

Cystic Fibrosis making a difference

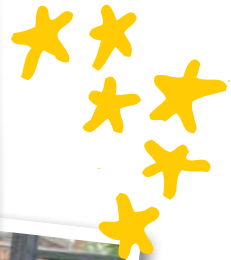
Robyn Davidson is balancing being a single mum with life on the transplant waiting list (see page 14).



Contents

| | |
|--|----|
| Introduction | 3 |
| Investing in cutting-edge research | 5 |
| Fighting for the best care | 9 |
| Mobilising our movement | 13 |
| Supporting people with cystic fibrosis | 17 |
| Generating more to do more | 21 |

Our year...



Welcome to the turning point

It has been an extraordinary 12 months of progress for the Cystic Fibrosis Trust – reflecting our renewed determination to beat cystic fibrosis for good.

2014 is the 50th anniversary of the Trust, and much has been achieved in our five decades. In 1964, most children born with cystic fibrosis died before they reached the age of 10. Today, over 50% of the more than 10,000 people with cystic fibrosis in the UK are adults.

Yet still half of those with cystic fibrosis will not reach their 40th birthday, and people living with the condition are forced to endure a daily burden of drugs and treatment with regular hospital visits and inpatient stays to keep them alive.

So instead of celebrating our 50th year, we dedicated ourselves to achieving the biggest impact for our community, today and tomorrow. Life with cystic fibrosis is constantly changing and we must stay ahead of the pace.

We are delighted on behalf of the wider cystic fibrosis community that HRH The Prince of Wales has chosen this year to become our new Patron, which will raise the profile of cystic fibrosis and the Trust among the wider public.

In April 2013, we published an ambitious research strategy setting out a new focus on building partnerships with industry and other top research organisations to maximise investment and impact. Since then we have already committed £4m to cutting-edge projects improving understanding, treatment and management of cystic fibrosis.

Our work through 2013/14 to improve the quality of care for people with cystic fibrosis saw 11 peer reviews of specialist NHS centres and the continued

development of the CF Registry as an essential data tool to enhance clinical performance and support vital research.

Over 4,500 people joined our campaign for 'Hope for more', to cut the number of people with cystic fibrosis dying on the transplant list.

All these initiatives and many others are only possible because of the extraordinary support we receive from our donors and partners. In 2013/14 we raised £10.81m. It is vital that we continue to grow our income because there is much more to be done before we reach the day when cystic fibrosis is no longer a devastating, life-shortening condition.

There are many opportunities ahead, including extraordinary developments in research and drug discovery, developing therapies that correct the basic genetic defect of cystic fibrosis.

We are developing ambitious plans to inspire and energise our community and beyond. It is vital that we work with stakeholders at every level, from people with cystic fibrosis to researchers and politicians, because together, we will beat cystic fibrosis for good.

Ed Owen
Chief Executive





Investing in cutting-edge research

"It's vital that the Trust funds projects like the Strategic Research Centre tackling *Pseudomonas*, so that we can find a way to detect it earlier, before it causes too much damage."

Read Natalie Crawford's story, page 6

Our ambitious strategy: year 1

In April 2013 we released our five-year research strategy, 'Investing in research to change lives', at our scientific conference, jointly organised with the Wellcome Trust. In this ambitious document we set out how we are going to lead the way in cystic fibrosis research: setting the agenda, working with the brightest and best researchers and clinicians around the world, and investing to ensure we achieve the maximum benefits for people with cystic fibrosis.

At the launch Dame Sally Davies, the Chief Medical Officer, welcomed the strategy and congratulated the Trust on its investment in medical research and its emphasis on boosting involvement of people with cystic fibrosis in setting the research agenda.

Trust Chief Executive Ed Owen said: "We now must exploit this moment to ensure that every pound we spend and every action we take is focused on accelerating treatments and therapies available to beat cystic fibrosis. I believe this strategy sets out an ambitious path to enable us to play our part in ensuring that, over the next decade, we do just that."

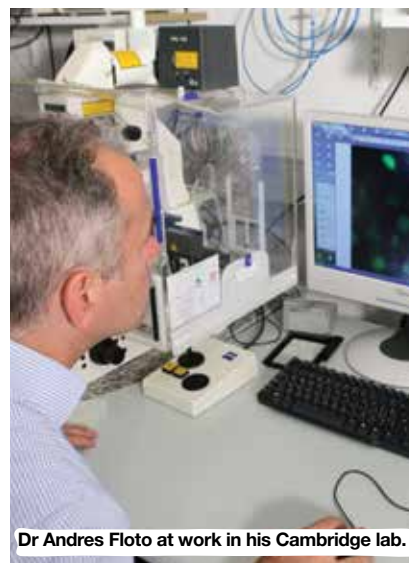
Speaking at the time of launch, Dr Janet Allen, Director of Research at the Trust, said: "The Trust is in a unique position at the heart of a hub linking the patients and their families to research workers, clinicians and scientists. We will invest in both clinical scientists and transformational research to benefit cystic fibrosis and we will leverage additional funding from other sources to maximise the impact on the lives of all people with cystic fibrosis. We will recruit the brightest and the best in cystic fibrosis research."

As part of this strategy, we outlined goals to accomplish in our first year, taking us up to the end of March 2014. Ultimately we were able to meet or surpass all of our key objectives.

Strategic Research Centres

One of our commitments for the first year of the strategy was to form up to two strategic research centres (SRCs), each costing £750,000 over three to four years. These virtual centres of excellence enable researchers across the world to work together to tackle specific problems in cystic fibrosis. In May 2013 we opened the call for applications, and in February 2014 announced the first two SRCs. The first is

led by Professor Jane Davies, investigating Pseudomonal infection in cystic fibrosis, the most common bacterial infection linked with lung damage in people with cystic fibrosis. The second, led by Dr Mike Gray, is looking at non-CFTR approaches to cystic fibrosis therapy. Because of the extraordinarily high quality of the applications, we were delighted to then fund a third £750,000 SRC, led by Dr Andres Floto, tackling *Mycobacterium abscessus*, a superbug which is generating increasing concern in the cystic fibrosis community (see Natalie's story, page 6). We are currently processing applications for a second wave of SRCs.



Dr Andres Floto at work in his Cambridge lab.

Natalie Crawford has *M. abscessus*, a multi-drug resistant superbug that is spreading through the cystic fibrosis population. Her three-year-old son Preston also has cystic fibrosis, and carries *Pseudomonas aeruginosa*, one of the most harmful bacteria for people with cystic fibrosis. This means that both mother and son pose a risk for each other, in case they spread their bacteria to each other.

Natalie was diagnosed with cystic fibrosis when she was five months pregnant with Preston, after a lifetime of repeated hospital stays for 'asthma' and 'pneumonia'.

She says: "Preston has *Pseudomonas* at the moment, he's just had his first round of IVs to try and combat the bug, and it hasn't worked. It's awful to watch him fighting the bug, and that's why it's vital that the Trust funds projects like the SRC tackling *Pseudomonas*, so that we can find a way to detect it earlier, before it causes too much damage to the lungs, and then treat it effectively.

"I have never cultivated *Pseudomonas*, and so Preston actually poses a risk. But he's a toddler, what am I going to do?

He often sleeps in my bed, and of course everyday things like kissing and cuddling are a hazard."

Preston has not shown any symptoms of *M. abscessus* yet, but he's so small that he hasn't been tested for it because that involves an unpleasant bronchoscopy. This means that he could still catch his mother's bacterium, which is a form of non-tuberculous mycobacteria.



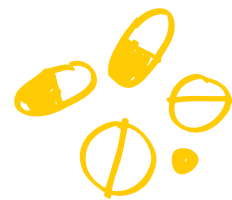
Natalie with her son Preston.

Dr Janet Allen, Director of Research & Care, explains why SRCs are a bold departure for the Trust, and why they will mean the brightest and best working together:

"Each of these groups is led in the UK, but they must pull together the best team of scientists wherever they may be based. This means that we are funding experts overseas for the first time in our history, and we can expand the pool of talent available to tackle problems associated with cystic fibrosis by encouraging people to get involved from non-medical disciplines outside of cystic fibrosis, such as organic chemistry, who can potentially bring a new perspective to our work."

Promoting and supporting clinical trials

It is vital to boost capacity for clinical trials in the UK so that treatments can be assessed and, where possible, reach those who would benefit from them, sooner. In its research strategy the Trust commits to trebling participation in clinical trials within five years, and so in October 2013 we invited applications from CF centres for part-funding for clinical research coordinators. ➔



These posts, which need to be match-funded by a centre's hospital, form the link between trial organisers and patients. The Trust is deliberately targeting hospitals that do not already have research coordinator capacity, to increase the number of centres that can support clinical trials. The first clinical research coordinator awards were announced in May 2014.

Investment in Venture and Innovation

The Venture and Innovation Awards (VIAs) promote transformational research projects and enable the Trust to leverage funding from third party organisations to boost investment in ground-breaking research. Through supportive funding, the Trust is able to encourage and support more research and enable additional impact from its investments for people with cystic fibrosis.

This year the Trust awarded nine VIAs, costing a total of £400,000 and leveraging an additional £1.5m in external funding (including gene therapy). One of these involved a partnership with biotech company NovaBiotics Ltd and Health Services Scotland to trial an established non-cystic fibrosis respiratory

drug, Lynovex®, as a treatment for persistent lung infection in cystic fibrosis. Because Lynovex®, which works by breaking down excessive mucus and killing the bacteria responsible for recurring infections, has already been shown to be safe in treating another condition, it has the potential to be fast-tracked for clinical development. This innovative partnership was highlighted at a Parliamentary reception hosted by the Association of Medical Research Charities (AMRC) and the BioIndustry Association (BIA). Ed Owen and NovaBiotics Chief Executive Dr Deborah O'Neil were invited to speak to MPs and peers about the partnership.

Another VIA announced this year will see a team exploring the potential for a multimedia pack to help children and families cope with the daily burden of cystic fibrosis physiotherapy. The project will be led by Dr Emma France at the Nursing Midwifery & Allied Health Professions Research Unit based in the University of Stirling. The Trust invested £20,000 in the audio-visual component of the project, resulting in additional funding from the Chief Scientist Officer at the rate of £10 for every £1 invested by the Trust.

Research sandpits

The Trust also committed to organising two research forums – known as sandpits – within the first year of the research strategy, aimed at bringing together experts from cystic fibrosis and beyond to identify areas of activity to address key research questions facing people with cystic fibrosis. The first sandpit, held in February 2014, brought together people with cystic fibrosis and carers, clinicians, commissioners and representatives of pharmaceutical and IT industries to explore the potential to use remote monitoring technology to enable people with cystic fibrosis to take greater control and management of their condition and improve their health and wellbeing.

The second sandpit, organised for May, identified important barriers limiting clinical trials in the UK, and discovered ways the Trust could help remove them.



Dr Janet Allen, Director of Research & Care



Fighting for the best care

"I'm delighted the Trust played a part in the development of the new adult cystic fibrosis centre in Nottingham. We kick-started the fundraising for the new centre with a donation."

Lynne O'Grady, Head of Clinical Programmes
Read about the Nottingham CF centre on page 9

Peer reviews

In 2013/14 the peer review programme, jointly sponsored by the Trust, the British Thoracic Society and the British Paediatric Respiratory Society, carried out 11 reviews of adult and paediatric CF centres in the UK, visiting and reviewing 33 hospitals. Peer reviews are an essential way of identifying and communicating best practice, and improving standards across the NHS. In each review, a thorough examination of clinical, psychosocial and business activities relating to the delivery of care for those attending the service is carried out and a report of findings is published for the commissioner, hospital management, the CF team, patients and carers.

Peer pressure

In 2007 we peer reviewed the adult CF service at Nottingham City Hospital, where the panel observed that excellent service was being provided to patients by an under-resourced multidisciplinary team which required improved facilities. On the back of the report, the Trust kick-started fundraising for a new CF centre with a £400,000 donation.

Opening in April 2014, the £6.6m Wolfson Cystic Fibrosis Centre offers a home away from home, with state-of-the-art technology to help overcome the problems of cross-infection, and hotel-style rooms and space for families.

People with cystic fibrosis cannot meet in person because of the risks of cross-infection,

and a long stay in hospital can be lonely, even though other patients may be in the room next door or across the hallway. However, the centre's hi-tech Information and Communications Technologies zone features video conferencing between rooms, which means that patients can talk to one another.



The innovative gym facilities at the Nottingham CF centre enable patients to exercise in view of each other, but without the risk of cross-infection.

UK Cystic Fibrosis Registry

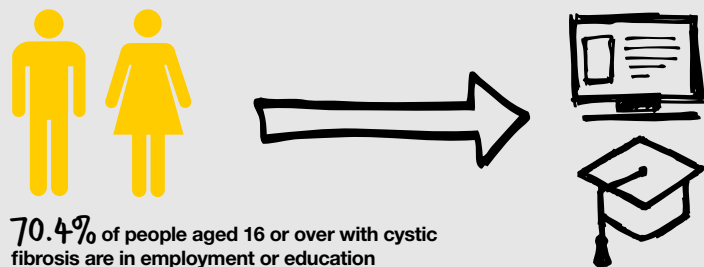
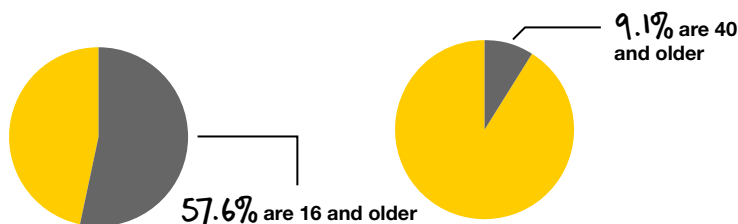
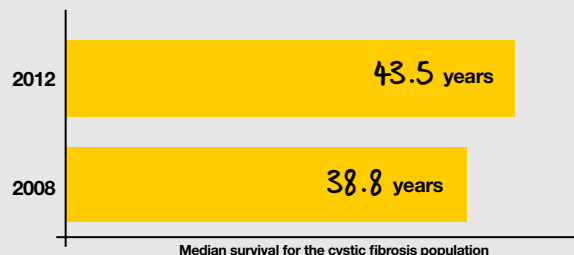
The UK CF Registry, hosted and funded by the Trust, is a vital tool that helps us monitor and audit CF care in the UK, and informs plans for clinical trials of new therapies and provision of future care.

Because the Registry contains over 99% coverage of the UK CF population, and over 89% complete data for all patients, it is also an increasingly valuable research tool. Between April 2013 and April 2014 we received 29 requests for data.

In September 2013, the Trust published the UK CF Registry Annual Data Report based on the data for 2012. The report showed that there were 10,078 people with cystic fibrosis registered. More than 57% were over the age of 16, illustrating how cystic fibrosis has moved from being a childhood killer to an increasingly adult condition. 70% of the adult population were registered as working or studying. The report also showed that the median survival for the cystic fibrosis population had risen to 43.5 years.

Cystic Fibrosis our focus

Cystic Fibrosis Trust update
Cystic fibrosis in the UK in 2012



Genotyping, preparing for a future of personalised medicine

In October we launched a pilot project funded by a grant from Vertex Pharmaceuticals, to help ensure that all people with cystic fibrosis have accurate information regarding their particular mutations. There are over 1,400 different CF mutations, but some older people with cystic fibrosis were tested many years ago, when fewer mutations were known.

Understanding someone's specific mutation will increasingly be a vital part of their care. For example, those with the G551D mutation (around four per cent of the UK CF population) can benefit from a transformational drug called ivacaftor (brand name Kalydeco), the first drug to treat the basic genetic defect that causes cystic fibrosis. The pilot study of 210 people with cystic fibrosis with two unknown mutations has been successful, and the Trust plans to roll out the scheme, with an information campaign to the cystic fibrosis community, to test the remaining 690 or so patients whose genotype is unknown.





Mobilising our movement

"Obviously the ultimate goal for the Trust is to beat cystic fibrosis for good. Until then, improving transplant rates is essential for giving everyone with cystic fibrosis hope."

Read Robyn Davidson's story, page 14

Campaign for Kalydeco

In May 2013 we were able to bring our Campaign for Kalydeco to a close, when the Welsh government announced that they would follow England, Scotland and Northern Ireland in making ivacaftor (brand name Kalydeco) available on the NHS to people with the G551D mutation of cystic fibrosis aged six years and over. This transformational drug, the first to tackle the root cause of cystic fibrosis, received European Medicines Agency approval in 2012, but funding the high-cost drug was a decision for each of the four parts of the NHS in the UK. The Trust immediately mobilised its supporters with a campaign which led to all the home nations, one by one, agreeing to make the drug available to those who would benefit.



Making benefits work

The Trust has been working hard throughout the year to help ensure that adults with cystic fibrosis will receive the support they need from the government's new disability benefit, Personal Independence Payment (PIP).

PIP is replacing Disability Living Allowance (DLA) for people aged 16 and over. The government hopes that its support will target those most in need.

We are working closely with government to ensure that the needs of people with cystic fibrosis are well understood and that the new benefit is fit-for-purpose in its ability to support our community.

In October 2013, we campaigned to underline the challenge that new rules on mobility support will bring and we continue to engage with the government and its assessment providers on how to make the benefit as effective as possible.

The Trust works in coalition with the Disability Benefits Consortium (DBC) – a group that represents over 50 disability charities – to keep a close watch on welfare support for disabled people.

Hope for more

In March 2014 the Trust launched a bold campaign calling for fair access to transplants for everyone, and an end to the scandal that one in three people with cystic fibrosis waiting for a lung transplant dies on the waiting list.

The report followed wide consultation, which began at a Parliamentary reception during CF Week (see page 22) in June 2013. Over 140 individuals and organisations from across the spectrum of cystic fibrosis and transplant care took part in the consultation, alongside people with cystic fibrosis, both pre- and post- transplant, making it the largest consultation of its type in the UK.

In March 2014 we presented the results from this consultation in 'Hope for more: Improving access to lung transplantation and care for people with cystic fibrosis', a report that set out a series of recommendations and commitments to boost the number of transplants for people with cystic fibrosis. At the same time we launched 'Hope for more: Campaigning for a national lung allocation system', a campaign encouraging our supporters to email their local political



representative and ask them to raise the critical need for a fair national lung allocation system with the Secretary of State for Health, Jeremy Hunt MP.

In 2014/15 we will be using this momentum to drive the agenda for change, with a parliamentary debate and an appearance by the Trust's Chief Executive Ed

Owen at a Parliamentary Select Committee hearing already taking place in April 2014.

Clinical Conference attracts record attendance

In September 2013 we held a unique two-day event, 'Moving forward together in a new era', for people involved in all aspects

of clinical cystic fibrosis care in the UK. Record numbers from the clinical community joined us in Manchester to hear about the latest developments in cystic fibrosis care and to share information and ideas.

In September 2014 we are going one step further, bringing together the worlds of research and clinical care for the UK Cystic Fibrosis Conference, the UK's largest conference dedicated to a multidisciplinary CF agenda.

Words to remember...

Robyn Davidson is a single mother of two and has been on the transplant waiting list since November 2013 after her lung function deteriorated rapidly because of her cystic fibrosis. She is coping with this with the support of her two daughters Sophie, 11, and seven-year-old Phoebe.

Robyn says: "The girls have always known that their mummy is not well but I keep the frightening odds of someone with cystic fibrosis dying on the lung transplant list hidden from them, because it wouldn't be fair and could damage what we have in case they stopped acting normally around me.

"The one thing I miss the most is running around with the girls. We live in the country and up until I became this ill, I enjoyed a very outdoorsy lifestyle."

Alongside the memories they have already built as a family, Robyn has just started to write her daughters letters just in case the worse was to happen.

"I have written the girls a letter each for when I go in to have my transplant in case the operation goes wrong. I've also started to write letters for them to open further down the line.

"Things like special messages for all of their birthdays, their wedding day and even for when a boy might break their heart for the first time. I want to give them these letters so that when they read them they can feel close to me and know that I have planned ahead for them but most importantly to let them feel my love when they will need it most, especially because I love them more than words can say."

4,500+

Supporters took part in our 'Hope for more' campaign.

9,000

emails were sent to MPs, MSPs, AMs and MLAs.

600+

news stories were generated covering the campaign... reaching an audience of 50 million.

Engaging our community

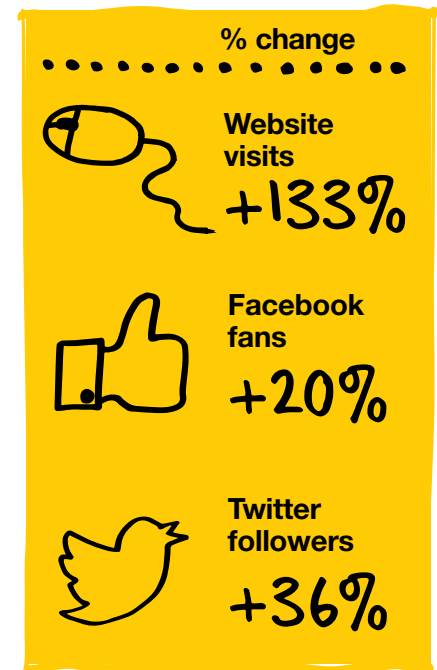
This year the Trust held a number of regional meetings, including in Birmingham, York and London, where supporters and health professionals were invited to come and share their experiences of cystic fibrosis, and hear from members of the Trust's Executive team about new developments at the Trust.

These meetings offer an opportunity for the Trust to listen to grassroots supporters.

This year the Trust has also revamped its online and social media presence, to be both more proactive and more responsive to our ever-growing online community. Because people with cystic fibrosis are unable to meet one another in person, the internet and social media are more important than for many other communities. Beginning with the launch of our new website and brand in March 2013, and continuing with the recruitment of a Social Media Executive, the Trust has seen a 133% increase in web traffic (April 2013 compared with April 2014) and great increases in Facebook and Twitter supporters. Social media has also been instrumental to delivering campaigns such as No Party and 'Hope for more'.



Supporters and health professionals came together at our York regional meeting.



Our 'cystic fibrosis affects more than just individuals' message which we posted on our Facebook page on Valentine's Day received an amazing response.



Supporting people with cystic fibrosis

"I hope this makes people aware not only of what cystic fibrosis is like for teenagers but also for what it is like for everyone else with cystic fibrosis."

Ben Witham, star of '...the rest is up to me' (<http://www.youtube.com/user/CFTrust>)

Read about '...the rest is up to me' on page 18

Our confidential helpline offers general advice, support and information on any aspect of cystic fibrosis, from new diagnosis to bereavement. As well as a listening ear and general information, we also offer financial support in the form of grants for things such as travelling costs for lung transplant assessment, help for people with cystic fibrosis moving away from home for the first time, and funeral costs. This year the helpline sent out 119 New Diagnosis packs, offering support for parents and families when a child has been diagnosed with cystic fibrosis.

As part of our review of our support services we consulted on people's priority financial support needs, and we developed a redesigned grants programme as a result. Changes to the grants programme will be implemented in 2014/15 to better meet people's needs.

To raise awareness of the support we offer, in April 2013 we based our direct marketing appeal around the helpline – the appeal raised more than £11,000. We are currently recruiting for helpline volunteers to support our helpline workers in answering calls and offer administrative support.

Engaging volunteers

This year we recruited a full-time Volunteer & Development Manager, who has helped roll out a dedicated volunteer recruitment programme.

This has already led to 46 volunteers joining the team, in areas such as campaigning, communications, event administration and HR. Volunteers are an invaluable resource, bringing outside expertise and experience and helping boost the numbers of staff we can draw on for any given project. Volunteers will play a key role in helping us mobilise our movement in the future, as well as supporting some of our other key areas of activity.

3,117

calls were answered by our helpline this year

249

grants were issued to help people affected by cystic fibrosis

£96,948

was awarded

"I'm learning all the time. It's amazing to see how everything works." – Deborah



Deborah Lynott, who works on the helpline, is part of an expanding group of invaluable volunteers

...the rest is up to me

In September we released ‘...the rest is up to me’, a film by and for teenagers with cystic fibrosis, which aims to break down the stigma of having a life-shortening condition with young people and their peers. The video, which was made possible by a donation from Genetic Disorders UK, the charity behind Jeans for Genes Day, also helped young people with cystic fibrosis hear from others with the condition, and realise they are not alone.

One of the film’s stars, Ben Witham, said: “I hope this film makes people aware not only of what cystic fibrosis is like for teenagers but also for what it is like for everyone else with cystic fibrosis, regardless of age. More people need to be made aware of cystic fibrosis and the work the Trust does. They do a really good job.”

Jacqueline Ali, Head of Information at the Trust, said: “It is important that we provide information and support to everyone affected by cystic fibrosis, whatever their age. We wanted to make a film that really represented young people with cystic fibrosis, and we got a fantastic range of responses when we put out the call.”



Holly van Geffen shares her experience of life as a teenager with cystic fibrosis in our film ‘...the rest is up to me’.

Cystic Fibrosis is no party

The Cystic Fibrosis Trust has come a long way since it was established in 1964, but when half of the population will not live to celebrate their 40th birthday, we decided not to celebrate our 50th anniversary. Instead, we set out to redouble our efforts to move closer to our goal of beating cystic fibrosis for good.

On 29 January we launched No Party, an interactive campaign that marks the achievements of people with cystic fibrosis and the cystic fibrosis community over the past 50 years, but above all recognises the mission ahead. We are looking forwards to a day when cystic fibrosis imposes no limit to life, when someone born with the cystic fibrosis gene enjoys the same opportunities and life chances as someone born without it.

The campaign began with a simple request – go to cysticfibrosis.org.uk/no-party, and blow up a virtual balloon (because it's online, there's no puff required!). This gives supporters and new friends an opportunity to share their stories of cystic fibrosis. Anyone blowing up a balloon is asked to commit to supporting the Trust by organising a No Party event to raise money and awareness, taking a campaign action to fight

for change, or by taking on a fundraising challenge event, such as a run or cycle. The site also features a video explaining more about the No Party concept.

Largely driven by social media, the campaign was a big success: in the first month more than 3,000 balloons were blown up, with pledges and the Trust gained over 2,200 supporters.

No Party is a theme that will run throughout 2014, with participants hosting No Party events, and the No Party balloon logo appearing across a wide range of materials. July saw a dedicated month of No Party events, to re-focus attention on the campaign and its message.



No Party campaign

Blew up a No Party balloon
3,244

Were interested in campaigning
1,800

Were interested in holding a
No Party event
592

Were interested in doing a
challenge event
1,354





Generating more to do more

"Partnerships with philanthropists, companies, trusts and grant givers are essential to deliver change. We are grateful for everything our partners do for us."

Sarah Bateson, Appeal Director, Cystic Fibrosis Trust.

The Trust has ambitious plans so that we can reach our ultimate goal of beating cystic fibrosis for good, reaching the day when people live a long, healthy life and die with cystic fibrosis, not from it. We would like to say a big thank you to our supporters for their astounding efforts in raising vital funds to support our work.

This year we met our fundraising target of £10.4m, a 7% increase on 2012/13 (see page 25).

While this is good news, especially in such a challenging financial climate, the Trust is aiming to increase income significantly, to fund an ambitious programme to deliver greater impact for everyone with cystic fibrosis.

In the past year, we have developed a new-look Philanthropy & Strategic Partnerships Team, bringing together a group of enthusiastic, dedicated individuals with specialist knowledge in areas such as corporate partnerships and major gifts management.

Partnerships are essential if we are to deliver vital change. We provide dedicated account management for each one, first setting a framework of how we will work, then developing clear

communication plans and finally, together with each new partner, determining at the outset what success will look like.

"We have some very ambitious plans for the future...we cannot do any of it without support."

Appeal Director Sarah Bateson, who joined the Trust in January 2014, says: "Partnerships and major gifts are vital to the Cystic Fibrosis Trust. We have some very ambitious plans for the future, including cutting-edge research and a revolution in personal care, and we cannot do any of it without support. Income from the corporate sector accounted for £1.3m last year, and trusts accounted for over £400,000.

"Of course, there are more ways companies and individuals can help beyond money – we are always interested in opportunities for promotion or engagement with new audiences, to help us raise awareness about cystic

fibrosis and the issues that affect so many lives. Then there are gifts in kind or pro bono support – they all bring great value."

We are committed to beating cystic fibrosis for good, investing in cutting-edge research, driving up standards of care and offering support for everyone affected by cystic fibrosis. We can't do that without our supporters, whether they are FTSE 100 companies or parents of a newly diagnosed baby with cystic fibrosis, which is why we understand the importance of a true partnership.



A ball sponsored by our corporate partner Fincorp raised over £12,000 (see page 22)

Fincorp is one of the UK's most established and respected bridging loan companies. For 25 years the company has been providing first and second charge bridging finance on residential properties in London and the South East. Fincorp has raised £30,000 for us through a combination of donations, fundraising events and sponsorship of the charity's annual ball.

As part of its 25th anniversary year the lender pledged a

minimum of £100 for every deal completed during 2013. Fincorp also sponsored their annual Charity Ball contributing to the more than £12,000 raised on the night.

Matthew Anderson, Director at Fincorp, said: "We are proud to be able to contribute something back to society and I'm particularly pleased that we're able to do something quite significant to support research and help for those suffering from cystic fibrosis."



The ball sponsored by Fincorp was a huge success

CF Week 2013

In the last week of June 2013 we held our national fundraising and awareness week, which this year was themed around transplantation, and the scandal that one in three people with cystic fibrosis on the lung transplant list will die before they can receive one. At a Parliamentary reception during the week we launched our consultation on how to boost transplant rates, sowing the seeds for what would become the 'Hope for more' report and campaign in 2014 (see page 13).

Our supporters helped raise almost £80,000 during the week, and we were able to put cystic fibrosis in the public spotlight.

Supporters across the UK joined in the fun and fundraising, with everything from cake bakes to big bounce races. The week got off to a flying start in Northern Ireland with a pop-up shop on Bangor's Lower Main Street raising over £4,000 in its first three days. Selling new and nearly-new clothes, bric-a-brac and toys, the shop was a collaborative effort, with local businesses and the local council all pitching in to make it happen. The shop even attracted the great and good, when



Deputy Mayor Sharon Gilmour came to lend her support to CF Week.

We were also privileged when the pupils of Sandbach High School and Sixth Form College in Cheshire dedicated their sports day to CF Week 2013. Alongside their regular competitions, the school organised a programme of special events, including a mass space hopper attempt to bounce the equivalent of a marathon – in the end, the pupils smashed their target, bouncing their way to 116 miles! Pupil Jasmine Tunney, whose mother has cystic fibrosis, said: “I didn’t know there was a Trust for cystic fibrosis. Thank you, you’re doing something really big that will help a lot of people.” The school raised over £1,000 for the Trust.

Because our 50th anniversary year is full of No Party events, the Trust is not holding a CF Week in 2014, but the success last year is another reminder of what our amazing supporters can do.

Watch some videos from CF Week on our YouTube channel:
www.youtube.com/user/CFTrust.



Supporters take to the streets for CF Week 2013, helping raise funds and awareness of cystic fibrosis.

Summarised accounts

The Trust's annual income of £10.8m in 2013/14 represents an increase of 11% on the previous year and reflects the deep and continuing commitment of our many supporters and partners to improving and transforming the lives of people with cystic fibrosis.

As a result of this on-going support, charitable spending has increased by 78% to £6.5m focused on delivering greater impact for those we are here for. The Trust has been able to increase significantly its research spending to develop new therapies and approaches aimed at tackling and beating the condition. Investment in research increased by 153% to £4.1m in 2013/14 as part of the roll-out of a new, ambitious research strategy published in April 2013.

We are also spending more on information, advice and support to those affected by cystic fibrosis including campaigns and communications to ensure the voices of those with the condition are heard loud and clear where it matters.

Our reserves position also improved enabling significant new investment in 2014/15 on ambitious new projects to increase our impact further.

It is encouraging that the Trust's income is increasing in those areas which we have identified as the basis for long-term growth and the continued development of a more ambitious and diversified fundraising model. There was, for example, a significant increase in income from legacies and from both corporate and trust sources. There was also an increase in income from the Trust's innovative partnership with pharmaceutical companies to use the UK CF Registry to study the safety of newly introduced cystic fibrosis drugs.

Voluntary income continues to represent more than 90% of our income, of which 44% comes from community fundraising, branches and groups. We are truly indebted to the extraordinary dedication and commitment of those who voluntarily give their time and energy to help beat cystic fibrosis for good.

Ed Owen
Chief Executive, Cystic Fibrosis Trust

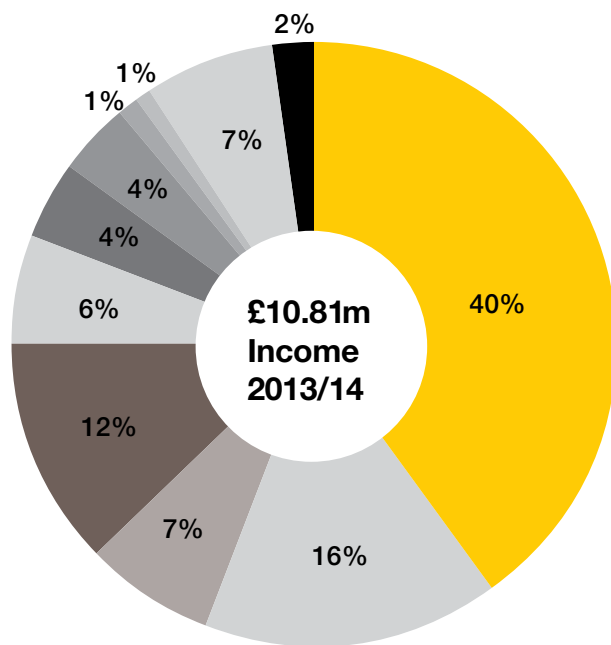
Report by the Trustees on the summarised accounts

"The summary financial information shows the income raised for our activities, the cost of raising the income and the amounts spent on our charitable activities. The information is taken from the full financial statements which were approved by the Trustees on 15 August. In order to gain a full understanding of the financial affairs of the charity, the full audited financial statements, trustees' annual report and auditor's report should be consulted. Copies can be obtained from the Company Secretary."

Signed on behalf of the Trustees.

Financial visual analysis

Income 2013/14 – £10.81m (2012/13: £9.73m)



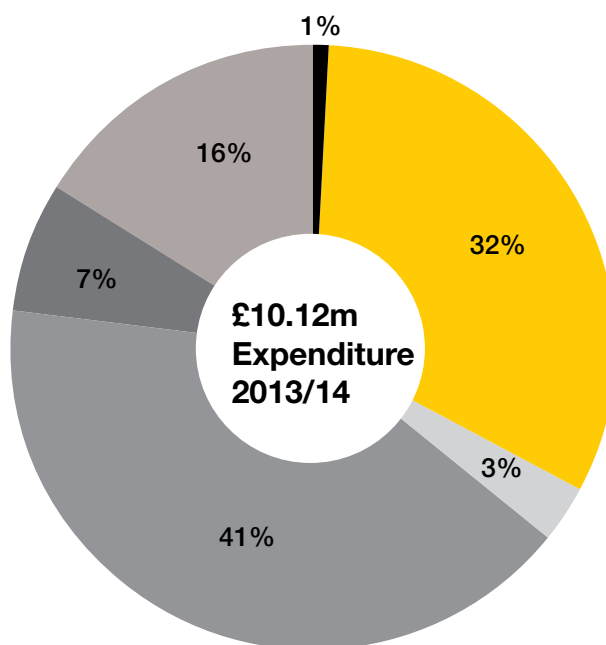
Income

£'000s

| | |
|--|--------|
| Branches, Groups & Community | £4,309 |
| Legacies | £1,777 |
| Individual donations | £788 |
| Corporate | £1,300 |
| Gift Aid | £633 |
| Regular giving and appeals | £428 |
| Trusts | £405 |
| Department of Health | £172 |
| Trading and merchandising | £797 |
| Investment & interest income | £166 |
| Other incoming resources: Fixed asset disposals gain | £31 |

£10,806

Total spend 2013/14 – £10.12m (2012/13: £7.2m)



Expenditure

£'000s

| | |
|-------------------------------|--------|
| Fundraising | £3,293 |
| Trading–Merchandising | £318 |
| Research | £4,118 |
| Clinical Care | £726 |
| Information, advice & support | £1,609 |
| Governance | £59 |

£10,123

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 Employee Designated Gift Fund
- BIA UK Bioindustry Association
- City Charitable Trust
- Mr A Johnstone & Ms V Clarke
- Compass Group PLC
- Constance Travis Charitable Trust
- Mr & Mrs Richard Cousins
- D'Oyly Carte Charitable Trust
- Elizabeth and Prince Zaiger Trust
- Enid Linder Foundation
- Fincorp
- Gerald Micklem Charitable Trust
- Joseph Levy Foundation
- Joseph Levy Memorial Fund
- Marjorie and Edgar Knight Charitable Trust
- National Grid
- Petrofac
- PF Charitable Trust
- Pilkington Charitable Trust
- Reading Textiles
- Robert Luff Foundation
- Star Cargo plc Group
- Swire Charitable Trust
- The Gay and Keith Talbot Trust
- Tomorrows
- Vertex Pharmaceuticals (UK) Ltd

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.

- Mr R Barnes
- Mr V Cave
- Ms J Clark
- Ms I Jones
- Mrs E Mahon
- Mrs J Mackinnon
- Mrs G Porteous
- Mrs T Pritchard
- Mrs V Sinclair
- Ms J Tyrrell

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

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





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Cystic Fibrosis making a difference

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