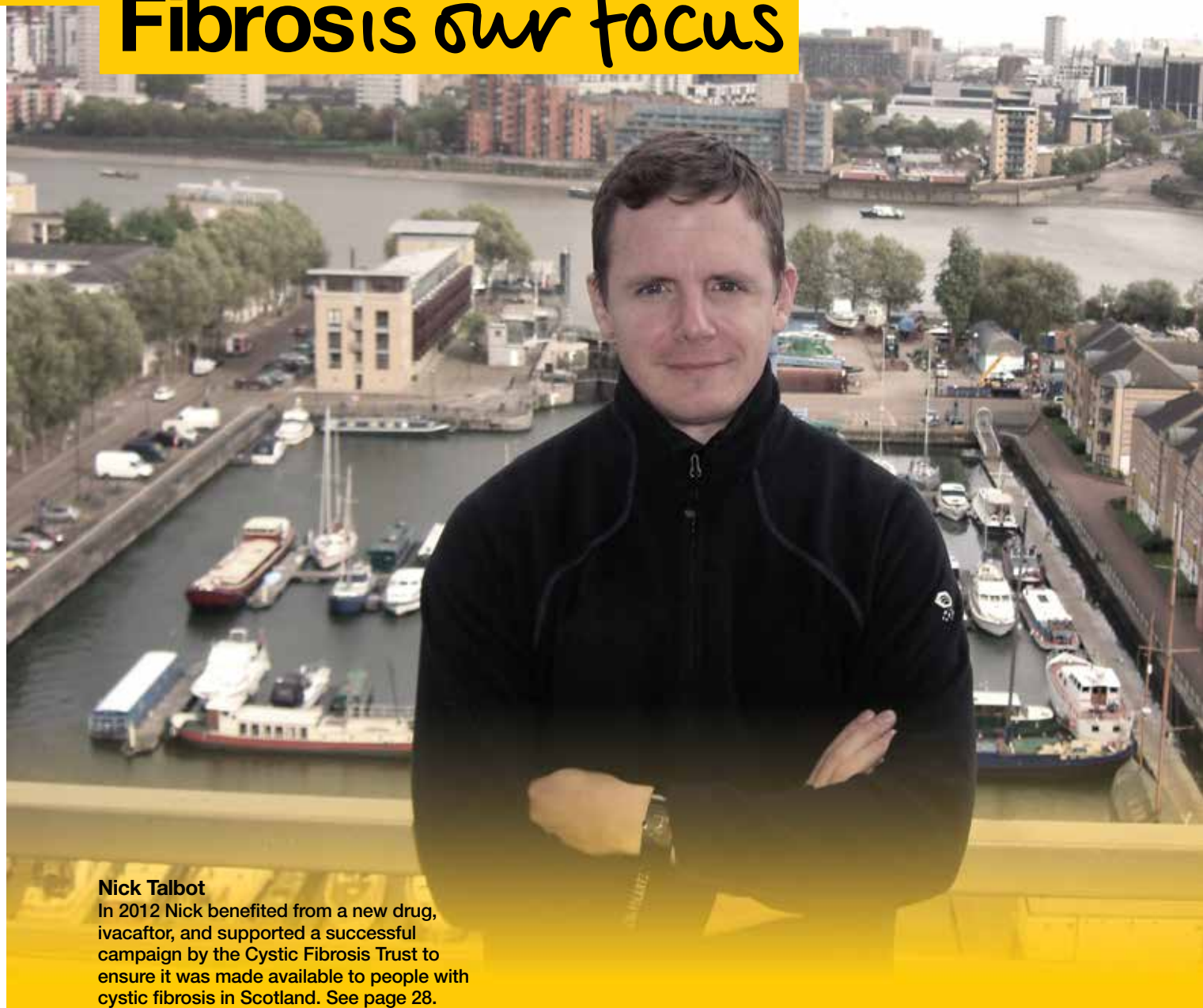


Cystic Fibrosis our focus



Nick Talbot

In 2012 Nick benefited from a new drug, ivacaftor, and supported a successful campaign by the Cystic Fibrosis Trust to ensure it was made available to people with cystic fibrosis in Scotland. See page 28.



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Debby Townsend and her sons Lewis and Reiss, who has cystic fibrosis, who featured in our exciting rebrand project (see page 33).





Berniece Phillips, who has cystic fibrosis, featured in our exciting rebrand project (see page 33).

Introduction

We are focused on transforming the lives of people with cystic fibrosis – and thanks to the **extraordinary commitment** of our supporters, we are developing our work to increase our impact.

Research is at the heart of our mission and throughout 2012/13 we developed a new strategy to ensure we were investing in world-class projects with the best hope of improving clinical understanding of the condition and developing new treatments to enhance the length and quality of life of those with cystic fibrosis.

This strategy, published in April 2013, lays the foundations for enhancing cystic fibrosis research over the coming years.

In clinical care, we worked with clinicians and commissioners to improve the quality of cystic fibrosis specialist services, including a revamped peer review process to ensure clinics provide minimum standards of care. Our renowned data registry was critical in helping deliver a new funding regime in England to help counter the “postcode lottery” of care across the NHS.

We helped provide vital support and advice to those affected by cystic fibrosis, and our new brand is helping to revitalise efforts to raise funds and awareness.

The rapid development of new therapies to treat the underlying causes of cystic fibrosis holds the prospect of transforming the lives of all with the condition – and the Trust will be at the forefront of these changes.

In 2012/13 we therefore stood alongside people with cystic fibrosis, their families and clinicians to ensure that Kalydeco – the first ever licensed drug to treat the underlying cause of cystic fibrosis – was made available on the NHS across the UK to those with the G551 mutation.

Our 50th anniversary in 2014 represents an opportunity to mark the progress that has been made in cystic fibrosis – from a solely paediatric condition to one which, today, affects more adults than children. But with half of all people with cystic fibrosis still not reaching their 40th birthday, so we will be redoubling our efforts to help beat cystic fibrosis for good.

Ed Owen,
Chief Executive, Cystic Fibrosis Trust






Investing in cutting-edge research

When we were founded in 1964 people with cystic fibrosis were unlikely to live much beyond five years. Today more than half live to see their 40th birthday.





This rise in length of life has come as a result of the dedication and commitment of many in the cystic fibrosis community over five decades. But there is much more to do.

Through careful investment in cutting-edge research, we want to lead the way for the research community.

The money we invest in research can lead to the development of new therapies and a greater understanding of cystic fibrosis.

By sharing our research findings with the scientific community we are nurturing a new generation of scientists who specialise in CF research, and who one day might help us beat cystic fibrosis for good.

Through continued support for basic and clinical research, we have paved the way for the treatments available to people with cystic fibrosis today. Our international reputation as leaders in cystic fibrosis continues to grow, and we remain one of the largest funders of research into cystic fibrosis in the UK and the world.

Shaping tomorrow's future today

In 2012/13 we recruited a new Director of Research, Dr Janet Allen. She was tasked with developing an ambitious new research strategy to guide our research programme over the next five years.

The new strategy, which was launched in April 2013, will build on what we have accomplished in the past, and develop new collaborations with industry, government and others to maximise investment in work that has a real potential impact on the lives of people with cystic fibrosis.

This strategy has been widely welcomed, with Simon Denegri, Director for Public Participation and Engagement in Research, at

the National Institute for Health Research (NIHR), describing it as “clear and visionary”.

Key points of the research strategy:

- Investing in tomorrow by backing transformational science to correct the basic defect
- Investing in today by working to help alleviate and manage the symptoms of cystic fibrosis
- Increasing the capacity and quality of clinical trials
- Recruiting the brightest and best to cystic fibrosis research
- Enhancing the involvement of people with cystic fibrosis in shaping research

Nurturing the next generation

“In 2005, I was appointed to the role of Postdoctoral Coordinator of the UK Cystic Fibrosis Microbiology Consortium.

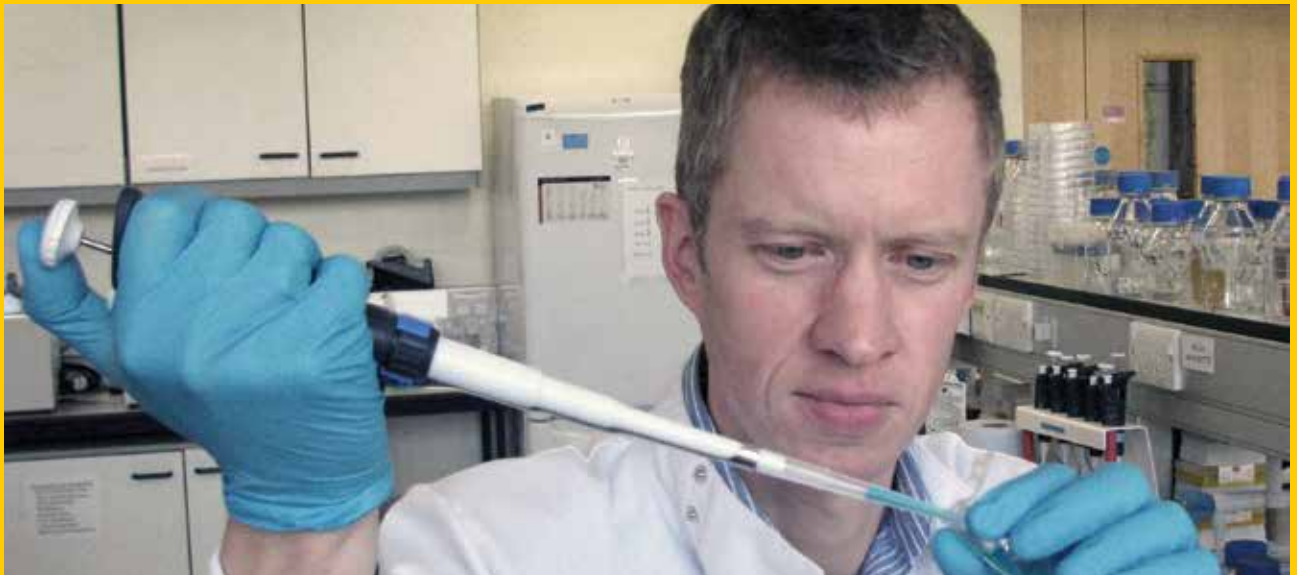
“Funded by grants from the Cystic Fibrosis Trust and the Big Lottery Fund, the Consortium brought together leading scientists and clinicians in the field with the aim of enhancing our understanding of the major bacterial infections of the lungs of people with cystic fibrosis and ultimately improving the management and treatment of such infections.

“What followed was an extremely exciting three years of science, during which time the Consortium made substantial contributions to the research field. From a personal viewpoint, my experiences over that period had an enormous influence on my subsequent academic research career.

“The innovative design of the Consortium presented me with the opportunity to develop my own research interests, shaping me as an independent research scientist and providing the springboard to my first academic position as a lecturer and research group leader at the University of Exeter.

“Those cystic fibrosis research interests born during the Consortium now underpin the research within my group at Exeter. Additionally, through my teaching to undergraduate bioscience and medical students, and the supervision of PhD students, I do my own small bit to ensure that the legacy of the Consortium lives on in the next generation of research scientists and clinicians.”

Dr Alan Brown, Lecturer in Microbiology at the University of Exeter



Supporters saving lives

Despite the considerable advances in treatment and care, many people with cystic fibrosis will reach a point where their lungs are so badly damaged that a transplant could be their last hope to prolong life.

Through the generous support of the Robert Luff Foundation, we funded a pilot study investigating the possibility of 'lung reconditioning' to increase the number of donated lungs that can be successfully transplanted.

The DEVELOP-UK study 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. Doctors are using a modified heart-lung bypass machine to prepare the organs. Air is pumped into the lungs, which can absorb oxygen, while nutrients are pumped through the blood vessels.

The technique can clear a build-up of water on the lungs or treat them with medication to clear infection.

In 2009 the Robert Luff Foundation granted us £500,000 over three years to roll out the research to all five UK transplant centres. Originally begun at the Freeman Hospital in Newcastle it has since been rolled out to other NHS transplant centres in London, Cambridge, Birmingham, Manchester and Newcastle. The British Transplantation Society said the technique could "dramatically" increase the number of lungs.

One of the first to benefit from a transplant in the EVLP study was Philippa (see opposite).

The pioneering research is something that Sir Robert Johnson, Trustee of the Robert Luff Foundation, feels passionately about. His son Bobby, who had cystic fibrosis, was put on the transplant waiting list, but tragically died before a viable lung could be found.

Sir Robert said: "Bobby was called four times to receive a transplant but each time was told that the donated lungs were unusable. The Robert Luff Foundation, created by Bobby's great uncle, was therefore especially grateful to be given the chance to support this pioneering work, albeit too late for Bobby."

Further support for this work has been announced in 2013/14.

As a result of the Robert Luff Foundation's amazing gift and the hard work of everyone involved in the study, the future could be brighter for many people waiting for that life-saving transplant.

100+

people will have received a donor lung under the EVLP study who otherwise may not have received one.

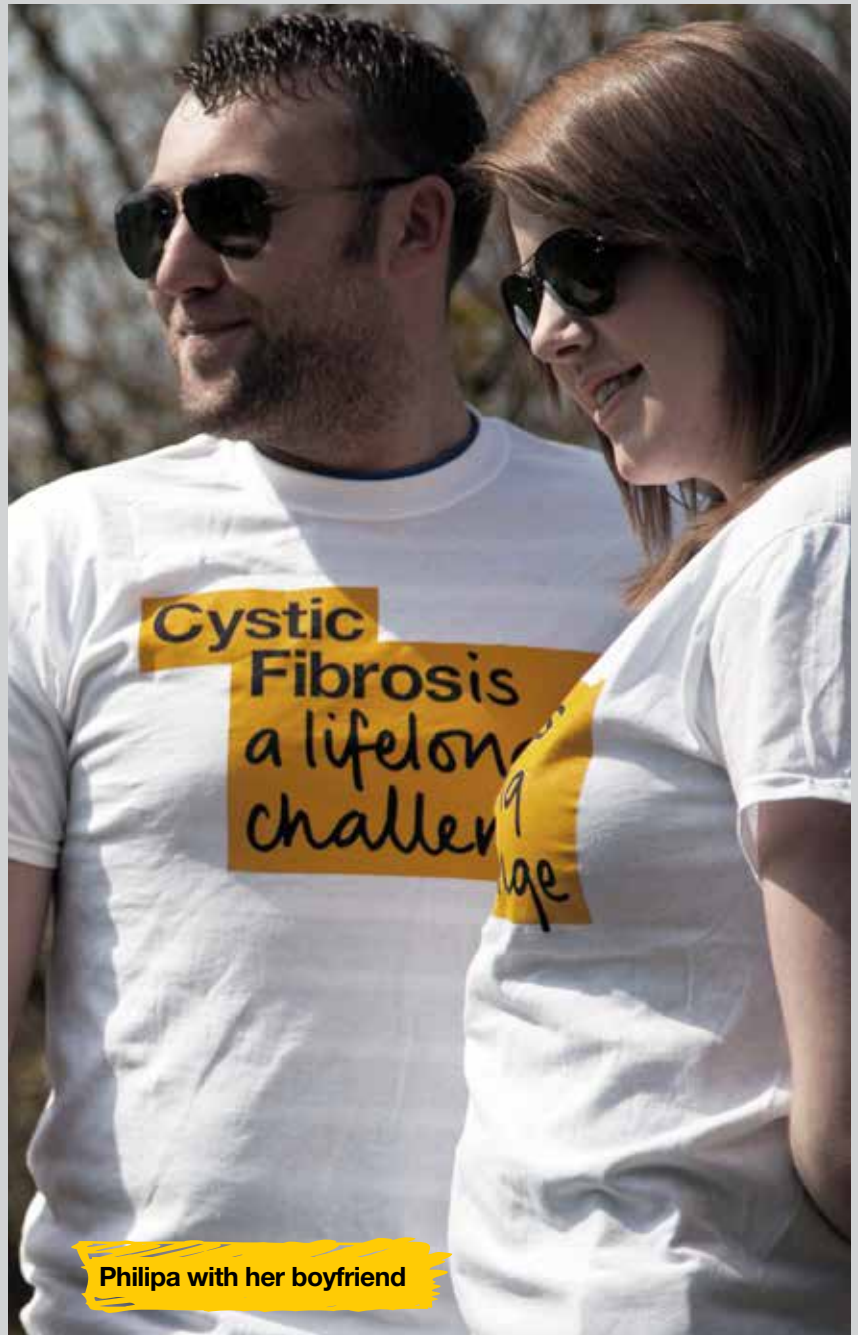


Philipa's story

"My life is so much better now I've had my transplant – thanks to research funded by the Cystic Fibrosis Trust I got my call. I hope everyone who needs new lungs gets their chance. I am so pleased that the research that saved my life is continuing thanks to the Luff Foundation. My transplant changed my life."

As Philippa's condition got worse, she had to put her university studies on hold, and began to spend more and more time in hospital. Her lung function reached as low as 17%, and she became confined to a wheelchair. At night she had to use a ventilator to help her breathe.

Today Philippa's life is completely changed. Her lung function is an astonishing 126%, she is hoping to continue her study, and is planning to marry her fiancé in May, on the eve of the third anniversary of her transplant.



Philippa with her boyfriend

Gene therapy grant

In March 2013 we announced a grant of £308,000 to the UK CF Gene Therapy Consortium (GTC) for its Wave 2 work to develop a viral mechanism for delivering gene therapy to people with cystic fibrosis. The 14-month grant complements a £1.2m grant for Wave 2 announced in 2012 from the Medical Research Council.

This work is being developed alongside the GTC's Wave 1 product that uses liposomes as a delivery mechanism. This work is in a Phase 2b clinical trial, with results due in 2014.

The Wave 2 product is some years behind Wave 1, but could have an even greater potential as a future treatment.

“We are pleased the Cystic Fibrosis Trust has awarded this contribution to our exciting Wave 2 programme. We are, as always, extremely grateful to the many donors who continue to support our work.”

Professor Eric Alton, Imperial College, London, and Coordinator of the UK CF Gene Therapy Consortium

The Trust will continue to invest in transformational, in collaboration with others, research to bring hope to people with cystic fibrosis and their families.

£1,627,000+
spent on research in 2012/13



Dr David Sheppard

Dr David Sheppard is a researcher and lecturer at University of Bristol, and has a long-standing relationship with the Cystic Fibrosis Trust, dating back when he was a newly independent researcher.

How many projects have you worked on with Trust funding?

Nine, including my current one – eight research grants and one PhD studentship.

How have you found working with the Trust?

Highly productive! It makes all the difference to know staff at the Trust. This means that I can pick up the telephone and discuss research ideas and how they might best be tackled.

How important is the Trust's support of the research and scientific communities?

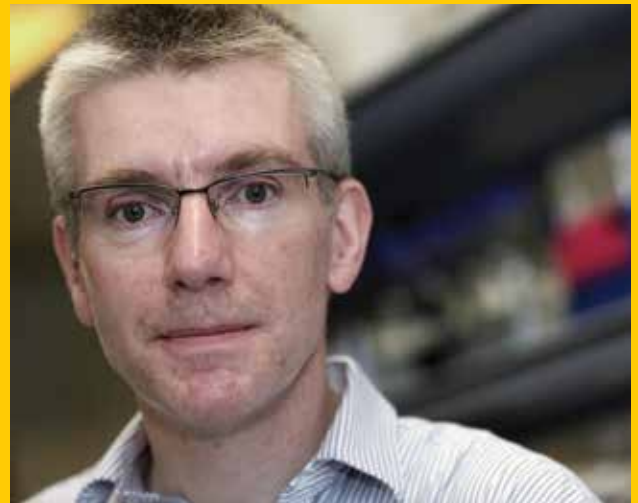
Without doubt the Trust's support is critical to the UK CF research community. Based on my own experience, the Trust helps in a variety of different ways. It nurtures the development of junior researchers on the path to independence. It provides invaluable support to retain experienced staff and hence an effective team.

The support it provides is a springboard to further funding from other sources, including UK government. By supporting scientific meetings the Trust promotes opportunities for international networking. By working together, we'll beat cystic fibrosis quicker.

Can you tell us a bit about your current project?

Cystic fibrosis (CF) is caused by malfunction of the cystic fibrosis transmembrane conductance regulator (CFTR) protein, which forms a gated pathway for chloride, one part of salt, to cross cell borders. To tackle defects at the root of CF, drugs have been developed called CFTR correctors and potentiators. Correctors allow the CFTR protein to be made correctly and delivered to the cell border. Like oil on a rusty gate, potentiators allow the CFTR's gates to work properly.

In previous work, Professor Stephen M Husbands (University of Bath), myself and our colleagues identified drug-like chemicals that act as both CFTR correctors and potentiators. The aim of our project is to understand better how these dual-acting chemicals work, and improve their design. The results will inform the development of drugs that tackle the root cause of cystic fibrosis.






Helen McCabe, Great North Children's Hospital specialist CF team member, with Heidi Finley and family

Driving up standards of care

**Thanks to improvements
in the treatment, care and
understanding of cystic
fibrosis, it is no longer just a
childhood condition.**





Everyone with cystic fibrosis should have access to the best quality of care, from birth to adulthood.

Improving quality through peer reviews

In 2012/13 we rolled out our Quality Improvement Programme (QIP), which is an essential part of our commitment to the ever-increasing quality of care for people with cystic fibrosis at every life stage.

The QIP includes a new, improved evidence-based peer review process, to enable us to drive up standards across all paediatric and adult CF centres in the UK. Following a full review of the peer review programme, we launched this improved process in September 2012.

The Cystic Fibrosis Trust undertakes the peer reviews in conjunction with the British Thoracic Society and the British Paediatric Respiratory Society (paediatric centres only).

Between April 2012 and March 2013 we conducted six peer reviews, and are due to carry out 11 in 2013/14. As part of our

commitment to providing high-quality, trusted information, we publish each peer review report on our website for clinicians and those who use the service. All CF centres in the UK are due to be reviewed in a five-year cycle.

A panel of independent experts visits a CF service and carries out a thorough review of clinical, psychosocial and business activities relating to the delivery of care for those attending the service.

The team assesses the service against the Trust's nationally recognised 'Standards of Care', highlighting areas of good practice and innovation that can be shared with other CF centres, as well as identifying areas where there are shortfalls or gaps in service provision. It then publishes its findings in a report for the commissioner, hospital management, the CF team, patients and carers.


The peer review work is supported by outcome data supplied by the UK CF Registry.

The panel is made up of a selection of specialists in cystic fibrosis from multidisciplinary teams around the UK, patient representatives (see opposite) and a specialist commissioner, supported by the Trust's Peer Review Manager.

Peer review in numbers


£5,000

is how much it costs to peer review a CF centre.



£55,000

is what we will spend on the 11 reviews scheduled for financial year 2013/14.



£20

is leveraged in NHS funding for the services we visit for every £1 we spend on the Peer Review Programme.

Sophie Lewis who has cystic fibrosis, is one of the Cystic Fibrosis Trust's Clinical Care Patient Advisers. Here she explains her role in the peer review process.

“My role involves managing the Peer Review Extranet, the Trust's secure database for managing all documentation generated by clinicians and peer review panel members.

“I also sit on the peer review panel, and distribute surveys to the parents/patients – their responses are an intrinsic part of the peer review as they highlight to the clinical team the perspective of people with cystic fibrosis and their carers on areas of excellence and areas of improvement.

“This feedback is included in peer review reports and so provides a valuable opportunity for people with cystic fibrosis to give their views about the care they receive and for this feedback to inform future service delivery.”



UK CF Registry

The Cystic Fibrosis Trust, in partnership with the wider cystic fibrosis community, has developed a high-quality patient registry that contains information about the location and health of patients. This helps us to monitor patient care and treatment, and is a vital tool in driving up standards of care.

The Registry is increasingly valuable as a research tool and we can now compare data with that collected by CF registers in the US and Europe.

The Registry continues to be developed and in 2012/13 we initiated a new Phase IV pharmacovigilance programme with industry, to monitor patient safety after the licensing of new therapies. The European Medicine Agency has recognised the importance of registry information, and has insisted that these studies are done via registry data.

In agreeing to this programme of work we can:

- ensure that patients gain early access to new drugs that have been through a rigorous safety assessment; and
- secure funding to help in the running costs of the Registry.

The Registry is increasingly valuable as a research tool

In March 2013 we published a guide to working with the pharmaceuticals industry, titled 'Working with industry to make medicines safer'.

Fair funding for cystic fibrosis care

We worked with clinical teams and commissioners of CF services to develop a Performance by Results (PbR) system to ensure consistency of care across the NHS in England. These changes were included as part of the wider NHS changes introduced in England from April 2013. The new funding arrangements draw on data

provided by the UK CF Registry, which the Trust funds and manages.

Conferences

Every year we hold a conference for specialist CF centre clinicians and allied health professionals. This brings together key clinical figures to discuss issues in centre management and patient care.


In September 2013 we went one step further, with a new two-day event: a day specifically for centre directors and a day for anyone involved in the provision of clinical care at a specialist CF centre.



Registry in numbers


10,078

people with cystic fibrosis
were recorded in 2012 on the
UK CF Registry



99%+

of people with cystic fibrosis in
the UK are on the Registry



89%+

complete data for all patients,
making the Registry one of the
most comprehensive data-sets
on cystic fibrosis in the world

Benham and Reeves

We are very proud of our charity partnership with Benham and Reeves, an international residential lettings agency, which has raised more than £30,000 to date, including a donation in support of plans to improve specialist care facilities for adults with cystic fibrosis attending King's College Hospital, London. They are working with us on different fundraising projects, and we are most grateful for their enthusiastic support in helping us raise awareness and much-needed funds.

During CF Week 2012 Benham and Reeves kindly sponsored space hoppers to be used in a Guinness World Record attempt at the Big Brize Bounce event with RAF Brize Norton. The event raised £10,000 and generated great awareness of cystic fibrosis through substantial media coverage.

“We began supporting the Cystic Fibrosis Trust in November 2011 and in a short space of time have had the opportunity to get involved in various ways, supporting the aims of the Trust. Their dedicated account managers have been supportive and enthusiastic and we look forward to continuing our partnership with the Trust.”

**Anita Mehra, Managing Director
of Benham and Reeves
Residential Lettings.**

Ways for companies to get involved include:

- Charity of the year and strategic partnerships
- Employee fundraising
- Payroll giving
- Joint promotions (cause-related marketing)
- Donation
- Volunteering and pro bono work
- Recycling
- Corporate sponsorship

Find out more at
cysticfibrosis.org.uk/company


Sam Carter and Jackie Rice on our helpline desk



Providing support for all

It is our job to provide high-quality, trusted information and advice to everyone affected by cystic fibrosis, ensuring we assist those who need us the most.





Cystic fibrosis is a complex and progressive condition that requires lifelong care, which increases with age. For a child with cystic fibrosis, much of the daily burden of care initially falls to parents or carers, before the child takes on responsibility for their own care in their teens.


We make sure that patients, families and carers have access to the information they need to understand cystic fibrosis and its impact.

Help is a phone call away

Helpline in numbers


3,000+

calls are received by our helpline every year



281

welfare grants were awarded by our helpline in 2012/13



£100,000+

was spent through these awards

We understand that everyone needs a helping hand sometimes. This could be a friendly, knowledgeable person to chat to, or expert guidance for a specific problem.

Our national telephone helpline plays a vital role in fulfilling our commitment to providing support for everyone affected by cystic fibrosis. The helpline offers confidential advice, support and information on any aspect of cystic fibrosis, including help through financial grants.

Cystic fibrosis can have an impact on any aspect of life for an individual or a family. We offer advice and guidance through every life stage, from a child's first diagnosis, through the transition to adult care, to balancing cystic fibrosis with maintaining employment and a family, and beyond.

We also understand that living with cystic fibrosis can involve a lot of extra expense, such as trying to find affordable holiday insurance, equipping a teenager leaving home for the first time, or someone with cystic fibrosis facing the huge costs involved in travelling for transplant assessment.

Supporting those who needs us most

Thanks to the generous donations we receive, we are able to offer a limited number of grants to help individuals and families cope with a wide range of one-off circumstances for which they need a helping hand to meet costs (see a selection of the thank you letters we received opposite).

Call our helpline on 0300 373 1000, 9am–5pm, Monday to Friday.

* How we've helped *

Helpline caller who received a £300 holiday grant.

“Thank you so much for the holiday grant you kindly gave to me. I am so looking forward to going on holiday in September. I am off into hospital tomorrow for a short spell and it shall make it all the easier for knowing I am having a holiday.”

Cystic fibrosis doesn't take a holiday, but sometimes a little break, a respite from the normal daily routine, can be a godsend for someone who lives with the condition.

Helpline caller who received a £300 grant to help with household items.

“A huge thank you to all involved for your continuous hard work in supporting all CF sufferers, and helping me in funding a new washing machine.”

Something simple like a washing machine can be an important factor in the daily challenge to stay healthy and directly benefit the health of someone with cystic fibrosis.

Helpline caller who received a £750 grant to help cover funeral expenses.

“Thank you for your very kind letter received on the recent passing of my beautiful daughter. On behalf of me and my family we would also thank you for your contribution towards funeral expenses. It has been of great assistance and very much appreciated. Family members and several of our daughter's friends are planning fundraising events and we will continue to be supporters of the Trust.”

We are aware that funerals can cost more than £4,000. This family really appreciated some financial help and a caring condolence letter.





Tackling cystic fibrosis together

In 2012 we became an official partner of Glasgow Warriors, a professional rugby club that plays in the Heineken Cup, the biggest club competition in the Northern Hemisphere, and which produced nine members of the 2011 Scottish World Cup squad.

The club helped us raise more than £38,000 with a 100ft free-air abseil from the West Stand of Murrayfield, the home of Scottish Rugby, in 2012.

Glasgow Warriors Chief Executive Kenny Baillie commented on the partnership: "The cause is close to the club's heart, as we know the devastating effect that the condition can have."

Information at hand

Providing extensive, accessible and easy-to-understand sources of information is essential to enable people affected by cystic fibrosis and the people who care for them to take an active part in their treatment and care. It is also key to increasing awareness and understanding of cystic fibrosis among the wider public, which helps us turn up the volume on the issues that matter.

Through factsheets, leaflets, magazines and e-communications, we look to keep our community up to date with the latest developments in all aspects of cystic fibrosis and CF care.

We also publish consensus documents, written by clinicians and scientists in a range of specialist areas, to support clinicians and allied health professionals involved in treating patients with cystic fibrosis. These can be accessed by the general public, to help them understand the levels of care they should expect.

We are committed to continuously improving the information we put out, to ensure that we consistently present up-to-date information in clear, concise language. As such, we monitor and regularly update our printed and electronic materials.

In 2012 we undertook research to revamp 'CF Today', our flagship magazine. With a circulation of around 18,000 this magazine features articles on research, care, social issues and news. We replaced the magazine with a new publication, 'is', to better engage our audience and help communicate more effectively.



A website for the world of tomorrow

As part of the Trust's rebrand process (see 'Being heard', page 32) 2012/13 saw a visionary project to overhaul and relaunch the charity's website.

After extensive research among our stakeholders, we set out to update or rewrite existing web content, and add new pages to fill any gaps in the information we provide. We also made it easier for users to find that information. The end result,

which launched in March 2013, is a more dynamic, eye-catching website design that represents a step-change in how we engage our audiences and way we talk about cystic fibrosis.

Fashioning the future with Fidelity Foundation

None of this would have been possible without the generous support of Fidelity Foundation, which donated £23,000 to support the development of the new website.

Following the relaunch, the second phase of the web project will be to work again with stakeholders and end users to identify new improvements to both its content and functionality.






Campaigning hard

We're lobbying decision makers hard in the interests of our community – from inequalities in care to greater support to help us search for a cure.





In 2012/13 we spearheaded a successful campaign to ensure that a new transformational drug, ivacaftor (brand name Kalydeco), was made available to those who would benefit from it in the UK.

Lobbying for Kalydeco

Kalydeco is the first licensed drug to treat the basic defect that causes cystic fibrosis. This treatment helps the cystic fibrosis transmembrane conductance regulator channels stay open for longer, which helps to correct the amount of salt and water that travels across the cell membrane.

The drug works for those who have the G551D mutation of cystic fibrosis – about 4% of the UK CF population. Early signs show that the drug is having a significant impact on the health and well-being of those taking it, with instances of people being able to come off the lung transplant list because of the improvement in their condition.

More than 15,000 people signed an online petition calling for the drug to be made available. The

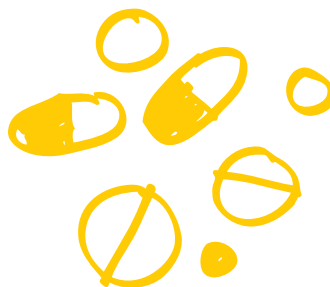
decision to fund Kalydeco for patients in England was made in December 2012.

However, while people in England were able to get this life-changing drug, people with cystic fibrosis living in Scotland or Wales were initially still denied access. This disparity was even felt within families, such as brother and sister Nick Talbot and Emma Mitchell (see opposite), one of whom was able to receive Kalydeco, while the other was not.

15,000+

supporters signed our petition for Kalydeco to be made available on the NHS

Nick and Emma helped in our campaign for Kalydeco to be made available across the UK. Funding was approved in Scotland in January 2013, and in Northern Ireland and Wales in spring 2013.



A reprieve for the Brompton

In June 2012, children's cardiac surgery at the Royal Brompton Hospital was threatened with closure. We joined with other respiratory charities to raise our concerns about the sustainability of the services for children's respiratory care, and also the hospital's world-class paediatric respiratory research programme.

As well as raising awareness and encouraging people to make their views known, we made our own submission to the Joint Committee of Primary Care Trusts.

In October 2013, Health Secretary Jeremy Hunt ordered a review of the decision to close the Brompton's unit and two other centres for children's cardiac surgery. The closure has since been postponed indefinitely.

Campaign in action

Nick Talbot is in his mid 30s, lives in London, and has been able to benefit from Kalydeco since January 2013. The result has been amazing, so much so that Nick is planning to climb to the summit of Mount Everest.

Nick's sister, Emma Mitchell is also in her mid 30s but lives in Lanarkshire, Scotland. Earlier last year Emma and Nick featured in national media coverage when Scotland had not approved Kalydeco for use on the NHS, while Nick was benefiting from this medication



in England. It meant that despite the two siblings having the same mutation, one was receiving the medication when the other was not.

Scotland approved funding for the drug in January 2013 via the Rare Conditions Medicines Fund, which now means that people in Scotland can benefit from this treatment. The Cystic Fibrosis Trust has been instrumental in influencing decisions on the approval of this medicine for people with cystic fibrosis across the UK.

"Me and my sister can look forward to a longer life"

Nick says: "Thanks to Vertex, the Cystic Fibrosis Trust and the NHS I've now benefited from a new medication which can only help a small percentage of people with CF and has meant that my lung function has improved and my health is even more stable. Me and my sister can look forward to a longer life, hopefully!"



Nick is hoping to raise £100,000 for the Cystic Fibrosis Trust with his epic Everest trek.

To find out about corporate sponsorship for this heroic feat, visit cysticfibrosis.org.uk/everestpartner.

Dry powder treatments

It is vital that people with cystic fibrosis are able to access the best treatments, when they come on the market. In the past year we have campaigned successfully to get a number of new treatments made available on the NHS.

In June 2012 the National Institute for Health and Clinical Excellence (NICE) issued a draft

recommendation that the inhaled drug mannitol should not be available on the NHS. Mannitol is a step change in terms of improving the quality of life for people with cystic fibrosis. Quick and easy to administer, mannitol improves patient lung function, resulting in one less two-week stay in hospital each year. This is potentially a substantial saving for the NHS, as a two-week hospitalisation costs around £3,000 per patient.

We campaigned for the treatment to be available on prescription for cystic fibrosis, and rallied our supporters. Posting a link to the NICE consultation on our website, we set out a four-point supporting argument that could be copied and pasted into the NICE feedback form.

On 26 October NICE announced it was reversing the decision, and would now recommend mannitol for use.

Teen film

Genes for Jeans Day gave the Trust £15,000 to fund a short interactive film for teenagers with cystic fibrosis. Building on the success of 'Oli and Nush', our animated film for children with cystic fibrosis, the new film is designed to increase engagement and decrease the isolation felt by a lot of teens who have the condition.

Because of the risks of cross-infection, people with cystic fibrosis can not meet each other. This is especially hard on teenagers, for whom the support of peers who can

share their experience and understand the challenges they face is so important. The new film will be available online through our YouTube channel. We hope that by addressing the subject of living with cystic fibrosis in adolescence, we will encourage young people to take greater responsibility for their own care and boost adherence to treatment. This will help them live longer, healthier lives.

The film is also designed to be used in schools and colleges as an educational tool, and



as a resource for healthcare professionals and care workers.

Teenagers can also share their experiences with one another, and offer support and encouragement through our forum, Facebook and Twitter pages.

Watch '...the rest is up to me' at <http://bit.ly/cfteens>.

Similarly, when NICE decided against recommending colistimethate sodium powder for inhalation (Colobreathe), we led a campaign to reverse the decision, and invited our supporters to engage.

Colobreathe also treats *Pseudomonas* infections, and offers patients benefit over current treatment.

In January 2013 NICE announced that they would recommend Colobreathe for use by people with cystic fibrosis across England and Wales.

An Evening with Michael Parkinson

On 7 November 2012 we presented a gala fundraising event at Home House, the exclusive London private members' club. 'An Evening with Michael Parkinson' began with a drinks reception and a welcome from actress and celebrity supporter Jenny Agutter.

Alongside a three-course meal and an auction, the evening

saw a presentation by Trust Chief Executive Ed Owen, and a moving speech by Oli Lewington about his life with cystic fibrosis, before Sir Michael Parkinson OBE talked about his fascinating career in broadcasting.

Two of our incredibly generous supporters, Paul and Gill Whight covered the costs of the event, meaning the full £70,000 raised on the night goes towards our work.



Jack Harris, who has cystic fibrosis, and a colleague raising awareness outside a Derbyshire Building Society



Being heard

Awareness of cystic fibrosis is pitifully low. We are determined to increase understanding, turn the volume up on the issues that matter and raise more funds for our work.



Rebranding the Cystic Fibrosis Trust

Like many charities, we struggled during the global financial crisis to sustain our income levels, even with our committed supporter base.

We knew that to fight this decline we had to reach new audiences and better engage with our supporters, by explaining better the impact of cystic fibrosis. Other charities have already shown that a well-articulated brand can help improve fundraising, and if we wanted to compete in a competitive charity

marketplace we had to invest to maximise our impact.

The first step in 2012 was to carry out research among our supporters, which formed the basis for an in-depth rebrand project. Our rebrand was an investment in our organisation that will bring financial benefits and help us better engage with the cystic fibrosis community, policy makers and the general public.

To achieve more for people with cystic fibrosis, we need to raise more funds so that we can support more cutting-edge

research and drive up standards of clinical care. There have been a lot of achievements over the last 50 years but there is still much more to be done.

Our new brand and website represent a huge cultural change for the Trust, changing the way we talk about both cystic fibrosis and the work we do. We have laid the foundations that will help wider plans to lead the way in cystic fibrosis research, and provide a cornerstone for the community in campaigning, support and care.



★ What other people said

"I am delighted to see that the Cystic Fibrosis Trust is rebranding and demonstrating its commitment to be at the forefront of CF research by securing substantial further funding."

Professor Andrew Fisher,
Institute of Transplantation,
University of Newcastle

"This new brand is an important and exciting moment for the organisation and the cystic fibrosis community as a whole."

Rt Hon Andy Burnham MP,
Labour MP for Leigh and
Shadow Secretary of State
for Health

"I am delighted to hear of the rebrand and hope this new-look Cystic Fibrosis Trust will ensure the charity goes from strength to strength and remains at the forefront of excellent care and research."

Lisa Morrison, physiotherapist,
Gartnavel Hospital, Glasgow



Calling for help

In July 2012 we launched the first ever Cystic Fibrosis Trust telephone appeal. Telephone fundraising is a great way for us to establish a more personal relationship with our supporters. It is also one of the most cost-effective forms of fundraising.

Regular gifts provide a steady income, which enables us to plan ahead so that we can develop better treatments for cystic fibrosis and, ultimately, beat it.

The appeal has been such a success that we have decided to continue using telephone fundraising during 2013/14 to ask our supporters to give a regular gift by direct debit.

Cystic fibrosis in the media

From April 2012 to March 2013, articles about cystic fibrosis and the Cystic Fibrosis Trust generated over 5,300 media cuttings. The press office uses campaigns, real stories from people with cystic fibrosis and events to help generate this publicity.

Among these was our Campaign for Kalydeco, which generated 216 media stories. BBC TV featured Kalydeco on its news broadcasts throughout September and October in England and December in Scotland. In addition, we received substantial press coverage on the campaign, including a feature

on Nick and Emma Talbot (see 'Campaigning hard', page 28) in the Daily Mail.

Real-life stories are what really help the Trust to raise awareness with the media, whether it's an issue we are campaigning on or an amazing story of someone taking part in one of our fundraising challenges.

The BBC's London Marathon coverage featured Mike Mackay from Essex, who celebrated five years since his lung transplant by completing the world-renowned challenge. Alex Sayers' North Sea Dip fundraiser featured on ITV's East Anglia local news in February.

The Trust's rebrand saw extensive coverage in

specialist magazines, raising the charity's profile with other businesses and charities. Other highlights included actress and ambassador Jenny Agutter receiving her OBE for her work with the Trust and other charities.

Media in numbers

5,300+

mentions in the media, generated by articles about cystic fibrosis and the Cystic Fibrosis Trust.



216

media stories generated by the Trust's Campaign for Kalydeco.






Mark Watkins from Newport running for the first time in the Cardiff Bay 5

How can you help?

Without the help of our supporters, nothing we did this year would have been possible.



How can you help?



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

With your help we will:

- Invest in cutting-edge research
- Drive up standards of care
- Support all those affected by cystic fibrosis
- Campaign hard for the cystic fibrosis community
- Shout loud, turning up the volume on the issues that matter.

Our achievements include:

- giving £308,000 to the Gene Therapy Consortium for its Wave 2 work (see page 11);
- continuing our support of the groundbreaking EVLP study to make more donor lungs available for transplant (see page 9);
- developing an ambitious strategy to lead the way in cystic fibrosis research in the next five years (see page 7);
- rolling out our Quality Improvement Programme and peer review strategy (see page 15);

- handing out over £100,000 in grants and answering more than 3,000 enquiries through our helpline (see page 21); and
- successfully campaigning to ensure access to the groundbreaking new treatment Kalydeco (see page 27).


From regular major donors, trusts and foundations, to regular donors and the people who sponsor their friends and family taking part in an event, we are grateful to everyone who has kindly given money to help us beat cystic fibrosis.

You are helping us to make the future brighter.

Giving in numbers


£15

could cover the cost of running our helpline for one hour, offering support and information for people affected by cystic fibrosis



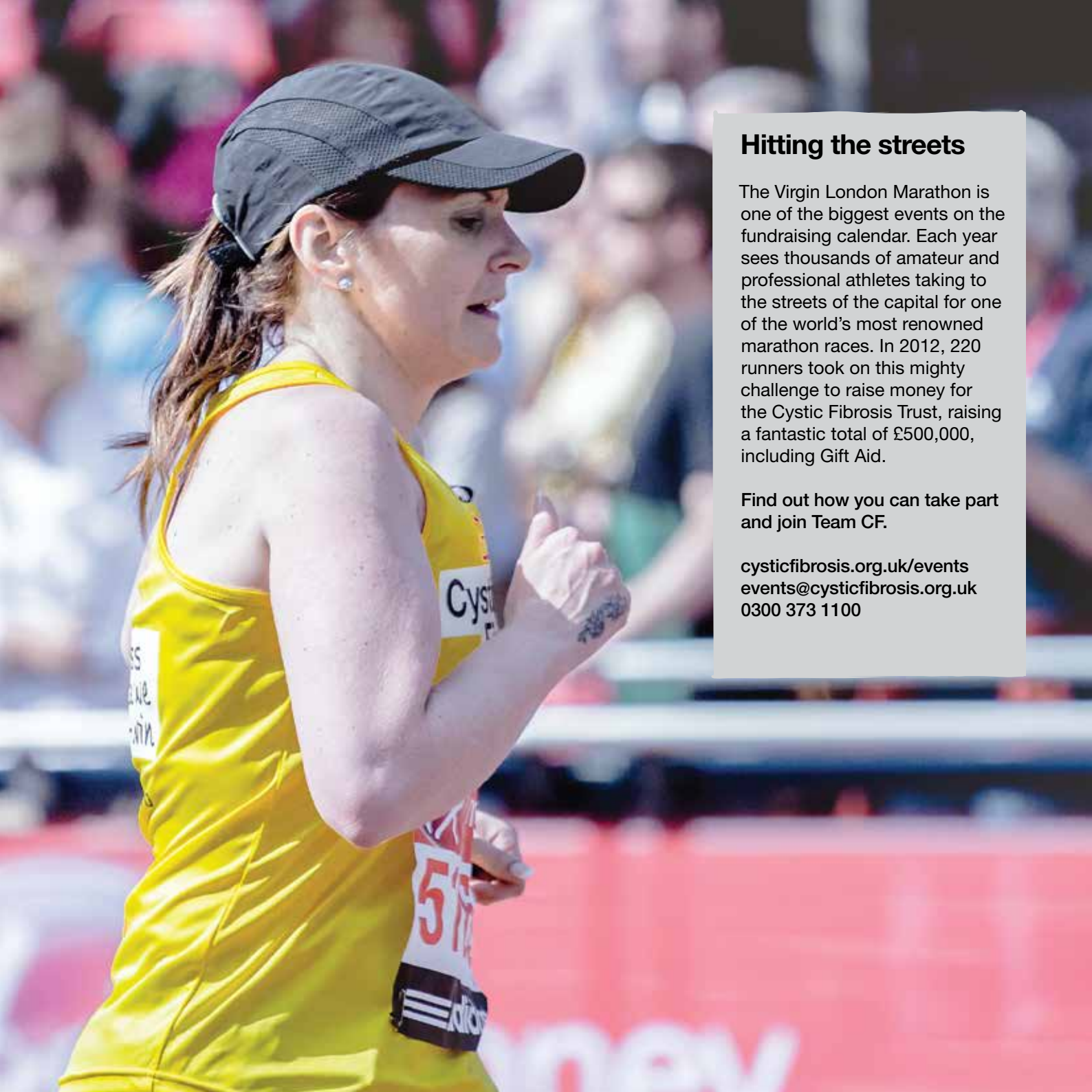
£80

could fund one day of research into detecting early signs of lung disease



£300

could provide one day of training for a future specialist CF consultant



Hitting the streets

The Virgin London Marathon is one of the biggest events on the fundraising calendar. Each year sees thousands of amateur and professional athletes taking to the streets of the capital for one of the world's most renowned marathon races. In 2012, 220 runners took on this mighty challenge to raise money for the Cystic Fibrosis Trust, raising a fantastic total of £500,000, including Gift Aid.

Find out how you can take part and join Team CF.

cysticfibrosis.org.uk/events
events@cysticfibrosis.org.uk
0300 373 1100

Leave a legacy

Ten per cent of our income comes from gifts people leave us in their wills. For many of our supporters, legacies are a natural extension of the support they give during their lifetime.

Some of the projects we have funded in recent years have only been possible because of legacies included many years ago. The legacies we receive today will help us to take this vital work forward, build on the accomplishments of the past and create a brighter future for everyone affected by cystic fibrosis.

Legacies come in all sizes – from a few hundred pounds to many thousands. Every gift we receive from a will can help us make a huge difference, and we are grateful to everyone who supports us in this way.

Elaine, one of our generous supporters who has kindly included a gift to the Cystic Fibrosis Trust in her will, shared with us the reasons behind including such a gift:

“For my husband and me it was a straightforward decision: I have cystic fibrosis, which wasn’t diagnosed until I was 32. I have benefited from the research and improvements to treatments that have been made over the years and hope that others with the condition can too.”

Please get in touch with us if you have any questions or would like additional information. Although we are not able to give legal advice, we can answer general questions about will-writing and gifts in wills.

For further information, please contact our Legacy team.

cysticfibrosis.org.uk/legacy
legacies@cysticfibrosis.org.uk
020 8464 8051



Elaine, who has included a gift to the Trust in her will.

In-memory

Making a donation in-memory is a personal and poignant way of celebrating the life of a loved one, while raising vital funds for people with cystic fibrosis and the people who care for them.

There are several ways to make a donation in-memory.

- Collections at funerals and memorial services
- Online
- By post
- By phone
- Fundraise
- Participate

For more information contact our In-memory team.

cysticfibrosis.org.uk/inmemory
inmemory@cysticfibrosis.org.uk
020 8290 8051

Regular giving

Regular gifts mean we can plan ahead, knowing we will have the funds to support our ongoing work. You can set up a direct debit or a standing order.

For more information contact our Supporter Care team.

cysticfibrosis.org.uk/donate
supporter.care@cysticfibrosis.org.uk
0300 373 1040

Trusts and foundations

Trusts and foundations are ideally placed to help us make a difference.

The generous support of the Robert Luff Foundation (see page 9) has enabled us to fund a study that could revolutionise how transplants are carried out in the UK and beyond.

For more information contact Laura McHale, Philanthropy Manager, Cystic Fibrosis Trust

laura.mchale@cysticfibrosis.org.uk
020 8290 8047

Sixty Five Roses Club

The phrase 'Sixty Five Roses' comes from a small child's attempt to pronounce 'cystic fibrosis'.


The Club is for supporters of the Trust who give between £1,000 and £5,000 each year. If they wish to, members can choose to support an area of work, such as research or support.

As a member of the Sixty Five Roses Club you will receive:

- acknowledgement in the Trust's Annual Review (although you may give anonymously if you prefer);
- a personalised annual update every autumn, letting you know what your support has helped us achieve; and
- an invitation to an exclusive annual reception and lecture.

For more information contact Laura McHale, Philanthropy Manager, Cystic Fibrosis Trust

cysticfibrosis.org.uk/sixtyfive
laura.mchale@cysticfibrosis.org.uk
020 8290 8047



£34,000

was donated by the Sixty Five Roses Club in 2012/13 to help us beat cystic fibrosis.

Summarised accounts

“The Trust’s income in 2012/13 held up well despite the continuing wider economic uncertainty.

“While it represented a fall from the previous year as result of the successful gene therapy appeal in 2011/12, income was higher than in each of the previous three years.

“This was, in part, due to the impact of contracts with pharmaceutical companies for reports on the safety of new drugs to people with cystic fibrosis using data from the CF Registry.

“This is also reflected in the increase in trading and merchandising costs, and new grants to specialist CF clinics for their work to maintain and grow the registry database.

“Our spending on charitable activities expenditure increased by 20% to £1.2m and our reserves available for use increased by 48%. This is enabling us significantly to increase our investment in research during 2013/14 – and to develop new initiatives to coincide with our 50th anniversary in 2014.

“Voluntary income continues to represent more than 90% of our income, of which 52% comes from community fundraising, branches and groups. This is a testament to the extraordinary commitment of our volunteers and supporters without whom the Trust would not be able to continue to improve and transform the lives of people with cystic fibrosis.”

Ed Owen
Chief Executive, Cystic Fibrosis Trust

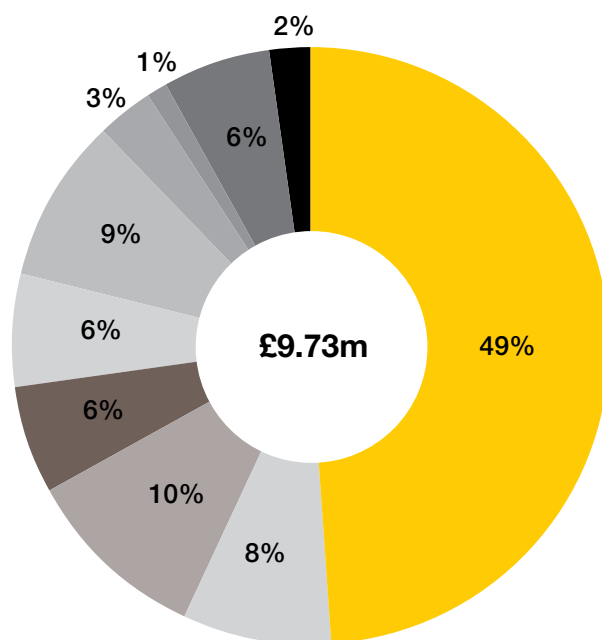
Report by the Trustees on the summarised accounts

The summarised financial information is extracted from the full Annual Report and Financial Statements for the year ended 31 March 2013 which were approved by the Trustees and signed on their behalf on 2 December. The statutory financial statements were given an unqualified report on 2 December by the auditors Crowe Clark Whitehill LLP and were 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 2013.

The summarised financial information may not contain sufficient information to gain a complete understanding of the financial affairs of the charity. The full Trustee’s report, statutory financial statements and auditor’s report, may be obtained from the Company Secretary or at cysticfibrosis.org.uk/annualreview.

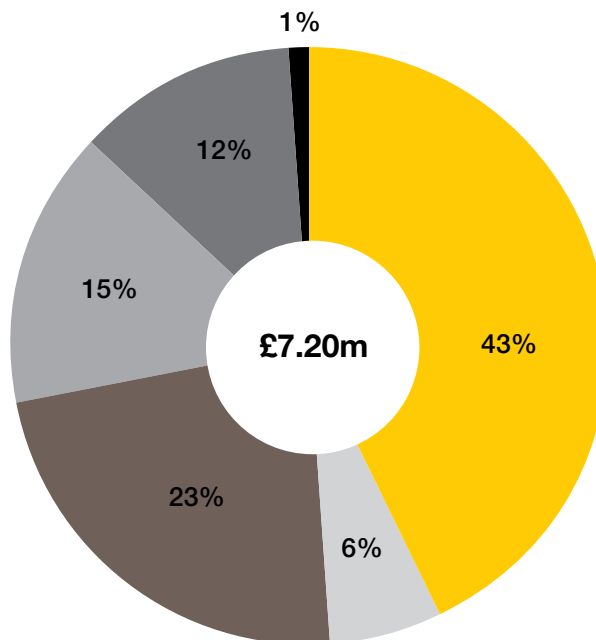
Income this year £9.73m (2011/12: £10.43m)



Income

Branches, groups & community	£4,723,564
Legacies	£805,042
Individual donations	£971,030
Corporate	£623,931
Gift Aid	£629,496
Regular giving and appeals	£860,879
Trusts	£275,285
Department of Health	£126,110
Trading and merchandising	£539,000
Investment & interest income	£169,000
Other incoming resources:	
Fixed asset disposals gain	£3,050
Total voluntary income	£9,726,387

Total spend this year was £7.2m (2011/12: £6m)



Expenditure

Fundraising	£3,094,906
Trading-merchandising	£421,000
Research	£1,627,724
Clinical care	£1,110,000
Information, advice & support	£884,320
Governance	£63,364
Total	£7,201,314

For every £1 we spend:

79p goes on charitable activities to help support the well being of people with cystic fibrosis.

21p goes towards running the charity.

Thank you...

We are grateful to all the individuals, families, companies and trusts that support our work, including those that prefer to remain anonymous. We do not have space to thank everyone, but we would particularly like to thank:

- The Atlantic Philanthropies
- Benham and Reeves
- BIA UK Bioindustry Association
- Boltini Trust
- Constance Green Foundation
- Elizabeth & Prince Zaiger Trust
- Enid Linder Foundation
- Fidelity UK Foundation
- Gilead Sciences Europe Ltd
- Iliffe Family Charitable Trust
- Jeans for Genes Appeal
- Joseph Levy Foundation
- Morgan Stanley International
- PF Charitable Trust
- RAF Brize Norton
- Roche Products Limited
- Robert Luff Foundation
- The Rotary Club of Gloucester North
- Star Cargo plc
- Swire Charitable Trust
- Vertex Pharmaceuticals (UK) Ltd
- Paul & Gill Whight
- Gordon & Johanna Branston
- Cartellieri Karlsen family

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.

- Mrs I Croker
- Mr L Harris
- Mrs C Johnson
- Miss J Tooby
- Ms B Waterhouse

We would also like to thank the members of the Sixty Five Roses Club for their support, including:

- C and J Harris
- Colin and Victoria Jones
- Mr and Mrs Tony Kelley
- Keith and Janet Paley
- Richard Parkinson
- Martin and Vivienne Powell

Cystic Fibrosis our focus

Find us online

- cysticfibrosis.org.uk
- twitter.com/cftrust
- facebook.com/cftrust
- cftrust.blogspot.co.uk

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give with confidence