibrosis. When her consultant told us exercise was important, we signed Eva up for swimming lessons – at two years old she swam five metres by herself and received the ASA's Disability Swimmer of the Year award in 2010.



The BBC has since invited Eva to be a 'hero' for their Big Splash swimming campaign in the run up to the 2012 Olympics. And Eva's swim school recently introduced a new class for pre-school children to swim without their parents, inspired by Eva's demonstrating just what toddlers can do in the pool given the chance.

There is no such thing as a day off from Cystic Fibrosis, however we have never let CF stop us doing anything – Eva wouldn't thank us if she missed out on any fun! As CF is incurable we focus on keeping Eva as well as we can for as long as we can, so if a cure or significant new treatment is found, she is well enough to take advantage of it. The reduced life expectancy for someone with CF is a crushing statistic for any parent to get to grips with, but gene therapy and other research the CF Trust funds gives us hope and motivation to keep going in the knowledge that Eva might one day look forward to the same future that her brother can.

Be Inspired Eva Higgins



“Eva is our inspiration for
living life as fully as possible.”

Investing in research

The Cystic Fibrosis Trust funds research that could improve the quality and/or length of life of people with Cystic Fibrosis. As there is still no cure, preventing the lung damage that claims the lives of 90% of people with CF remains a focus, but we fund a diverse range of research reflecting the complexity of the disease and its effects.

Addressing the organ crisis

Lung transplant can be a treatment for Cystic Fibrosis when conventional treatments are no longer effective, and people with CF have a good prognosis post-transplant. Unfortunately, due to a lack of suitable organs, many people with CF on the waiting list will die before they receive the new lungs they need.

Pioneering research started at the Freeman Hospital in Newcastle and initially funded by the CF Trust is helping to address this. Using a technique called ex-vivo lung perfusion (EVLP), lungs deemed unsuitable for transplant are 'reconditioned' to improve their quality so that they can be successfully transplanted. EVLP has already resulted in six people with Cystic Fibrosis receiving lung transplants, which otherwise may not have been possible, since the research started in 2009. Last year the Trust was delighted to receive a grant of £175,000 from the Robert Luff Foundation, which has been used to roll out EVLP to all five adult lung transplant centres in the UK and will make the technique more widely available to CF patients.



“Our ultimate aim is to make waiting list deaths a thing of the past.”

**Professor Andrew Fisher,
Principle Investigator of EVLP
study, Freeman Hospital,
Newcastle upon Tyne.**

Understanding the basic defect

Cystic Fibrosis is caused by a faulty gene that disrupts the action of a protein called cystic fibrosis transmembrane conductance regulator (CFTR), which controls the movement of salt in the body's cells and causes a build up of thick sticky mucus that damages the lungs and other organs. By gaining a greater understanding of CFTR, scientists can develop targeted treatments to correct its action and prevent this damage.

£350,000

In 2010–11 the CF Trust spent over £350,000 on non-gene therapy research.

One such study funded last year aims to identify novel targets to correct the dysfunctional salt transport in Cystic Fibrosis. Excessive salt absorption through channels in CF epithelial cells causes airway dehydration and impairs normal airway clearance, leading to infection and inflammation in the CF lung. Identifying enzymes involved in activating these salt channels could help develop new drugs to rehydrate the airways and promote normal clearance mechanisms, contributing to an improved quality of life and prognosis in people with Cystic Fibrosis.

Another study, still ongoing, is investigating in detail the structure of the faulty CFTR protein. From this, a better understanding should be gained of how it works as a salt channel, assisting development of new drugs and improving understanding of how certain drugs in development currently work, speeding up their progress to patients.

Tackling infections

Repeated microbial infections in the CF lung cause lung damage that over time becomes irreversible. Therefore increasing our understanding of the harmful microorganisms which infect and damage the CF lungs is of the utmost importance.

We awarded two grants last year to researchers investigating one of the most harmful infections in CF, caused by the *Burkholderia* species of bacteria. Infection with



these bacteria is unfortunately very difficult to eradicate and is associated with increased mortality in Cystic Fibrosis.

One study is investigating how *Burkholderia* species respond when the patient also has diabetes – which 30% of adults with CF will develop. When CF patients develop diabetes, their lungs become even less efficient, and their life expectancy is further reduced. Evidence suggests that the conditions which arise during diabetes (either as a result of the diabetes itself, or its subsequent treatment) might alter the way that *Burkholderia* behaves within the CF lung, and that this may influence the severity of the infection. This research will reveal the direct impact that diabetes has on the *Burkholderia* infections of the CF lung, and help guide the most effective management of CF-related diabetes.

In another study, an emerging strain of *Burkholderia* known as *Burkholderia multivorans*, which is becoming particularly problematic but about which very little was known, was investigated in detail (see over page).

“Our research has thrown up a few surprises and given both us and others in the field some new avenues for further study.”

It is estimated that between 3–5% of people with Cystic Fibrosis in the UK are infected with *Burkholderia* bacteria. Until recently, very little was known about one species in particular – *Burkholderia multivorans* – which is emerging as a significant pathogen in Cystic Fibrosis. Hence there was an urgent need to discover more about these bacteria.

Although the CF lung seems to be more susceptible to other infections, the smaller number of people with Cystic Fibrosis that do contract *Burkholderia* infection unfortunately tend to suffer quite severe effects. It seems that certain people, particularly those in hospitals, are particularly vulnerable. While it used to be the case that infection by *Burkholderia* was virtually impossible to eradicate, this is not so much the case any more. However even if successfully treated, infection can return and in some cases this becomes chronic and causes irreparable damage to the lungs.

Burkholderia multivorans is particularly good at becoming resistant to antibiotics. In our research funded by the CF Trust we used a technique called a microarray to sequence the genome of *B. multivorans* – the easiest way to understand a bacterial species. We looked at the genes and pathways it uses to become resistant, which could be targets for treatment.

Our research has thrown up a few surprises and given both us and others in the field some new avenues for further study. We have mapped so many interesting pathways and



already have a couple of interesting leads. Overall, we have a much better understanding of how *Burkholderia* bacteria resist antibiotics and grow during CF infection. Further increasing our understanding of *Burkholderia multivorans* will help us develop therapeutic strategies to combat future infections with these problematic bacteria.

Be Inspired Professor Eshwar Mahenthiralingam and Dr Andrea Sass, Cardiff University



Gene therapy

Over the past ten years, the Cystic Fibrosis Trust has invested over £30million in gene therapy research, conducted by the UK CF Gene Therapy Consortium, which aims to treat CF in the lungs by replacing the faulty copy of the CF gene with a healthy one.

A gene therapy product has been developed by the Consortium, safety studies have been carried out and 2011 saw the conclusion of the run-in study to refine the series of tests needed to assess the effectiveness of the treatment and select patients for the next stage of the trial. At the time of writing, the challenging fundraising environment and rising costs of research meant that during 2010–11 we had to significantly revise our commitments to the gene therapy research. A major funding drive was therefore underway to raise the funds required for the next stage of the research – a Phase 2 clinical trial in which participants will receive a dose of either gene therapy or a placebo once a month for 12 months.

Gene therapy: at a glance

Gene therapy has the potential to improve both length and quality of life. Whereas most conventional treatments treat the symptoms of a disease, gene therapy treats the underlying cause (in the case of Cystic Fibrosis, this is the defective CF gene). Unlike other CF treatments in the pipeline, gene therapy would work on all CF mutations. It would be delivered by inhalation via a nebuliser – a quick and easy method of taking medication. Although the person would still have symptoms of CF elsewhere in the body, successful gene therapy could lead to a significantly improved prognosis for people with Cystic Fibrosis.

Joined up thinking

The Cystic Fibrosis Trust was responsible for bringing together the UK's three leading Cystic Fibrosis gene therapy research groups to form the UK CF Gene Therapy Consortium. This method of working enabled this pioneering research to progress at a much faster rate and progress since the development of the Consortium in 2001 has been considerable.

We are now aiming to replicate this success in other areas by aligning more closely with researchers and clinicians in Europe and internationally. In the past year we began supporting the European Young Investigator Programme, providing travel grants for promising CF researchers to attend scientific meetings. In addition, we sponsor the European Clinical Trials Network, which aims to speed the delivery of new medicines to the clinic by co-ordinating trial activity across Europe.

Funding research that could have imminent or significant benefits for people with CF remains at the core of our charitable purpose, and we are proud to be a leading investor in CF research in the UK.

£4.5m

**Last year the CF Trust spent
£4.5million on this potentially life-
changing research**



Informing, empowering, enabling

To complement our research and clinical care programmes, we also provide information, advice and support to people affected by Cystic Fibrosis. In 2010–11 the CF Trust spent almost £900,000 providing essential services. We also do our best to raise the profile of CF in the wider community.

Easing the burden

Living with Cystic Fibrosis can be a financial burden. Up to 60 tablets per day, regular hospital visits often involving overnight stays... the costs can soon add up. Last year we provided welfare grants amounting to £107,000 to families and individuals affected by Cystic Fibrosis.

We helped over 100 young adults with CF live independently by providing start up grants for them to set up home for the first time. We helped over 30 young people pay for their prescription charges for the first year (adults with CF in England have to pay for their life-saving medication unless they become exempt for another reason, such as developing diabetes). We contributed to the travel costs of over 30 individuals being assessed for a transplant, a process which can involve costly transplant centre visits. Two people with CF die each week; we assisted over 60 bereaved families with funeral expenses. We also helped over 20 adults with Cystic Fibrosis enjoy a break in the UK or abroad which they may otherwise have been unable to afford.

Support and advice

Our three helplines offer advice on grants, benefits and general information about Cystic Fibrosis. Last year, our helpline staff responded to over 1,700 enquiries. The helplines are complemented by our Ask the Expert email service, which last year received on average 30 queries each week.

Info for all ages

Average age of diagnosis with Cystic Fibrosis is at its lowest ever thanks to nationwide newborn screening. Responding to the need for information for a younger age group, the CF Trust last year produced an animated DVD aimed at four to eight year olds. *Getting nosey about CF* proved a huge hit, with almost 10,000 hits during its first month on YouTube and earning praise from both children and adults alike, demonstrating the importance of providing information about CF for all ages.

“Fabulous video – my four-year-old daughter watched it and said ‘that’s just like me.’”

Quote from parent about *Getting Nosey about CF*, animated DVD for children.

Raising awareness, enlisting support

It can be hard to persuade those not directly affected by Cystic Fibrosis to care about those who are, especially since you can't catch CF or develop it later in life. We do our utmost to raise the profile of CF at every opportunity, and the Cystic Fibrosis Trust is regularly called upon to provide expert comment and case studies in print, radio and television. We work hard to bring the message about CF to the wider public.

“Without the CF Trust forum, we would have felt very lost.”
Quote from parent to a child with CF

The importance of being online

As people with Cystic Fibrosis can pass on harmful 'bugs' to one another, they are advised to avoid contact with others with the disease – which can be a source of considerable frustration and isolation. The internet is therefore of huge significance, providing a means to connect with others free from the risks posed by physical contact.

The CF Trust is working hard to improve its online presence to better engage with the CF community and enable easy interaction between those affected. Activity on our Twitter and Facebook pages has rocketed in the last year – currently we have around 37,000 fans of our Facebook page and over 3,500 Twitter followers, demonstrating the importance of the digital experience. Another means of chatting and sharing information online is provided on our website forums; separate forums are available for parents, adults, partners, teens and fundraisers, and are among the most visited pages on our website with over 5,000 registered users.

We have also embraced the use of e-newsletters as a simple, quick and cost-effective way to provide timely updates to the CF community.

Informing and empowering

Along with our digital platforms, our extensive library of publications including factsheets, clinical guidelines and our regular magazines such as *CF Today* also help us provide up to date, accurate information to people affected by Cystic Fibrosis, empowering them to make better decisions about their health and care. We regularly review the information we provide and seek feedback from our audiences to ensure our information is comprehensive and relevant.

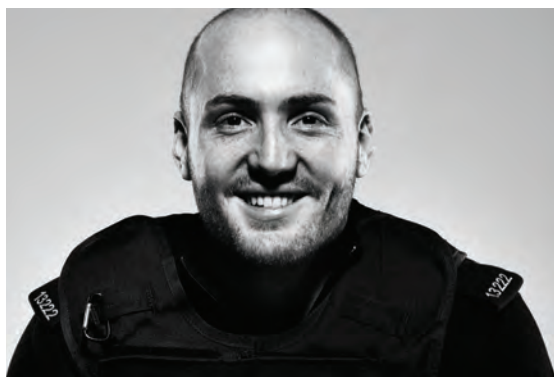


“I may have CF but I’m still living my dreams and there’s no reason why everyone else can’t. The future is in our hands.”

PC Sam Norman, 25

Picture the scene... I'm 19 at university having the time of my life; drinking, partying and playing sport for the university. All of a sudden I started coughing up large amounts of blood. After months of tests and scans the bombshell is dropped – I've got Cystic Fibrosis. But as soon as I walked out of the hospital doors I stopped and thought, I'm no different to when I walked in there, I now just have a label. That's how I live my life.

I'm now 25 and have been a police officer for four years. I was working as a special constable when I was diagnosed anyway so my life really hasn't changed. I live my life exactly the same as all my friends and colleagues. I don't see myself as special or unfortunate, in fact I'm fortunate in life that I'm quite healthy, but others are not so lucky. That's why I chose to jump out of a plane from 15,000ft with my good friend Nigel Barker in order to raise money for the CF Trust (my fundraising was supported further by Greater Manchester Police).



The CF Trust is an awesome cause and helps so many people live a better quality life – paying for a 12-month prescription charges certificate is just one way the Trust has helped me.

We all have dreams in life and mine was to be a police officer. I may have CF but I'm still living my dreams and there's no reason why everyone else can't. The future is in our hands.

Be Inspired Sam Norman



Fundraising

We couldn't do all of the things we have mentioned in this Review – working to improve the lives of people affected by Cystic Fibrosis through our research and clinical care programmes, and providing information, advice and support where they are needed – without our dedicated fundraisers, supporters and volunteers.



The Cystic Fibrosis Trust has around 100 fundraising Branches, Groups and Committees in the UK – committed supporters of the charity who along with families, friends and colleagues organise fantastic events such as walks and balls or take part in our own events to raise vital funds.

Alongside these, individual fundraisers, often directly affected by CF, hold coffee mornings, jump out of planes, shave their heads or climb mountains to raise funds for us. Many of our supporters prefer simply to make a donation towards our work.

However people choose to support us, we work hard to ensure they are supported and inspired in their fundraising ventures. The Cystic Fibrosis Trust has a network of 20 regional fundraising managers across the UK, on hand to organise events and offer assistance and guidance to those planning or taking part in a fundraiser themselves. We also have a dedicated events team managing our popular and diverse range of larger events – challenges such as the Brighton Marathon, a new event which last year raised over £44k; overseas adventures such as Kilimanjaro treks and

“We really value the support we get from our Regional Fundraising Managers. They don’t just encourage us to fundraise, but they also provide that tangible contact with the CF Trust.”

Fundraiser and parent of a child with CF

London-Paris cycles, which last year saw income rise by 200% to almost £250k; and campaigns such as The Big Cake Bake, which last year saw our income from coffee mornings and cake sales double to over £45k.

Relationships with companies are very important to the Cystic Fibrosis Trust and there are many ways in which businesses can lend their support; we have enjoyed many beneficial partnerships in the last year such as that with Opus Energy, which you can read about on page 24.

We receive funding from charitable trusts and major gifts from individual donors, often enabling us to fund world-leading research projects such as gene therapy (see page 14) and improving the availability of lungs for transplant (see page 10). And there are those who leave legacies to the Trust in their

wills, which mean so much to those with CF who will benefit from this generosity in the future.

We are enormously grateful for the efforts of all those who do so much to fundraise for us, enabling us to strive towards our common goal – improving the length and quality of life of everyone with Cystic Fibrosis. By fundraising for the Cystic Fibrosis Trust, or supporting us in a different way, you will be making a real difference to the lives of people affected by Cystic Fibrosis. You're also guaranteed great support and encouragement from us along the way. In the coming pages, you will read about people who have been inspired to support the Cystic Fibrosis Trust, and on page 26 you can find out about the different ways you can help.



Why I'm inspired to support the CF Trust

Andrew and Allison Murray, Fife

When our daughter Fiona was diagnosed with Cystic Fibrosis, we were as devastated as any parents would be. Not knowing her long-term prognosis, we tried to give Fiona lots of different experiences which would also provide beneficial exercise, so from an early age she went to gymnastics, dance classes and badminton, and started to play flute. Fiona is now in her last year at Strathclyde University studying BA in Applied Music.

Since Fiona was born, we have looked out for news of medical developments. Despite several false starts, medical treatment has improved, and we felt that fundraising to support the scientists involved in research into new treatments was crucial. We organised our first fundraising event a couple of years after Fiona was born, and in 1995 for our first big fundraiser we sailed a Hebridean galley from Islay down to Glasgow, with a crew of 16 changing every day to optimise sponsorship.

Since 1998 we have organised an annual sponsored cycle run for the Cystic Fibrosis Trust, from Callander (outside Stirling) to Balquhider and onwards to Killin, which provides up to 50 miles off-road cycling. The event attracts around 150 cyclists and usually raises between £10,000–£15,000.

You can support the CF Trust in many different ways. Search out your local fundraising Branch, or regional fundraising manager, and offer your help. The CF Trust website will tell you what's going on in your area, and gives



ideas on how to fundraise. Or you could brainstorm and come up with a novel idea of your own to catch the attention of the public and potentially raise lots of funds! If you're happy to talk about Cystic Fibrosis, offer to go out to local groups or organisations to keep them informed and raise the profile of the Trust in your area, as well as keeping your local newspaper up to date with any planned events.

We would encourage all families with a Cystic Fibrosis connection to get involved in fundraising so the CF Trust can continue to fund research – future medical developments for people with Cystic Fibrosis depend on our support.

The 2012 Callander to Balquhider Cycle Event is planned for Saturday 19 May – details can be found at www.cftrust.org.uk under 'Cycling'.

Ben Shephard, Celebrity Patron

The Cystic Fibrosis Trust is a charity that – despite the clichéd term – is very close to my heart. I've been involved with the Trust for several years and during that time have met many inspirational children and adults living with CF, and many more inspiring fundraisers and supporters doing all they can to raise funds and awareness. One thing that always stands out for me is how determined and positive people living with CF are, despite having to do so much treatment every day just to keep well.

The CF Trust offers a diverse range of fundraising events throughout the year, and the enthusiasm of all those who get involved is truly infectious. In the past I've run the Tresco Marathon (held on the Scilly Isles on the same day of the London Marathon) on two occasions, been battered and bruised in celebrity rugby and football matches, and took part in the Coast to Coast Challenge – along with Andrew Roberts who has a son with CF, we ran a marathon a day for five days from Cumbria to Tyneside. Exhausting, but worth it (for some reason I've agreed to do it again!).

The outlook for people with Cystic Fibrosis continues to improve, thanks largely to the efforts of those who are directly affected by Cystic Fibrosis, and to the pioneering work of the Cystic Fibrosis Trust, investing in research, improving access to and quality of specialist care and providing practical support to people affected by CF in a range of ways. Despite these efforts, CF continues to claim two lives a week



“The outlook is improving, but our support is needed as urgently as ever.”

– meaning our support is needed as urgently as ever.

I hope that reading this Review you will also be inspired to support the CF Trust. Together we can continue to make a real difference to the lives of those living with Cystic Fibrosis. If you'd like to find out more about how you could get involved in fundraising, challenge events or help in other ways, visit www.cftrust.org.uk/help.

Why I'm inspired to support the CF Trust

Opus Energy

Opus Energy recently extended their pledge to the Cystic Fibrosis Trust, aiming to raise £15,000 for us by the end of 2011. Opus Energy's Managing Director, Charlie Crossley Cooke, explains why they've had such fundraising success:

"The decision to make the Cystic Fibrosis Trust our chosen charity has proven a very popular one with all the staff at Opus Energy. As one of our employees has a young child living with Cystic Fibrosis, it's been a real pleasure to support a charity that really is close to the company's heart.

Opus Energy's staff know that their efforts are benefiting sufferers of CF who live in their area. Whilst it's important for any organisation to give back to their community, it's even more rewarding for our fundraisers when their efforts are contributing to such a worthwhile and relevant cause.

So we've had no trouble persuading everyone to throw themselves into all manner of events and challenges. Everyone here has enjoyed the chance to take part in really memorable experiences, alongside the added bonus of fundraising for continued research into Cystic Fibrosis.

Our fundraising has taken many forms, from office 'worst-dressed' days, a Christmas wrapping service and 6-a-side football, right up to enormous personal challenges – parachute jumps, the London to Paris team bike ride, and



"It's important for any organisation to give back to their community."

staff member Adam Kelly's seven marathons in seven days.

Opus Energy set out last year to raise £10,000 for the Cystic Fibrosis Trust, and thanks to all our staff's support we've matched that comfortably. After that it was an easy decision to extend our pledge to £15,000 by the end of the year.

I'd like to thank everyone at the Trust for giving us such a great cause to support, to our own fundraising team for their ideas and organisation, and of course every member of staff who's helped support our chosen charity throughout 2010 and 2011."

Leaving a legacy to the CF Trust

Legacies continue to play an important part in funding the work of the Cystic Fibrosis Trust. In the last financial year we received £895,000 in legacy income and would like to thank all those who supported us in this way and their families.

To put things in perspective, last year's legacy income could have almost covered the costs of our information, advice and support programme for the entire year. With this income we were able to provide 284 welfare grants, provide detailed medical documents to help drive up clinical standards, and run the helpline service.

In March 2011 we received a legacy of £43,800 from the estate of Mrs Gladys Mary Tichborne, who passed away in August 2008. Mrs Tichborne's son Frank was an executor to his mother's estate and he tells us about this generous gift.

"Mum was a caring person who suffered cancer and then latterly a stroke from which she finally succumbed. My mother left all the residue of her estate to charity with instructions that each of her six children could choose their own charity. My wife Patricia and I chose the Cystic Fibrosis Trust for our share, in memory of our dear niece Aimi Barr who courageously lived with CF without complaint until the age of 20.

Aimi was very active, however inevitably she spent much of her last 18 months in a wheelchair due to her breathing difficulties, and had to carry large Oxygen cylinders with her

"My wife and I chose the Cystic Fibrosis Trust in memory of our niece."

when she ventured out. Aimi's parents Anne and Jack were continually looking for ways to improve her mobility and quality of life."

Mr and Mrs Tichborne and Aimi's parents wanted to support the Trust's work in helping to improve the quality of life for those living with CF now. This legacy is helping to fund nebulisers and other areas of our work to ensure a better life for people living with CF today.

In last year's annual review we told you about Rosie's Lasting Legacy – our new legacy campaign which we launched in autumn 2010. We have had a fantastic response to the new campaign and want to thank everyone who has replied to our legacy campaign or taken part in a focus group, giving us your views on this form of giving. Between October 2010 and March 2011, 129 of our supporters let us know they were leaving a gift in their wills to the Trust. Since the average value of a legacy to the Trust is £11,300, this amounts to potential income of almost £1.45million. We have also had many enquiries and requests for the legacy brochure.

If you would like to receive information about leaving a gift in your will to the Cystic Fibrosis Trust please contact Sue Whitehead on swhitehead@cftrust.org.uk or telephone 020 8290 8051.

How you can help

As you have read, there are many ways in which individuals, families and companies can support the Cystic Fibrosis Trust.

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 campaigns

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

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 / Direct Debit

You can make a donation by using the form on the next page, by calling 0300 373 1040 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. You will find a Direct Debit form on the next page.

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.

Thank you for your support.

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 or by calling 0300 373 1040.

Please fill in your name and address – IN CAPITALS

Title _____

Full name _____

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.

/ /

My employer is _____

We may contact you to help us with a charity of the year nomination.

2. I'd like to make a regular donation of:

£2 ☐ £5 ☐ £10 ☐ Other £

monthly / quarterly / annually* starting on the

3rd / 17th / 28th* of _____

*Please delete as applicable

Banks and Building Societies may not accept Direct Debit Instructions for some types of accounts.

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.

INSTRUCTION TO BANK/BUILDING SOCIETY TO PAY BY DIRECT DEBIT

Name(s) of Account Holder(s) _____

Account Number

Sort Code -

Originators ID 8 0 3 1 4 3

Signature _____

Date _____

For office use only:

3. I'd like to make a one-off donation of:

£5 ☐ £10 ☐ £50 ☐ Other £

Please make your cheque/postal order/CAF voucher payable to 'Cystic Fibrosis Trust' OR you can debit your:

Visa ☐ Mastercard ☐ Maestro ☐ Amex ☐

CAF Charity Card ☐

Card Number

Valid From Expiry Date

Issue Number (Maestro)

Security Number Last three digits on signature strip on back of card (four on AMEX)

Signature _____

Date _____

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

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☐ (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.

Date _____

Your Gift Aid declaration is not valid if you do not date this form.

*To qualify for Gift Aid, you must pay an amount of Income Tax and/or Capital Gains Tax (but not including council tax or VAT) at least equal to the amount that the Cystic Fibrosis Trust and all charities you support reclaim on your donations in the appropriate tax year (6 April one year to 5 April the next), currently 25p for each £1 donated (28p on every pound for donations up to 5 April 2008).

Save us money

To save us money if you would prefer not to receive an acknowledgement please tick here ☐

Please note if you are setting up a Direct Debit we need to send you a written confirmation as a legal requirement.

Please help us to keep our records up to date:

Are you connected to Cystic Fibrosis? (please tick)

Adult with CF ☐

Parent of a child with CF ☐ Child's DOB

Family member ☐ (please advise) _____

Healthcare professional ☐ (please advise) _____

Other ☐ (please advise) _____

If you would like any help or advice regarding Cystic Fibrosis please call our helpline on 0300 373 1000 Monday to Friday between 9am and 5pm.

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 for details of our Privacy Policy.

Acknowledgements

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

A J N Steelstock Ltd
AMW Charitable Trust
Graeme and Gemma Cochrane
Adam Constable
David and Barbara Dein
Mark and Dorothee Cresswell
Sir John Fisher Foundation
The Donald Forrester Trust
Hills Prospect Plc
John Horniman's Childrens Trust
The Iliffe Family Charitable Trust
Nigel Langdown Fund
Charles and Sally Leggat
The Joseph Levy Foundation
The Light Fund
The Enid Linder Foundation
The Robert Luff Foundation
Julian and Lynn Spooner
Star Cargo Plc
Richard and Christine Stevens
The Gay & Keith Talbot Trust
Christopher and Elaine Taylor
The Constance Travis Charitable Trust
Dennis Turner
The Waterloo Foundation
Sir Samuel Scott of Yews Trust
The Elizabeth and Prince Zaiger Trust

We would also like to thank those individuals who have generously left a legacy to the Cystic Fibrosis Trust, a small number of whom are listed below.

Miss Phyllis Carter
Mr Henry Cross
Mr Terence Fishlock
Mr Frederick Gazeley
Mrs Irene Gilson
Miss Rachel Hopkins
Mrs Doris Law
Mrs Corrie Lindsay-Oliver
Mr Adrian Mann
Mr Graham Ramsden
Ms Dora Thompson
Mrs Gladys Tichborne
Ms Sarah Tonkyn
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Mr Edwin Wallen
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Mrs Mary Wrigley

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(from 14 November 2011)

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Vacant

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FRCP FRCPE FRCPCH DCH
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Matthew Reed
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Nikki Samsa
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Professor Brandon Wainwright
Director of the Institute for
Molecular Bioscience,
University of Queensland,
Australia

www.cftrust.org.uk

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Registered as a Charity Number 1079049
(England and Wales) and SC040196 (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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