Issue 3: Summer 2014

is

The magazine of the Cystic Fibrosis Trust

Striking a chord

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Welcome

We're over halfway through our 50th anniversary year, and so much has happened. In January we said we would redouble our efforts to reach our goal of beating cystic fibrosis, and we have been working hard to live up to that commitment, from our hugely successful 'Hope for more' campaign, which put transplantation at the top of the agenda (see page 4), to our first groundbreaking research sandpits (see page 11).

I've also been working hard, training for the Dulwich Park Fun Run (see page 6). Don't worry though, there is plenty to come! In September we will be launching our brand new UK CF Conference, the largest event in the UK dedicated to a multidisciplinary cystic fibrosis agenda (page 10). We are also holding a third research sandpit, this one on adolescence and cystic fibrosis.

In this issue, you can read about the three Strategic Research Centres we have set up thanks to your generosity (pages 20–22), and the dawning age of personalised medicine (pages 24–26). You will also discover Breath Cycle (pages 14–17), a project exploring what singing can do for people with cystic fibrosis.

Henry Fogarty
Editor

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Cover photo: 14-year-old Alex, whose life was transformed by Kalydeco (see page 24).

Some pictures in this publication may be posed by models or taken from library images.

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Shannon Sweeney (participant with cystic fibrosis) on screen and Aidan McCusker, part of Scottish Opera Connect Chorus, performing together at the launch of Breath Cycle. Read more in 'Striking a chord' (pages 14–17)

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Credit: Bartosz Madejski.

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‘Stars’ tribute funds launched

The Trust has launched ‘Stars’, a new online tribute fund that offers supporters a way to celebrate the life of a loved one and keep their spirit alive, while raising vital funds to help beat cystic fibrosis.

Replacing the Stars in the Sky tribute site, ‘Stars’ gives users more ways to personalise and share their fund, with photographs, words, music and video, and allows family and friends to post their own messages and memories.

Julia (left) raises money in memory of her sister Joy (right)

Donations made in memory can be shown on the relevant fund page, to highlight the efforts of everyone involved in raising tribute funds.

Julia White, who raises money to support the Trust as a tribute to her sister Joy, said: “Joy was a bright and vivacious person who lived life to the full. She was a strong supporter of the Trust and participated in new drug trials. When she passed away we wanted to do something positive in her memory.” Julia set up ‘Joy*ful girls’, a group that holds a fundraising event every year in memory of Joy, which raised over £9,000 at its most recent event in November 2013.

To find out more visit cysticfibrosis.org.uk/tributefund.

Campaign demands hope for more

Supporters rallied to the Trust’s ‘Hope for more’ campaign in March, sending over 9,000 emails to urge politicians to press the Government for a national allocation system for donor lungs.

The campaign accompanied the release of the Trust’s ‘Hope for more’ report, which set out recommendations for policymakers and health professionals on how they can help to end the tragedy of one in three people with cystic fibrosis waiting for a lung transplant dying before they can receive one.

In a moving introduction to the report, David Kingston, whose daughter Emma died awaiting a transplant, wrote: “The report contains actions that people working in health policy need to take. I want to give hope to all those people on the transplant list now and in years to come.”

The campaign reached an audience of 50 million people, with 600 stories appearing in the press. Since then, the Trust has continued to keep this burning issue at the top of the agenda, with Chief Executive Ed Owen giving evidence to a Parliamentary committee on transplantation, and Kerry McCarthy, MP for Bristol East, holding a debate in Parliament. As a result, UK Minister for Public Health Jane Ellison MP has expressed concern about the number of deaths on the waiting list, and NHS Blood and Transplant has confirmed that it is reviewing the current lung allocation system.

To read the report visit cysticfibrosis.org.uk/hopeformore.

David Kingston pictured with his daughter Emma, who died waiting for a transplant, introduced our ‘Hope for more’ report calling for urgent action to boost transplant rates.

Jason McCartney MP (@JasonMcCartney) tweets about organ donation: “Excellent WH debate on #organdonation. As Chair of All Party Group on #CysticFibrosis @cftrust I spoke of need for national lung allocation.” **You can follow the Trust @cftrust. twitter.com/cftrust**

Yellow… is it me you're looking for?

Supporters throughout the UK had fun in the sun with a huge range of No Party events in July. The Trust kicked things off with staff raising money by wearing something yellow to work and holding a picnic – and invited anyone to join in the fun via Twitter.

Throughout the day the Trust shared pictures of yellow-clad staff and the picnic, and the community followed suit by posting their own 'yellow' photos using the hashtag #CFyelfie.

"We had over 300 #CFyelfie photos shared across Twitter and Facebook."

Bev Burnham-Jones, Senior Fundraising Manager – North, said at the event launch: "We wanted to do something that brings people together online. Because of the risk of cross-infection, cystic fibrosis can be a hugely isolating condition, so we are taking things virtual. We had over 300 #CFyelfie photos shared across Twitter and Facebook, and raised almost £2,500 from text donations!"

"In our 50th year, we are redoubling our efforts to reach our goal of beating cystic fibrosis for good, and this month of No Party events is a fun way for people to get involved and mark our 50th anniversary. Of course, people can also hold No Party events any time in the year, and we're very grateful to everyone taking part."

Visit cysticfibrosis.org.uk/howto for tips on organising your own No Party event.

Not so mellow yellow: Staff at the Trust's Bromley HQ get in the #CFyelfie spirit.

It's a merry life cheating death

Turning 40 is a milestone for people with cystic fibrosis, one which too many do not reach, and for blogger Tim Wotton, it provided the inspiration for his first book.

In 'How Have I Cheated Death? A Short and Merry Life with Cystic Fibrosis', Tim explores his physical and mental battle with cystic fibrosis and his recently diagnosed type 1 diabetes. The south London-based writer also discusses the importance of family support, and talks about his marriage to his wife Kate, and their rollercoaster journey with IVF that led to the birth of their son Felix.

"Having a book published and available for anyone in the world to read feels awesome, humbling and bewildering in equal measures," says Tim. "I am hoping to reach a global audience – the CF community, sufferers and their families should derive some hope and survival strategies from my story, while wider audiences will hopefully understand CF better and appreciate what it takes to combat it on a daily basis."

The book, which features an introduction by actress and long-time Trust supporter Jenny Agutter OBE, is available to buy from online retailers including austinmacauley.com, and amazon.co.uk, as well as in WH Smith, Waterstones and Foyles bookstores (ISBN 9781849637190).

Eyes on the prize: Grace Miller doesn't let cystic fibrosis stop her winning the children's race at the Dulwich Park Fun Run.

Amazing Grace wins the day at Dulwich Park Fun Run

Over 250 people turned out for the annual Dulwich Park Fun Run this year, organised by CFTwo, with 12-year-old Grace Miller showing them how it's done as she raced to victory in the children's one-mile race for the second year running, despite having cystic fibrosis.

Following in the footsteps of her hero Mo Farah, Grace has represented Tower Hamlets at the London Mini Marathon, and loves running, which keeps her fit and serves as a distraction from her other passion, supporting the recently relegated Fulham FC.

Grace said: "Last year when I won the Dulwich mile I was having IVs and had a cannula flapping around on my arm! So I enjoyed it more this year. We managed to get a big crowd to come along and they all saw me win. It was really fun."

As well as the 10k, 5k and kid's race, this year's event saw the inaugural buggy push, which long-time actress and Trust supporter Jenny Agutter OBE took part in wearing a 1950s' dress and pushing a vintage pram. Jenny was accompanied on the day by some of her 'Call the Midwife' co-stars.

This year's event raised more than £17,500 for the Cystic Fibrosis Trust.

Visit cysticfibrosis.org.uk/events and find a fundraising challenge to take on!

The adults also got in on the action at Dulwich Park with the 5k and 10k races.

Breaking barriers: The Wolfson's hi-tech gym enables people with cystic fibrosis to work-out together even though they are in different rooms.

State-of-the-art CF unit provides home from home

A new £6.6m adult CF centre at Nottingham City Hospital, part-funded by the Cystic Fibrosis Trust has opened. It uses technology to overcome some of the challenges posed by the dangers of cross-infection and offers hotel-style rooms and space for families.

The Wolfson Cystic Fibrosis Centre, which opened in April, received £400,000 from the Cystic Fibrosis Trust following its peer review of the adult CF service in 2007. The centre's hi-tech Information and Communications Technologies zone features video conferencing between rooms, which means that patients can talk to one another. People with the condition cannot meet in person because of the risks of cross-infection, and a long stay in hospital can be lonely.

Lynne O'Grady, Head of Clinical Programmes at the Trust, said: "We are delighted to have played a part in the development of the centre. When the service was reviewed it was recognised that an excellent service was being provided to patients by the under-resourced multidisciplinary team who required improved facilities. We kick-started fundraising for the new centre with a donation."

Peter Homa, Chief Executive at Nottingham University Hospitals, said: "This new unit will completely transform the treatment of CF patients. Patients can not only receive all the treatment they need in one place, but also feel comfortable and 'at home' during the long periods of time they spend in hospital."

Bianca Nicholas showed what people with cystic fibrosis can do when she performed U2's 'One' on BBC One's 'The Voice UK', receiving some great feedback from the judges. The 24-year-old also wowed patrons at the Trust's 50th anniversary gala.

News in brief

Trust partnership leads to new clinical trial

The partnership between the Cystic Fibrosis Trust, biotechnology firm NovaBiotics Ltd and Health Sciences Scotland is progressing to a Phase IIa clinical trial to assess the safety and initial effectiveness of the drug Lynovex® for people with cystic fibrosis. Lynovex®, already a recognised treatment for a non CF-related condition, could break down mucus produced in the airways of people with cystic fibrosis, and has been shown to kill the bacteria responsible for the recurrent respiratory infections experienced by many with the condition. Dr Janet Allen, Director of Research & Care at the Trust, said: "It is exciting to see how our partnerships with industry are helping to deliver new and successful ways to help treat this condition."

Prince of Wales becomes Patron

Credit: Hugo Bernand

The Trust's 50th anniversary year was given added impetus with the announcement that His Royal Highness The Prince of Wales would be its new Patron, for an initial term of five years.

In a personal message for the Trust's 50th anniversary gala in London's Banqueting House on 8 May, His Royal Highness wrote: "Having for so long felt deeply about the suffering of cystic fibrosis patients, I am delighted to take on patronage of the Cystic Fibrosis Trust from Princess Alexandra in this, the Trust's 50th year. By funding groundbreaking research, improving the quality of care and providing invaluable advice and support, the Trust carries out extraordinary work on behalf of the 10,000 people with cystic fibrosis in the United Kingdom."

George Jenkins, Chairman of the Trust, said: "HRH Princess Alexandra …has been a very important part of our organisation for most of its history, and on behalf of the whole of the cystic fibrosis community in the UK I wish to thank her for the wonderful support she has provided over this time.

"We are delighted that HRH The Prince of Wales has agreed to become the Patron of the Trust, especially as he has a deep understanding of the inspirational courage and determination of those affected by the condition."

News in brief

New posts to give clinical trials a boost

The Trust has announced part-funding over three years for clinical trial coordinator posts at three CF centres, providing a link between patients and trial organisers. The four posts will be at King's College, London, and Newcastle – in both cases shared between the adult and paediatric units – and Manchester adult CF centre. Dr Erika Kennington, Head of Research at the Trust, said: "It is particularly important that we increase the number of clinical trials in the UK because drugs can be licensed more quickly if the trials have taken place in this country.

The Trust's first overseas expedition saw 19 explorers, including TV personality Sian Lloyd and Kerry McCarthy MP, brave desert temperatures and rocky terrain on a 27.5km trek to the lost city of Petra, in Jordan, in February. The total raised is on course to reach £50,000.

Watch the Petra Trek video by going to cysticfibrosis.org.uk/petra. Don't forget you can also view other videos from Trust initiatives and events at youtube.com/cftrust.

200 runners took part in the Virgin Money London Marathon for Team CF in April, cheered on by Cystic Fibrosis Trust 'kerb crews' and a legion of supporters, and raising over £360,000, with more to come in.

Kalydeco could treat more genotypes

Thousands more people worldwide could soon benefit from ivacaftor (Kalydeco), the groundbreaking drug that tackles the root cause of cystic fibrosis. Ivacaftor is currently available for people with the G551D mutation, around 4% of the UK CF population.

Now a phase III trial of ivacaftor in combination with another compound, lumicaftor, has found that the combination significantly reduced the rate of pulmonary exacerbations for people aged 12 and over with two copies of the F508del mutation (around 50% of the UK CF population). This could slow down the rate of damage to the lungs and reduce the number of hospital stays for people on the drug. The combination also led to an improvement in lung function (FEV_1) of 2.6–4.0%. The drug's manufacturer, Vertex, will now apply for licences in the USA and Europe.

In a separate development, the European Committee for Medicinal Products for Human Use has recommended the approval of Kalydeco for people with cystic fibrosis aged over six years old, who have one of eight non-G551D gating mutations: G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P or G1349D. This amounts to around 250 people in Europe, including 30 in the UK. The recommendation will now be considered by the European Commission, which has the authority to approve medicines for the European Union.

Kalydeco is an example of a new type of medication, aimed at specific genotypes. Read our feature on the dawning era of personalised medicine – see page 24.

News in brief

Calling tomorrow's business leaders

The Trust launched the Helen Barrett Young Entrepreneur Awards in June. The new initiative offers financial support and mentorship for people with cystic fibrosis aged 18–32 either setting up their own business or looking to develop one further. The three-year scheme was set up in memory of Helen Barrett, who founded a successful gym with her partner, despite living with the condition herself. The Trust is handing out £11,000 of awards in the first year, which was made possible by a private donor and match funding from employment specialists A4e.

Find out more and apply by 8 September at cysticfibrosis.org.uk/entrepreneurs.

UK CF Conference to break new ground

On 4 September the Trust is staging the largest event in the UK dedicated to a multidisciplinary cystic fibrosis agenda, bringing together both clinical care and research content.

The Renaissance Hotel, Manchester, will welcome clinicians, centre directors, researchers and parents of people with cystic fibrosis. There will be a global line-up of speakers including Preston Campbell III, Executive Vice President for Medical Affairs at the Cystic Fibrosis Foundation, and Tim Kelsey, National Director for Patients and Information with NHS England, who will both give keynote speeches.

In another first for the Trust, people with cystic fibrosis and the wider CF community will be able to stream all of the speeches live online. For further information see **cysticfibrosis.org.uk/ukcfc**.

The five medical undergraduates who took part in the Trust's Sir John Batten Memorial Studentship programme over the summer will each present a poster at the conference, with prizes for the top three awarded at a ceremony bringing the event to a close.

Ed Owen, the Trust's Chief Executive who will present the opening speech at the conference, said: "The Trust is raising its level of ambition to improve and transform the lives of people with cystic fibrosis, and this conference is an important part of this."

Don't get your tinsel in a tangle—order your Christmas cards early this year.

Our Christmas shop is now open, with a great range of cards and gift ideas. Everything you buy brings us closer to beating cystic fibrosis for good—**place your order today.**

Call 01227 811 670 or visit cysticfibrosis.org.uk/cardshop.

On the right track: Network Rail staff at King's Cross raised over £9,000 by cycling the equivalent of London to Edinburgh and back in 24 hours.

Neil Worrall (@NeilWorrall_UK) tweets in support of the Trust's #CFyelfie initiative: "Those blooming Brazilians love a #cfyelfie for @cftrust @CFAware pic.twitter.com/B4vtw7SoUt."
You can follow the Trust @cftrust. twitter.com/cftrust.

Experts from a wide range of backgrounds came together with the CF community to explore how to boost participation in clinical trials.

Forum brings community together to boost clinical trials

The Trust's Clinical Trials Forum in May brought together clinicians, pharmaceutical companies, regulators and wider research experts, along with people with cystic fibrosis and parents to help find ways to increase and improve cystic fibrosis clinical trials in the UK.

The day-long workshop featured presentations that were streamed live online, as well as roundtable discussions to identify issues that prevent more people taking part in clinical trials in this country, and how the Trust can help break down those barriers.

Oli Rayner, the Trust's Special Adviser, Research & Patient Involvement, said: "The forum addressed the key issues head-on and helped us map out our plans to facilitate high-quality clinical trials and improve opportunities for participation. With parents and an adult with CF in the room, a virtual panel of CF adults and a live web stream, the patient perspective was at the heart of the discussion."

The forum was the second in a programme of research sandpits to promote collaboration between established cystic fibrosis researchers and experts outside of cystic fibrosis to address major problems. In its five-year research strategy, launched in April 2013, the Trust pledged to identify and run two research sandpits within the first year of the strategy.

Family adherence project is a scoop!

The Trust has announced part-funding for a research project to explore the potential for a multimedia pack to help children and families cope with the daily burden of cystic fibrosis physiotherapy.

Supporters voting in a poll on the Trust's website chose the name 'SCooP' (Supporting Children's Physiotherapy for cystic fibrosis), and a cystic fibrosis group on Facebook then helped choose the winning logo (above). The project, led by Dr Emma France at the Nursing Midwifery & Allied Health Professions Research Unit based in the University of Stirling, got underway in May.

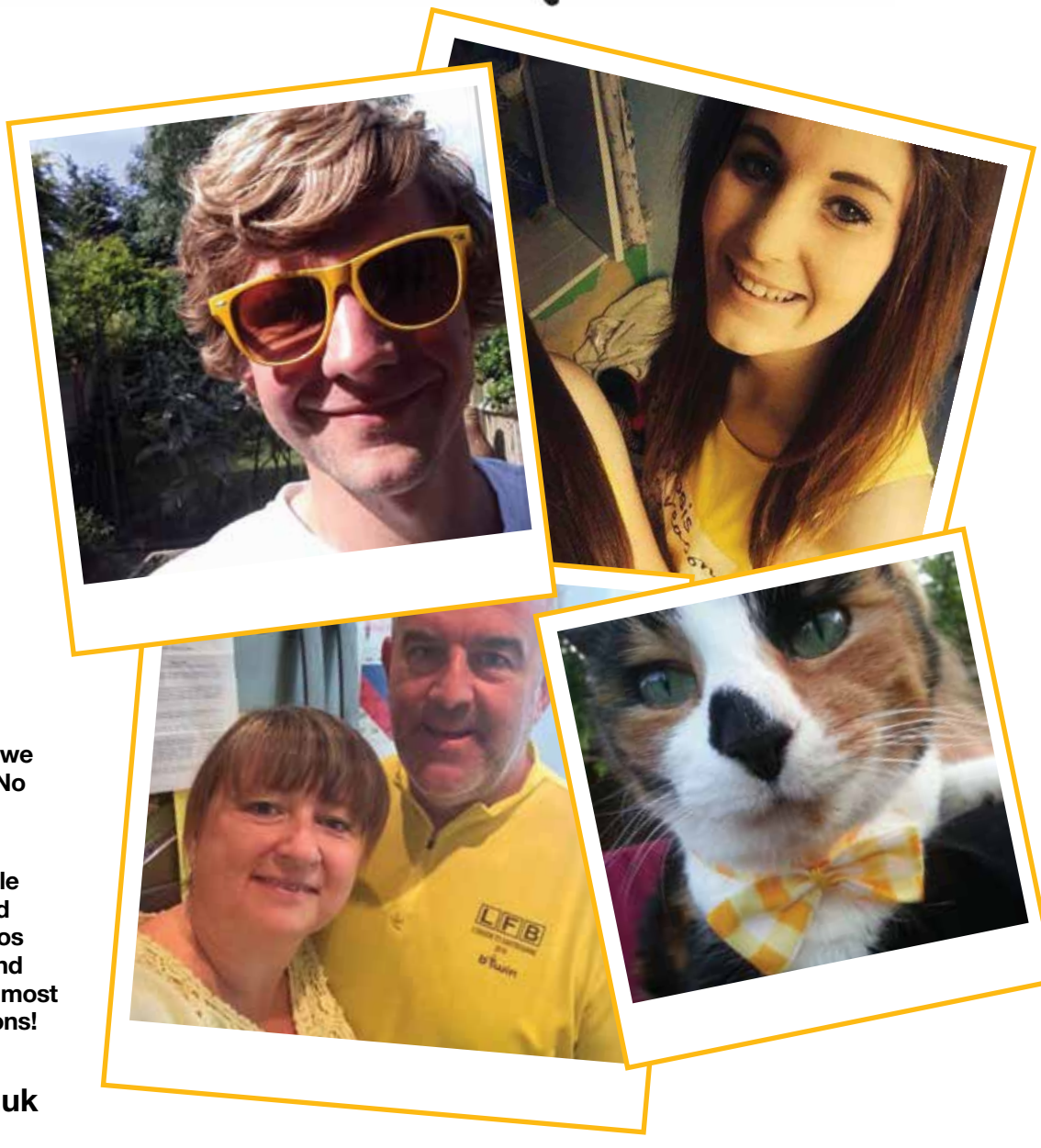
Dr France said: "In developing this new audio-visual package, our work will lead to a cost-effective and accessible intervention tool. It will change the way children and their carers experience their condition and treatment, particularly in the crucial early years when commitment to that treatment is so vital."

The Trust's offer to invest in the audio-visual component of the project resulted in additional funding from the Chief Scientist Officer at the rate of £10 for every £1 invested by the Trust.

Dr Janet Allen, Director of Research at the Trust, said: "Leveraging is one of the key elements of our research strategy, leading the way with our own funding – to encourage major investment in research. This project is also an example of our commitment to promoting venture and innovation in research."

For more information contact Dr France on 01786 466421 emma.france@stir.ac.uk.

Cystic Fibrosis worth getting dressed up for



Thank you for coming to the party!

Yellow was the order of the day on 1 July, when we launched our month of No Party events.

We were delighted that so many of you were able to join in the fun. We had over 300 #CFyelfie photos shared across Twitter and Facebook, and raised almost £2,500 from text donations!

cysticfibrosis.org.uk

#CFyelfie

There is still plenty of time to organise your own No Party event this year – visit cysticfibrosis.org.uk/howto for more information.

Striking a chord

Breathing new life into physiotherapy: Gareth Williams, Marie Claire Breen and Cara Doran at the Trust's 50th Gala.

Because of the risk of cross-infection, people with cystic fibrosis are not able to go round and meet with others in their neighbourhood who have the condition. But they could stay in and sing with their friends, who have cystic fibrosis, as far away as the other side of the Atlantic Ocean.

That is the conclusion of a project in Glasgow organised by the CF centre at Gartnavel Hospital and the Scottish Opera Company. It showed that forming a 'virtual' choir, in which the members sing and interact online, can help them deal better with their condition and improve their ability to appreciate music – as well as being great fun.

'Breath Cycle' is the brainchild of the composer-in-residence at Scottish Opera, Gareth Williams. He was very familiar with the challenges of dealing with cystic fibrosis as he has an old college friend with the condition and had looked after children who were affected in his previous job as a special needs music teacher.

As part of Scottish Opera's outreach activities, Gareth's job involved thinking of ideas to encourage more people to take an interest in operatic music – and maybe have a go themselves. He wanted to form a choir made up of people who had never considered themselves to be singers and realised that people with cystic fibrosis would be an ideal choice. "What grabs me about this condition is that we could do a community music project with a group of people who can't actually be a community," he explains.

So Gareth contacted Gordon MacGregor and his colleagues from the Gartnavel CF service to help recruit members for the choir, and the Scottish Opera soprano Marie Claire Breen, who agreed to provide one-to-one training sessions for its members in correct breathing and singing techniques.

Dr MacGregor managed to persuade the Wellcome Trust to meet the costs of running 12-week training programmes for three groups of singers with cystic fibrosis from February 2013 onwards. They were given fortnightly training sessions with Marie Claire but most of the work was done at home using vocal exercises supplied on CDs or MP3 files.

The members also recorded videos of their efforts, which were posted online for Marie Claire and the other members to offer suggestions and comments. Due to the risks of cross-infection, those members have never actually met in person, but they communicated regularly through online services such as Skype and Google+, and many have formed lasting friendships. One of the participants Yvonne Hughes (see below) adds that three people in her group of 14 have also gone on to join regular choirs, including one teenager who has been accepted as a member of the Scottish Opera youth choir.

The training wasn't just about learning the technical aspects of singing and improving posture; the choir also worked together on pieces ▸

Yvonne Hughes was a member of the first group and found that it wasn't a chore to complete this homework, as it fitted neatly with her busy role as a Public Affairs Officer for the Cystic Fibrosis Trust in Scotland. "I was practising my scales in the house every day and singing in my car as I drove around Glasgow. I had to learn how to project, which made my lungs feel better and I found that I was holding myself straighter, which was really helpful. I had never really sung before, but with training I got much better and learned how to sustain notes and sing higher which helps keep my lungs expanded," she recalls.

of music written specially for them by Gareth with words by the Toronto-based librettist David Brock.

The wonders of technology have also allowed the choir to perform 'together' on two occasions: a conference in Scotland last year and at the Trust's 50th anniversary gala in London in May. Individual performances by the various members were recorded, edited and projected on a screen. So at the gala, four singers recorded their piece for Gareth's work about cystic fibrosis called 'Five ways of looking at fire in the dark', while one member, Cara Doran, sang her part live.

The project provided convincing proof that people with no musical background can rapidly develop the skills needed to perform a challenging choral work and that having a serious condition affecting their breathing was no impediment to their success. But Dr MacGregor also wanted to see if there were any positive effects on their medical condition.

Gartnavel staff took before-and-after measurements of various physiological parameters of 14 members of the first group that completed the 12-week study.

"I had to learn how to project, which made my lungs feel better." – Yvonne Hughes

"There were suggestions of improvement in the lung function marker FEV_1, which rose by a median of 13%. However, this was not statistically significant as the study numbers were too small. There was a suggestion of improvement in how subjects cleared gas from their lungs – the Lung Clearance Index – but again this did not reach statistical significance," Dr MacGregor said. He plans to publish a scientific paper on the project in a medical journal and says the results were sufficiently encouraging to plan a larger trial with enough subjects to provide statistically convincing results. Another good reason for developing the concept of the virtual choir to another level is that it would be great fun for all those involved.

"I frequently run studies using different new drugs, but this study with Scottish Opera has been one of the most memorable and enjoyable that I've been involved in and has been an extremely positive experience for the people with cystic fibrosis who participated," Dr MacGregor noted at the time.

Gareth Williams is also keen to continue the work when he takes up a new post as a research fellow at the University of Edinburgh in September, where he will be exploring the social and medical benefits of music.

One of his ambitions is to work with the university's Informatics department to see if its staff can develop the technology that would allow virtual choir members to ▸

At the Trust's 50th anniversary, Gala the team integrated videos of the Breath Cycle singers with a live performance.

Credit: Bartosz Madejski.

sing together live online. Existing technical platforms like Skype are too slow to allow a group of singers to interact in real time on their own computers but Gareth reckons this a challenge that can be overcome.

Up to now his main focus has been on creating the materials that the singers will need, rather than the actual physical performances, he explains. So most of his time has been spent on creating the music, the vocal exercises and the training videos that the singers need before they can start thinking about singing live. But now that is available online, he wants to help other groups of people, irrespective of whether or not they have a medical condition like cystic fibrosis, to enjoy the physical and emotional benefits of singing in a virtual choir.

There is already interest from the Aberdeen CF centre to set up its own patients' choir and the idea can be repeated at other hospitals around the country. "I would also like to open it up for international collaborations. We are talking to people at St Michael's Hospital in Toronto, where David the librettist is from, and there has been some interest from a hospital in New York.

"So we will try to do something similar with people who have cystic fibrosis over there. It would be great to get people singing with each other on both sides of the Atlantic. Distance isn't an issue, it doesn't matter whether the people you are singing with are one mile away or a thousand," Gareth says.

"I plan to create more online resources for different age groups and different types of choirs. There is no reason, for example, why we can't produce songs that will encourage parents to sing along with their children. I have even heard that the nurses and physios at Gartnavel have formed their own choir – the idea is to inspire people to sing, and if we can do that for some, then we can do it for everyone."

Hitting all the right notes: Gareth Williams highlights the physical and emotional benefits of singing in a virtual choir.

Credit: Bartosz Madejski.

To the point: Cara Doran and Marie Claire Breen provide a demonstration of a Breath Cycle exercise.

Credit: Bartosz Madejski.

If music be the food of love...

Many of our supporters have written and recorded songs to raise money and awareness for the Cystic Fibrosis Trust.

Two of these, 'Breathe With Me' by Sussex singer annaJo, who has cystic fibrosis (www.breathewithme.info), and 'These are our Days' performed by St Aidan's CE High School, Harrogate, in memory of former St Aidan's pupil Helen Hawcroft, are available to buy via iTunes among other platforms.

Read more about these and some of our other great supporter-led fundraising ideas at cysticfibrosis.org.uk/supporterinitiatives.

Getting active

Manchester Marvel Ryan Williams ran a 10k run dressed as Captain America, for his two-year-old "hero".

The 36-year-old communications manager from Glossop, Derbyshire, entered the Great Manchester Run for the Cystic Fibrosis Trust as a thank you for the support it has given to his son Cadellin, who was diagnosed with cystic fibrosis at two weeks old.

The Captain America outfit, Ryan says, was "a conspiracy between Cadellin, and my four-year-old daughter Anwen! She asked me about the Marvel superhero because they were talking about the movie on TV. I told her that he was a brave person who protected people and she said, 'Perhaps he could help us to look after Cadellin'."

The event itself was emotional and rewarding for everyone. Ryan says: "My dad had travelled with me, to help me prepare and as some much-needed moral support. It kind of squared the circle: me doing this for my son, and my dad being there for me."

As the kilometres ticked by and the sun blazed, Ryan found himself buoyed by the fantastic spectators. He says: "The crowd came into their own. Around every corner there was someone shouting, 'Well done Captain, you can do it'. It's hard to explain just how helpful that support can be. Plus I had the lingering thought that somewhere around the course my dad was lurking with a camera, and I just couldn't let him catch me walking!"

Ryan crossed the line in an impressive 61 minutes, although as he says: "The big hug I got from Cadellin reminded me that it wouldn't have mattered if I had taken a week. He was proud of me, just like I am of him."

A superhero and his proud dad: Four-year-old Cadellin inspired Ryan to take on the Great Manchester Run.

Be inspired by Ryan and Cadellin, and take on a challenge to raise money for the Trust – visit cysticfibrosis.org.uk/events.

Don't forget you can find highlights of the latest news and read comments on our facebook page. Like our page and stay connected with the Trust at facebook.com/cftrust.

cysticfibrosis.org.uk/legacy

Cystic Fibrosis counting on your support

"You support us, so let us help you with a Free Wills offer."

– Michael Clark,
Legacy & In-memory Manager

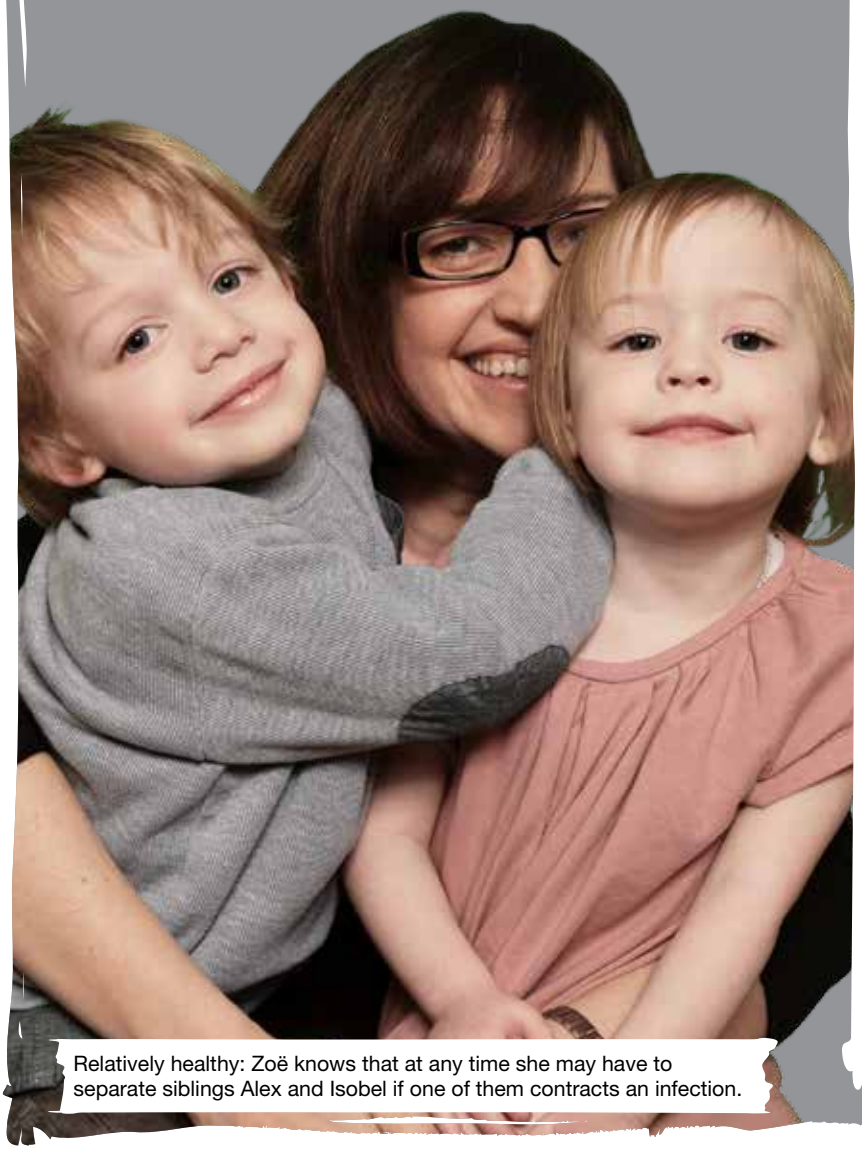
"Over 10% of our income comes from gifts in wills. Leaving a gift to us in your will, when you've taken care of your loved ones, is a great way to join the fight against cystic fibrosis and leave a lasting legacy for future generations.

"Our Free Will offer provides a convenient way for you to write or update your will, and we hope you may choose to include a gift to us."

For a free information pack, contact Michael Clark before the end of September.
020 8290 8051
legacies@cysticfibrosis.org.uk

Getting strategic about research

People with some serious conditions are often united by the shared experience of dealing with their condition. However, for those with cystic fibrosis, their condition is the very thing that keeps them apart.



Relatively healthy: Zoë knows that at any time she may have to separate siblings Alex and Isobel if one of them contracts an infection.

Fear of the dangers of cross-infection means that even children from the same family will sometimes have to live separate lives. Alex and Isobel Elliott, four-year-old twins from Nottingham are normally inseparable – until the moment that one of them develops a chest bug.

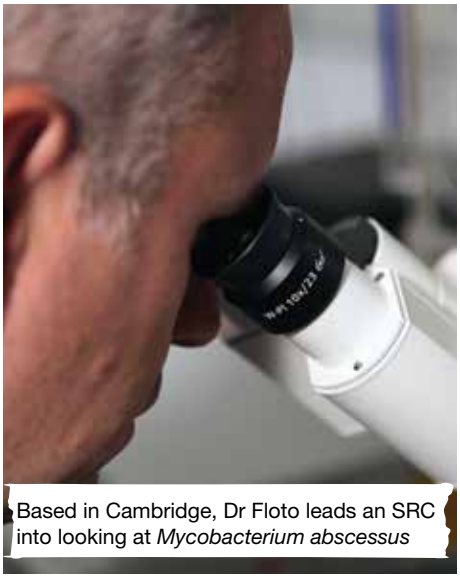
"I have to separate them because the risk of cross-infection is too great. I tell myself it is for the best, but I can't help feeling that I am neglecting the other twin," says their mother, Zoë. "It's something they have to accept. However, once the novelty of being apart has worn off, they pine for each other. No doubt it will only get more difficult the older they get."

A new project is now underway that could lead to earlier diagnosis and treatment for one of the bugs that poses such a problem for Zoë and her children, courtesy of a new initiative funded by the Cystic Fibrosis Trust. This year the Trust set up the first three in a new network of strategic research centres (SRCs) – collaborations between research groups at different institutions in Britain and abroad. Each of the groups will receive funding worth around £750,000 over three to four years, to work on new ideas for improving the diagnosis and treatment of cystic fibrosis. ▸

In its five-year research strategy, published in April 2013, the Trust committed to set up two SRCs in 2013–14, but subsequently added a third because of the extremely high quality of the applications received.

"The programme was made possible by our fantastic supporters – the money they've raised in recent years meant we could fund a third SRC," said the Trust's Chief Executive Ed Owen.

"The idea is to create consortia of scientists focused on using their science to find solutions for conditions in people with cystic fibrosis," explains Dr Janet Allen, Director of Research at the Trust. "The consortia must be led from the UK but must pull together the best team of scientists wherever those scientists are found. So for the first time, we will fund experts overseas and we are also hoping to expand the pool of talent available to tackle conditions associated with cystic fibrosis by encouraging people to contribute who would not normally think of themselves as CF researchers – people in non-medical disciplines such as organic chemistry, who can potentially make an important contribution to our work."



Based in Cambridge, Dr Floto leads an SRC into looking at *Mycobacterium abscessus*

Professor Jane Davies

Based at Imperial College, London, Professor Jane Davies will lead one of these first three groups, a multidisciplinary team involving scientists from Italy and the Netherlands. They will focus on *Pseudomonas aeruginosa*, the most common bacterial infection linked with lung damage in people with cystic fibrosis, and the very bug that has meant that Zoë has had to isolate her twins over long periods on three separate occasions.

One of the questions they hope to answer is: could there be a better way of detecting this particular bacterium at an earlier stage when it is much easier to treat? Pseudomonas is usually identified by growing in the laboratory any bacteria that may be present in sputum samples brought up during physiotherapy exercise.

But in very young children like Alex and Isobel, getting those samples can be tricky so Jane's team is trying a different approach. They are collecting, concentrating and analysing the minute traces of chemicals found in human breath. Paolo Montuschi from the Catholic University of the Sacred Heart in Rome is a world expert in using sophisticated analytical techniques to examine the condensed breath of people with asthma. He will be passing on his knowledge to the team to help them search for compounds produced by the Pseudomonas bacteria that may serve as a unique chemical fingerprint.

"If there is evidence that Pseudomonas may be down there, we would then be justified in using more invasive techniques like bronchoscopy to look more closely," Professor Davies explains. "There is some suggestion that we could look for the same chemical fingerprints in blood, sweat or urine. That's pushing the boundaries of the science a little at the moment but it is the sort of challenge that a team like ours can take on."

One of the reasons why Pseudomonas is such a difficult bug to get rid of once it has become established in the lung is that the bacteria produce a slimy chemical film that blocks off antibiotics from reaching areas of deep infection. So another project that the team will be taking on is to test chemicals such as nitric oxide, which it is believed may act like detergents in breaking down the film and allow standard antibiotics to reach and destroy the infection.

The team will also be testing non-standard approaches to killing bugs using special viruses called bacteriophages that grow inside the much larger bacteria. Studies in animals suggest that these viruses, which cannot infect more complex organisms, not only destroy the bacteria but will also produce a rapid reduction in the inflammation that is so damaging to the airways of people with cystic fibrosis.

Professor Davies is recruiting a team of postgraduate researchers, including one who will be responsible for ▸

managing a clinical trial of the bacteriophage treatment delivered through a nebuliser in patients with chronic Pseudomonas infections. "The first phase of the trial will just confirm that this is a safe treatment, but we will also be looking at measurements of its effectiveness, seeing what effect it has on lung function, so this is really exciting," she said.

Dr Andres Floto

Another of the SRCs will take a closer look at *Mycobacterium abscessus*, a species of bacteria that is lesser known as a cause of disease in people with cystic fibrosis but is generating increasing concern. Dr Andres Floto of Cambridge University is heading a team that includes scientists based at Colorado State University in the US.

Dr Floto says this emerging bug is a particular problem because it is often highly resistant to normal antibiotics and is easily transmitted from patient to patient, probably because it can survive for a long time in the hospital environment. He and his team have a library of gene sequences from different strains of abscessus and will be looking to find the particular genes responsible for this transmission and severity of the disease. For this they will be working with Mary Jackson in Colorado, who has expertise in the techniques for switching individual genes on and off to examine the effects that has on the bug's behaviour.

Dr Floto's team will also be working on novel antibiotics that could provide new and more effective treatments for this type of bacterial infection. They also hope to devise new methods for stimulating the body's own immune defence to put up a more effective fight against a bug, which he acknowledges is proving "staggeringly difficult" to treat in the 5–15% of people with cystic fibrosis who have been exposed to it.

Dr Michael Gray

While two of the first three SRCs are looking at the consequences of cystic fibrosis in terms of bacterial infections, another is carrying out more basic research into methods to deal with the underlying cellular defect. This team is headed by Dr Michael Gray of the University of Newcastle, who will be organising an international team involving researchers from the US, Germany and Portugal.

While most CF researchers around the world are focusing on the cystic fibrosis transmembrane conductance regulator (CFTR) protein that regulates the movement of chloride in and out of the cell, Dr Gray's team is taking a different approach. CFTR is essentially a door or channel that lets in specific chemical molecules, such as chloride, a component of salt. Dr Gray and his team are looking at alternative channels, and believe that one of these minor thoroughfares can be opened up by medical treatments so they can take on a bigger role in regulating this chemical traffic.

He says the fluid on the lung surface in people with cystic fibrosis is unusually acidic and by adjusting that chemical imbalance, they will not only improve that person's lung function, but they will also be less vulnerable to the sort of bacterial infections that the other two SRCs are trying to combat.

Dr Allen says that creating these multinational, multidisciplinary teams to help battle cystic fibrosis is an ongoing project and applications are coming in from other groups with fresh ideas for overcoming the scientific and practical challenges posed by the condition. "We will be picking out the best of these and hope to announce one or two new SRCs at the beginning of next year."

For Zoë, the twins, and thousands like them, the importance of groundbreaking research like that carried out by these SRCs, is all too apparent. Zoë says: "Recently I got the news that every parent dreads, that both Alex and Isobel have 'grown' something in their airways that needs immediate treatment. Fortunately they've grown it at the same time, which means I don't have to separate them; however it's another stark reminder that my children live with a life-limiting condition."

Find out more about the Trust's research strategy at cysticfibrosis.org.uk/researchstrategy.

Read more on SRCs and watch videos with Professor Davies, Dr Floto and Dr Gray at cysticfibrosis.org.uk/src.

Day in the life

For 23-year-old Zanib Nasim, who attends the cystic fibrosis unit in Wythenshawe, living with her condition provided the inspiration to study for a pharmacy degree at Manchester University.

Zanib is determined not to let cystic fibrosis keep her from her life-long dream, even if balancing her daily treatment regime and a full university schedule can be a challenge itself.

"I was diagnosed with cystic fibrosis when I was around two or three months old. I have always been in and out of hospital throughout my life, and meeting different people in hospital actually inspired me into my career path. Since I was very young I have always wanted to pursue a career in pharmacy. I think cystic fibrosis played a big role in my choice as I wanted to make a change to cystic fibrosis treatments. I knew from the beginning this would be a challenge but with some determination nothing can be impossible.

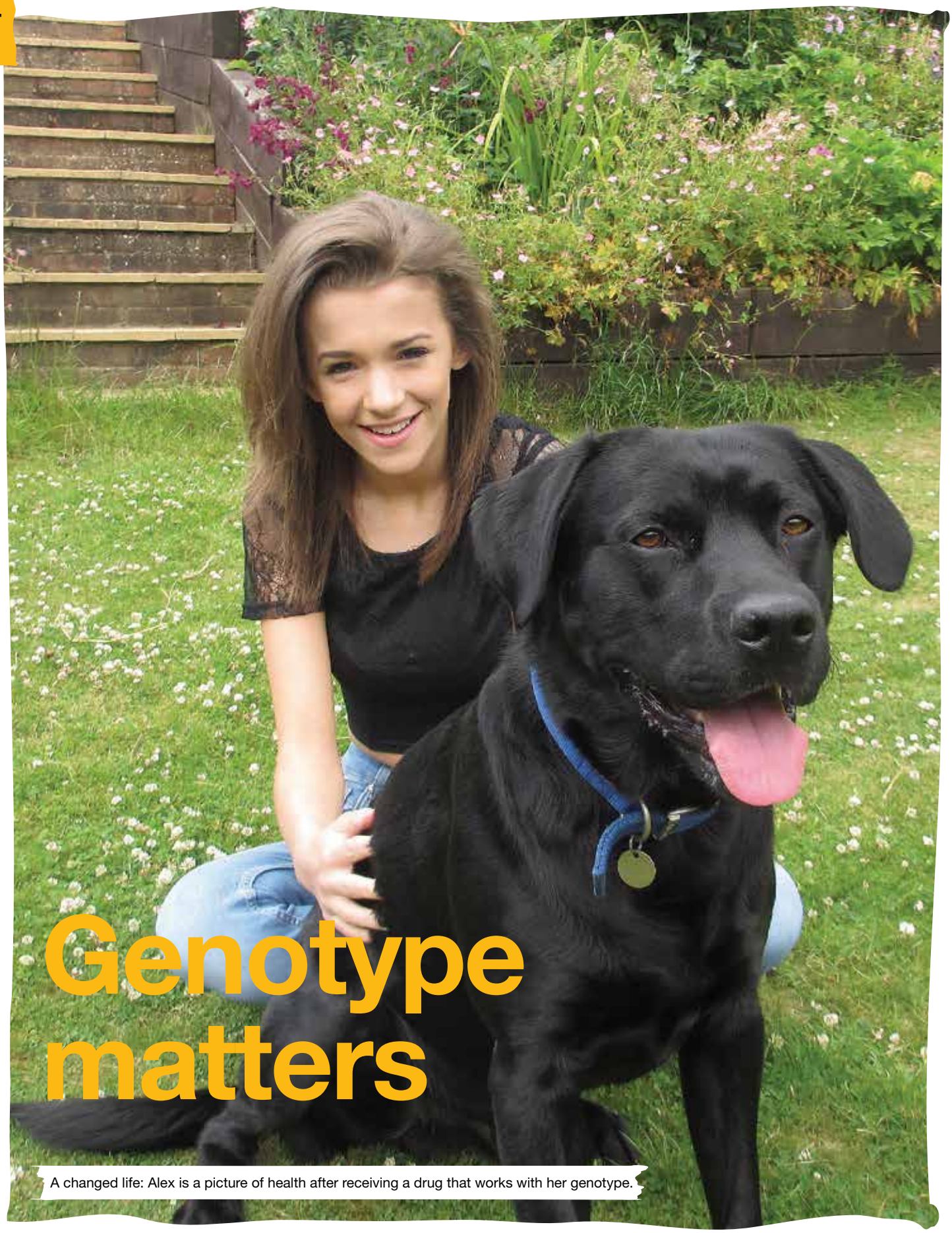
So, my normal day consists of waking up in the morning and doing my treatments, then a full day at university which can vary but normally is 9am to 4 or 5pm. This consists of having lectures and practicals, and after a long day I am pretty exhausted as you can imagine. After the university day, I normally would rest and try juggling my physio routine with some work.

During university, I have found it difficult keeping up with treatment due to having such a busy schedule. I do try my best, although at times things don't really go to plan – I just try to take one day at a time and do my best for the day.

I have had to show some determination and motivation to get where I am. It wasn't easy but I wouldn't say it was impossible. I just think to myself, 'if others can do it then why can't I?' There is nothing impossible if you really put your mind to it. It's been difficult at times coping with cystic fibrosis and university but I have managed to complete my third year of my pharmacy degree. I am very lucky to actually have got so far – although I have managed, it has been difficult, with many hospital admissions throughout my school, college and university life and many courses of oral antibiotics. I think at times I am very stubborn when I'm not feeling well, which isn't a great thing. I guess no one likes to admit feeling ill but everyone does get unwell once in a while.

I've had amazing support from my parents who have always been there for me, I don't think I could have got where I am without their support and help. Even though I am an adult now I still do have my mum telling me to do my treatments, which does sound weird. I think she's been the key to my motivation and has helped me through a lot. And not to forget the CF team who've helped me with balancing my time; they've always tried to help me work out different routines to help me fit my treatment into my busy days at university.

I just think nothing is impossible and if you put your mind to it you can achieve your dreams."



Genotype matters

A changed life: Alex is a picture of health after receiving a drug that works with her genotype.

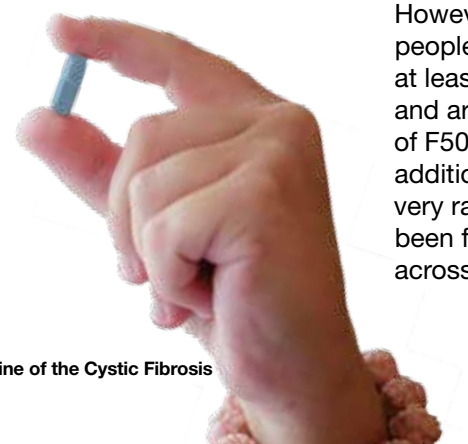
It is only Alex who takes the little blue pills twice a day but her whole family feels the benefits.

"Our whole family life has been transformed": Alex (left) pictured with her older sister.

The 14-year-old Hampshire schoolgirl's life was changed beyond recognition when she began taking ivacaftor (brand name Kalydeco) for her cystic fibrosis in 2010. Before being accepted on to a clinical trial for the new drug, she was a tired-looking, withdrawn child. Now she has grown into a tall, energetic teenager who, as her father David says, "looks a picture of health".

There have also been a few changes for David, his wife and Alex's older sister. "Our whole family life has been transformed," he says. "We are no longer having to endure long protracted treatments in the morning and evening, no more night-time coughing, no more painful intravenous antibiotic treatment. Alex's digestive system is now completely normal as well. Now she can come and go as she pleases, and stay over with friends without worry."

Alex may be considered fortunate in that her cystic fibrosis is caused by G551D, the particular mutation that ivacaftor was developed to treat. But although that defect is only found in around four per cent of the total cystic fibrosis population, it has now been shown that the drug is equally effective in eliminating signs of the disease in eight other very rare CF mutations (non-G551D gating).



Vertex, the American pharmaceutical company that developed ivacaftor, has been authorised by the US authorities to market the drug for the treatment of each of those eight groups of CF patients. It has also applied to the European Medicines Agency (EMA) for a license to launch the drug in the European Union for the same conditions and a decision is expected reasonably soon.

But what about all the other people in the UK with cystic fibrosis who have a different genetic mutation?

Dr Janet Allen, Director of Research at the Cystic Fibrosis Trust, says that over 1,400 different mutations have been recorded worldwide in the gene responsible for CFTR protein, the structure on the cell surface that is the underlying cause of cystic fibrosis. However, in the UK, the majority of people with cystic fibrosis possess at least one copy of F508del and around half have two copies of F508del. So many of these additional reported mutations are very rare and they have only ever been found in one or two people across the globe.

In the UK, all newborn children are tested for cystic fibrosis through the standard heel prick test. The test now routinely includes a genetic test for 30, or at some NHS testing centres 50, of the commonest mutations and this panel of tests will identify the vast majority of cystic fibrosis cases. Interestingly, half of the additional rare gating mutations that ivacaftor could potentially treat (if it receives EMA approval and goes on to be licensed in England, Scotland, Wales and Northern Ireland) are so rare that they are not included, even in the larger panel.

Normally, if a disease affects a very small population, pharmaceutical companies are unlikely to begin developing a drug as the potential market will be too small to justify the costs. But as the ivacaftor story shows, a medicine created for one mutation may work in several others.

Moreover, now that it has been shown that a single drug can effectively treat cystic fibrosis, research teams around the world are looking for different compounds, which could be used in other groups of patients. ▸

So the future treatment strategy for cystic fibrosis and many other conditions will increasingly be determined by the patient's individual genetic code. "We are now entering the age of personalised medicine," Dr Allen says.

When the Trust first looked at the register, it was found that there were some 1,249 entries with question marks against one or both versions of the CFTR gene. In some cases further research filled in these blanks, leaving only around 900 patients whose mutation is unknown.

In the past, once a clinical diagnosis of cystic fibrosis was made, the exact details of genotype did not influence treatment. "At the time, it probably didn't matter that there was a question mark in the genotype column of their medical records, as it wasn't thought it could affect their treatment. But now that information could be crucial". says Dr Allen. As we move forward, it will become more and more important for people with cystic fibrosis to understand their genotype better as it will influence their response to treatments. These types of treatments are known as personalised medicines.

For those where the genotype has not been identified a more detailed genetic test is required. As it costs around £600 to carry out the full genetic analysis needed to identify the specific mutation in each patient, the Trust cannot afford to fill in those gaps in the database on its own. But Vertex provided sponsorship to conduct those tests on an initial group of 210 people and it is hoped that that funds will be found to test some or all of the remaining 690 or so patients whose genotype is unknown.

The results of the tests on the first group are being analysed and will be presented at the Trust's brand new UK CF Conference in Manchester in September (see page 10). However, Dr Allen points out that the study has already thrown up some very interesting findings, including some previously unknown mutations.

> The future treatment strategy for cystic fibrosis will increasingly be determined by the patient's individual genetic code.

As the CFTR gene was only discovered as recently as 1989, it is no mean achievement to have come so far in discovering how it works and what happens when it doesn't work correctly – and to have built up such a comprehensive register of what exactly is causing the problem in the vast majority of people with cystic fibrosis in the UK. But alongside this increased understanding, there is a growing awareness that cystic fibrosis is a much more complicated disease than anyone would have imagined: not all people with the condition have a mutation that shows up in the currently available genetic tests.

Nonetheless the Trust is determined that people with cystic fibrosis will have the opportunity to find out their specific mutation, as far as possible with current tests. So the Trust will campaign to ensure that there is the funding available to run a complete analysis that will identify the specific mutation for every person in the UK born with this dreadful, but potentially beatable, condition.

"If you are a person with cystic fibrosis, it now becomes important to know your genotype even if it is one of the very rare ones," Dr Allen says. "That is because a drug that may be available on the market for another genotype could potentially be of value to you. So we not only feel it is vital for every person with cystic fibrosis with an unknown genotype to have the necessary tests, we believe that it is their fundamental right."

The dawn of a new era

Since the discovery of the cystic fibrosis gene in 1989, a treatment that could target this basic genetic defect has been the holy grail of cystic fibrosis research. In recent years, this dream has started to become reality. Ivacaftor (Kalydeco) was the breakthrough, having a transformational impact on people with the G551D mutation, around four per cent of the UK CF population.

Now we see the potential for Kalydeco widening to include a small number of people with very rare non-G551D gating mutations (around 30 people in the UK and 250 Europe-wide). In addition, the recent release of the Phase III data for the combination of lumacaftor and ivacaftor for people with two copies of F508del provides hope that additional treatments may become available for people with mutations that are not gating mutations.

It is important to understand that ivacaftor is not a cure for cystic fibrosis, and it may still be a while before those who could stand to benefit can access the drugs.

However, these studies reinforce that modulation of CFTR is possible with drugs. The age of one-size-fits-all treatment for people with cystic fibrosis is coming to an end. We are at the dawn of a new era, one where every person with cystic fibrosis will have a personal treatment plan tailored to their specific genetic requirements.

Professor Stuart Elborn, CBE
Queen's University, Belfast

Out in the community

Setting up a challenge and asking strangers for sponsorship can be daunting, but imagine what it's like for an 11-year-old with Asperger's syndrome.

When Rueben Gilchrist from Milton of Campsie took part in the Tenner Challenge – to earn as much as possible from £10 – he devised a 12-mile sponsored walk in memory of his uncle Ryan, who died from cystic fibrosis aged just 21.

Rueben's mother Naomi couldn't have been more proud: "Rueben came home and told me his idea was to use his money to buy a pair of walking boots and do a sponsored walk for cystic fibrosis," she says. "That was a very emotional talk!"

First they set up a Facebook page (where Rueben now has almost 200 followers) and a Virgin Money Giving account, and then put sponsor sheets and collecting tins in local businesses.

Naomi explains that Rueben's Asperger's was always an issue: "His routine was very disrupted. Routine is very much a part of life that Rueben needs. Talking and approaching people was another difficulty, but with the chemist and so on, I would let them know he was coming to ask them to have a sponsor sheet in their shops. Rueben and I would discuss what he would say. He did so well!"

If Rueben struggled, the great public response and the memory of his uncle spurred him on. "There were lots of times when Rueben felt the pressure of what he was doing – he's very much a perfectionist and was worried about letting people down," Naomi says. "But all the amazing comments that people left on his Facebook page gave him a massive confidence boost."

"When we finished he said: 'I did it, I did it for you Ryan' - there were lots and lots of tears."

Reuben says: "I found the whole experience quite hard for lots of different reasons but I just reminded myself that Ryan would have been so proud of me if he was here and that he took every step of my walk with me, in my heart."

Rueben, Naomi and uncle Anthony did the walk in March, shortly before the fifth anniversary of Ryan's passing. Naomi says: "Rueben loved the walk and to be perfectly honest was still running circles around both Anthony and I at the end! When we finished he said: 'I did it, I did it for you Ryan' - there were lots and lots of tears."

Rueben raised over £1,500 from his trek, and won prizes for the most money raised and as the most inspiring individual. June Ross, the Trust's Regional Fundraising Manager for Scotland, said: "Rueben is such an inspirational young person and I would like to thank him, his family and friends who supported him. I can't wait to hear what he plans to do next."

Rueben and his mum have now decided to do something each year to raise more money and awareness for the Trust, and are even considering the Munros mountains!

Challenging steps: Rueben found it hard to approach people for sponsorship.

Local hero: Rueben made the headlines with his amazing fundraising effort.

Two-point perspective

The miracle of birth: Emma underwent six attempts at intrauterine insemination (IUI) before becoming pregnant.

Emma Harris describes the challenges of getting pregnant, while opposite Dr Frank Edenborough provides an expert comment on fertility.

"As my husband and I sat staring at the pregnancy test stick, I suddenly looked a little closer. Over the last 11 years I had lost count of the number of tests I had taken, always with the same result – negative. Was it my imagination or was this one different? Was that a faint pink line I could see appearing? Was it possible that I was… yes, actually pregnant?!

The memory of that morning is etched clearly in my mind. It was two weeks after our sixth attempt at undergoing a fertility procedure called intrauterine insemination (IUI) and I was already certain we had yet another failure. What was supposed to be the most simple, natural thing in the world – conception – had become the most impossible feat. Even now, five years on and with my beautiful son by my side, I still pinch myself and wonder at the fact that something so simple for others, actually happened to me.

During the previous years, I had searched the internet at length for information for women with cystic fibrosis on fertility, pregnancy and parenthood, with little result.

I also struggled to find others to talk to who were going through these issues. While expecting my son, I met my fellow CF patient, Alison Smith (pictured below, with her daughter), online and we became good friends.

Alison had also battled infertility and was also pregnant following IVF treatment. After discussing the lack of resources for women like us we thought "why not create our own?"

Four years on, www.CFmothers.com has a membership of 550 women from 16 countries worldwide. The website provides information on everything from decisions about parenthood, genetic testing and pregnancy, to adoption, surrogacy and parenting with cystic fibrosis. Our members chat constantly through the website's Facebook group, and deep and lasting friendships are formed.

Fertility is one of our hottest topics of discussion. Last year I researched the experiences of 160 CF mothers in the group. The results showed that whilst 44% had experienced normal fertility levels (where conception occurred within 12 months), 22% had experienced sub-fertility (taking longer than normal to conceive) and 34% had required fertility treatment.

Over the last three years I have really enjoyed being able to work with researchers on other issues, too, such as the impact of motherhood on cystic fibrosis and the effect on fertility that the drug ivacaftor

"It's great to feel that I can help to build up research and awareness that was so lacking."

appears to have for some women. It's great to feel that I can help to build up research and awareness that was so lacking until recent years.

My road to becoming a parent may have been long and difficult, but it was more than worth it in the end. Every day, I feel so incredibly lucky that I finally became a mummy. The workload is huge and managing it alongside cystic fibrosis often takes every ounce of energy I have, but the rewards are indescribable. As I hold my little boy in my arms and hear him laugh I know that I'll spend my whole life fighting for him and loving him with all my heart."

If you would like to be involved in developing the Trust's new resource on fertility issues, please email Patrick Stoakes, Interim Head of Information & Support, at patrick.stoakes@cysticfibrosis.org.uk.

Expert comment

Dr Frank Edenborough
Consultant Respiratory Physician
Sheffield Adult CF Centre
Northern General Hospital

Heart-warming stories such as this are becoming more common as women with cystic fibrosis are living longer and enter adulthood fitter and stronger. Up to 70% are thought to be able to conceive naturally. However, cystic fibrosis can affect female fertility in several ways.

Poorly women with cystic fibrosis can have anovulatory cycles (no eggs produced) or no periods at all and will be unlikely to conceive.

Sometimes healthy women with cystic fibrosis still struggle and the most common reason for this is probably sticky mucus blocking the entrance to the womb – a problem that can be overcome by intrauterine insemination (IUI), as in Emma's case. Artificial reproductive techniques include not just IUI but the more commonly used in-vitro fertilisation (IVF), which can help with problems other than just the mucus plug. The success of both techniques can be increased by hormones to increase egg production during one period cycle before harvesting the eggs.

The commonly used cystic fibrosis drugs are generally safe in pregnancy. It is much more harmful to the baby if the mother becomes unwell during the pregnancy so taking all the usual treatment is important. It is common for more treatment to be required including IV antibiotics to keep mum healthy. Sometimes the baby has to be induced early to protect the mum's health. The most important cause of premature birth (before 37 weeks), which is the biggest single risk to the baby's health, is a decline in the mother's lung function.

Pregnancy after transplantation is possible but there are risks to the transplanted lungs, the mother's health and increased risks to the baby.

Being a parent is fantastically fulfilling, but all women should consider pregnancy carefully, and discuss it openly with their CF teams. As Emma reports, it requires careful planning, the pregnancy can be hard work and looking after a baby has to be balanced with ongoing care for the mum's cystic fibrosis. The CF teams can help in tailoring treatment and exercise regimes and the mum's family should be encouraged to help provide time for treatment and rest. And I cannot describe the reward better than Emma does!

Amanda Chalmers (@PurpleChalmers) tweets about her marathon effort: "Made it into @runnersworlduk 4 my @BrightonMarathn escapades! @CFAware @cftrust #cf #lung-transplant #aliveandliving pic.twitter.com/p9rmXoriFF." **You can follow us on Twitter @cftrust.**

Just ask

Deborah Lynott joined the Cystic Fibrosis Trust as a Helpline Volunteer in February, and is looking forward to putting her personal experience of cystic fibrosis to good use. Deborah had two children with cystic fibrosis, Robbie and Marissa, both of whom sadly passed away in 2009, aged 21 and 15 respectively.

What made you want to volunteer?

When my children died, I took time out, finding who Deborah was. After a while, I wanted to be part of something again.

Cystic fibrosis has always been close to me because of my children, and seeing what the young people go through in particular.

Seeing my children dealing with diabetes was also a turning point for me. I've lived with the condition for a long time, I feel privileged to offer that experience.

How are you finding volunteering with the Helpline?

It's brilliant, it really is. It's quite a journey from where I live to the office in Bromley, but I feel very rewarded when I finish each shift, knowing I've made a difference. It's funny to watch how things change – treatments and life with cystic fibrosis. I feel I have a great insight through my children, especially things like the importance of adherence to physiotherapy. You may think you can skip a session and make it up by doing extra later, but it doesn't work like that!

What have you been working on so far?

I've been helping out with a lot of administration, survey work, and listening in on some of the calls, so that I can spend time on the phones. It's been really interesting, I'm learning all the time.

I was a bit scared at the thought of answering calls, because it's still upsetting knowing that someone could be passing away or dealing with the shock of a first diagnosis. But I'm more confident now.

What's it like being part of the Trust?

I really like being part of the team. Everyone in the office has been really nice and friendly, everyone says "hello".

It's interesting to see this side of it. When I used to call up, as a mother of two children with cystic fibrosis, and ask for a factsheet or something like that, I used to imagine one person in a tiny office, but it's an amazing place. I sit near the Policy and Communications teams, so I get to hear them on the phone – they are so professional and straightforward.

On the day I'm in we have a 'Flash Meeting' where everyone gets together in the office or down the phone, to catch up on important things going on in the Trust.

It's amazing to see how everything works, and to see what's happening in research and care and all these things. I'm sure that the people who call in appreciate everything that's being done.

If you need help, support or just a friendly person to chat to, call or email our confidential Helpline.
0300 373 1000
helpline@cysticfibrosis.org.uk*
Monday to Friday, 9am–5pm

***We will respond to emails within three working days.**

cysticfibrosis.org.uk/volunteer

Cystic Fibrosis worth a minute of your time

"Volunteering can make a huge difference."

– James Atkins, Volunteer & Development Manager

The Cystic Fibrosis Trust relies on the kind support of volunteers in every aspect of what we do. Whether you are looking for events, office, or fundraising experience, we have a place for you.

For more information about volunteering, contact James Atkins 020 8290 8062; volunteering@cysticfibrosis.org.uk, or visit cysticfibrosis.org.uk/volunteer.

cysticfibrosis.org.uk/nycm

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Get to the Big Apple for free! Run for Team CF for a unique experience in the city that never sleeps!

TCS New York City Marathon
Sunday 2 November 2014

To enter contact the Cystic Fibrosis Trust
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