Issue 2: Winter 2013/14

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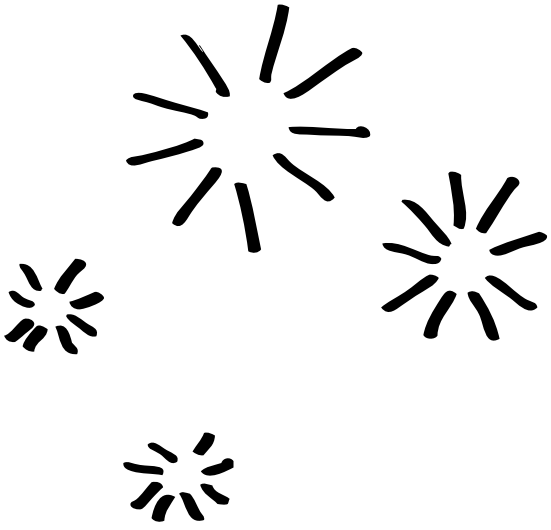
The magazine of the Cystic Fibrosis Trust

Marking the Trust's 50th

Tackling adherence to transform lives

Trials or tribulations?


Cystic
Fibrosis
no party



We won’t celebrate being 50 until everyone can

The Cystic Fibrosis Trust is 50 years old. But we’re not about to throw a party.

Although we’ve achieved a lot in our first 50 years, we haven’t yet achieved our ultimate goal. We haven’t yet beaten cystic fibrosis – completely beaten it – once and for all.

So instead of partying, we’re working harder than ever. Working for the day when everyone with cystic fibrosis can receive the treatments that will transform their daily experience. When everyone can live a long and healthy life in spite of their condition. When everyone can celebrate their 50th birthday – and look forward with confidence to celebrating many, many more.

That’s our goal. When we reach it – and with your support we will reach it – the Cystic Fibrosis Trust will no longer be needed. And that’s the day we’ll finally be ready to throw a party.

Blow up your No Party balloon at cysticfibrosis.org.uk/no-party

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Welcome

Welcome to the first issue of is magazine in our 50th year (and also my first as editor!). The chances are you have been involved with the Trust and its work at some point. So thank you, on behalf of the Trust, for all your support and encouragement during our first 50 years.

As you will read on pages 12–14, our 50th anniversary is not a time to celebrate, not when many people with the condition still don't live to see their 40th birthday.

Instead, we are redoubling our efforts to create a future where we have beaten cystic fibrosis and everyone with the condition can expect a long and healthy life. That future starts here and by joining our 50th anniversary campaign, you can be part of this watershed moment.

In this issue you will also see how technology is changing the way young people engage with their treatments (pages 16–18), and read about the exciting state of cystic fibrosis research today, and the importance of clinical trials.

Together we can make 2014 the year the game changed.

Henry Fogarty
Editor

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FRSB give with confidence

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50 ways to say thank you for 50 years

Fifty 'thank you' awards are being launched by the Trust this year to mark 50 years of hard work and dedication from people from all areas of the cystic fibrosis community.

Categories for consideration include health professionals, researchers, fundraisers, volunteers and ambassadors who have helped raise awareness of cystic fibrosis issues and the Trust. There will also be recognition for special achievements – those who have dedicated their life to helping people with cystic fibrosis, or who have achieved something remarkable.

"Everything the Trust has achieved has been as a result of talented, selfless people throughout the UK and beyond, who are willing to go above and beyond to support the Trust and make a difference," said its Chief Executive Ed Owen. "This year we wanted to say thank you to those who have given and continue to give their support."

The Trust is inviting the whole cystic fibrosis community to get involved by nominating the person or people who they feel deserve recognition. A panel of judges featuring members of the Trust and the wider community will decide who wins the awards, which will be handed out at various Trust events during the year.

Visit cysticfibrosis.org.uk/50awards for more information on the nomination process and criteria.

Interim cross-infection guidelines to combat superbug

A working group brought together by the Cystic Fibrosis Trust and including healthcare professionals and experts on microbiology and cross-infection has released new advice to help protect people with cystic fibrosis from catching infection with *M. abscessus.*

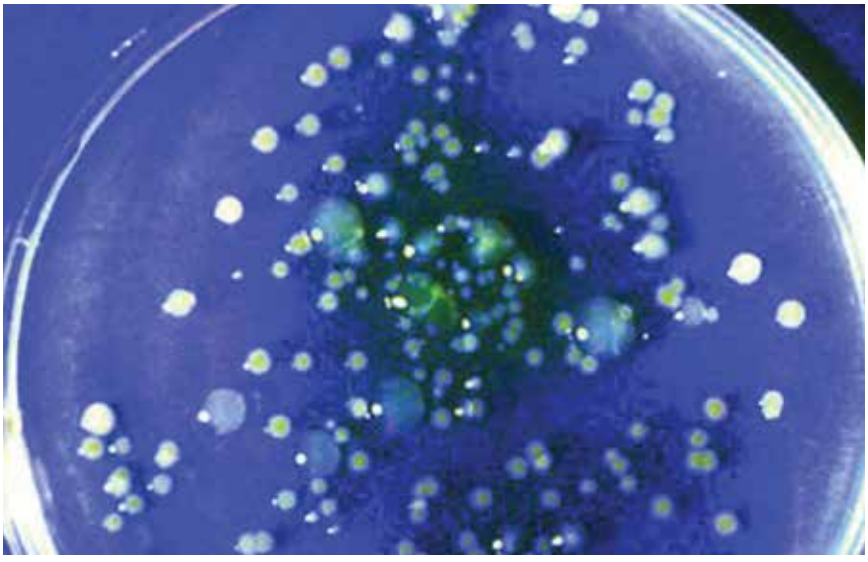
The group was set up in the wake of a report in the Lancet in 2013, that revealed evidence from a group of academic physicians at Papworth Hospital that *M. abscessus* could transfer between people with cystic fibrosis in spite of existing cross-infection policies.

The group's new recommendations include: all centres should have a local cross-infection policy specific to *M. abscessus* that addresses issues of monitoring and cleanliness; people with cystic fibrosis, their carers and hospital staff should have hygiene measures explained and be kept informed of their infection status; and surveillance of infection should be performed at regular intervals, with appropriate measures put in place if a person tests positive for *M. abscessus.*

Dr Andrew Jones, Consultant Respiratory Physician at University Hospital South Manchester, who chairs the group, said: "Infection control continues to be a major issue for cystic fibrosis care. Following a consultation, new interim national guidelines have been developed to protect patients from the risk of cross-infection to transmissible bacterial infections such as *M. abscessus.*"

People with cystic fibrosis who have concerns about this issue should speak to their clinician.

You can find more on cross-infection and the interim guidelines at cysticfibrosis.org.uk/crossinfection.



1,000 Cranes:
By Oliver Knott, the video is based on a Japanese belief that if you fold 1,000 cranes in one year then a wish will be granted. http://bit.ly/Cranes1000

Improving the rate of successful transplantation

The Trust is shortly to release a report based on the findings of the open consultation launched in 2013 to address the severe shortfall in successful lung transplants being carried out for people with cystic fibrosis.

While transplantation serves small numbers, it is crucial for those that need it. There are nearly 80 people with cystic fibrosis waiting for a lung transplant in the UK, and this is likely to increase as survival rates for those with the condition improve.

The wait can be agonisingly long and one in three people with cystic fibrosis on the lung transplant list dies before they can receive one.

The Trust launched its consultation after identifying issues that are preventing people with cystic fibrosis from getting a lung transplant, guided by patients who came forward to share their experience.

Jessica Jones, Policy Adviser at the Trust, said: "We wanted the consultation to fundamentally explore the issues that are creating these problems and we have brought together experts in cystic fibrosis and transplantation to design meaningful ways of addressing these challenges. The real work is just beginning and we hope our report will make a significant positive impact."

The report will be released in late February, followed by a campaign to make sure its recommendations are taken on board by policy makers.

News in brief

New partnership to test treatment for lung function

The Cystic Fibrosis Trust has partnered with NovaBiotics Ltd and Health Sciences Scotland to develop Lynovex® as a treatment for persistent lung infection in cystic fibrosis.

The drug is already a recognised treatment for a non CF-related condition.

Dr Janet Allen, Director of Research at the Trust, highlighted how this partnership illustrates the Trust's emphasis on collaboration with industry, as detailed in the research strategy launched in 2013: "Working collaboratively with academics and industry increases our capacity to support transformational research projects. This work forms part of our five-year strategy which aims to see the Trust engage closely with partners in research and industry."

Campaigning hard for equal access to vital medicines

In the past few months the Trust has been lobbying decision makers in Scotland and Wales to ensure that vital medicines for people with rare conditions such as cystic fibrosis are appraised fairly when assessing their value.

In October the Scottish government gave cause for hope when it asked the Scottish Medicines Consortium to find and apply different approaches to evaluating drugs for small populations, in order to increase access. The Trust is calling for any new system to take into account quality of life benefits and allow for a lack of available research data.

A Task and Finish Group has been set up to review the appraisal system, and CF specialist Dr Gordon MacGregor has been invited to join. The aim is to implement the findings of the review by spring.

Ed Owen welcomed this move by the Scottish Health Minister: "The Cystic Fibrosis Trust has been lobbying the government to ensure that concerns regarding the existing arrangements for appraising new medicines were heard."

"The Kalydeco issue laid bare the need for change, and we are encouraged that the government has responded to the concerns raised by us and other medical charities and patient groups."

In Wales the Trust urged supporters to write to their local Assembly Member to petition the Minister for Health & Social Services, Mark Drakeford AM, pressing for the recognition of the holistic benefits of medications for rarer conditions in the Welsh Assembly's review.

‘No Party’ campaign marks Trust’s 50th year

The Cystic Fibrosis Trust is asking all of its supporters to mark its 50th anniversary, not by celebrating, but by joining with it to finally beat cystic fibrosis.

The Trust’s ‘Cystic Fibrosis is No Party’ campaign, which launched in January 2014, is asking everyone within the cystic fibrosis community to blow up a balloon online, and share their experiences of cystic fibrosis and what they are bringing to the ‘No Party’.

“How could we celebrate our 50th anniversary when we know many people with cystic fibrosis are still not living to celebrate their 40th birthday?” said Iain McAndrew, the Trust’s Director of Marketing. “Instead, we want our 50th year to be the moment when the cystic fibrosis community comes together and seizes the moment to beat cystic fibrosis for good.”

“After blowing up a balloon, supporters can choose whether they want to help improve the lives of people with cystic fibrosis by adding their voice to one of our campaigns, or organising their own No Party event, be it a quiz night, coffee morning – or even a No Party party!” added Iain.

Read more about the Trust’s 50th anniversary, see pages 12–14.

To blow up your balloon and read the stories and experiences of other ‘No Party’ goers, visit cysticfibrosis.org.uk/no-party.

George’s ‘grand’ cycling tour

Where others relax on holiday, Trust Chairman George Jenkins set himself the target of riding 1,000 miles over the summer to raise money for the Trust and awareness of cystic fibrosis.

Along the way he raised an incredible £4,500!

George completed his challenge when he crossed the finishing line of the Prudential RideLondon-Surrey 100 on 4 August. George took part in this 100-mile cycle challenge alongside 32 other Trust supporters, including some who had travelled down from Edinburgh to take part.

George was elected as Chairman of the Cystic Fibrosis Trust in July 2012. He is also Deputy Chairman of NHS Blood and Transplant, whose staff selected the Trust as their Charity Partner for the year, and Chairman of Port of Dover and Dover Harbour Board. George was awarded the OBE for services to healthcare in the 2011 Queen's Birthday Honours.

After his last ride, George said: "I am absolutely passionate about the Cystic Fibrosis Trust and the work it does to give people hope now and for the future. I lost my son Adam to cystic fibrosis and I am determined to do all I can for the cause so thank you to everyone who sponsored me. Those Surrey hills were not easy!"

Be inspired by George and take on a fundraising challenge in our 50th year – visit cysticfibrosis.org.uk/events.

George Jenkins OBE, Chairman of the Cystic Fibrosis Trust, cycled 1,000 miles during the summer of 2013 to raise money.

Registry Report reveals majority of people with cystic fibrosis now in work or study

The UK CF Registry Data Report for 2012, released in October 2013, reveals that cystic fibrosis is increasingly moving from a childhood killer to an adult condition.

The new statistics show that the median survival for people with cystic fibrosis in the UK has increased to 43.5 years.

The report also reveals that cystic fibrosis is less of a barrier to normal life, with 70.4% of people with the condition able to work or study, and a significant number considering themselves retired.

The UK CF Registry is one of the most comprehensive data sets on cystic fibrosis in the world, containing details for over 99% of the UK CF population.

Trust Chief Executive Ed Owen welcomed the findings but focused on the future, saying: "The 2012 Registry Report proves that cystic fibrosis is a condition that has benefited from improvements in treatments, standards of care and access to new medicines.

"As we enter our 50th anniversary year in 2014, we will be working even harder, in conjunction with scientists and clinicians, to improve survival rates and quality of life."

For the first time a separate summary document was published alongside the full scientific report.

Read and download both reports at cysticfibrosis.org.uk/registry.

News in brief

Peer reviews put patients in position of power

In the last few months the Trust has undertaken a number of peer reviews of adult and paediatric cystic fibrosis services around the UK.

Jointly organised by the Trust, the British Paediatric Respiratory Society and the British Thoracic Society, peer reviews look at the clinical, psychosocial and business activities relating to the delivery of care.

To make the process more accessible to patients, the Trust now publishes a one-page summary of the review alongside the full report.

Read the peer reviews and summaries online at cysticfibrosis.org.uk/peer.

Coalition of charities to focus on Who Benefits?

In September the Cystic Fibrosis Trust joined a coalition of more than 50 organisations set up to give a voice to the millions of people who have been helped by benefits.

The nationwide campaign aims to change the way we think about people who receive benefits, using real stories to show the reality of who needs help, why they need it and the difference it makes.

The Trust wants to hear from people with stories about how benefits have supported them.
Contact Louise Banks, Senior Communications Manager, (louise.banks@cysticfibrosis.org.uk; 020 8290 7912).

Re-vamped clinical conference looks to new era

September 2013 saw the Cystic Fibrosis Trust's new-look, two-day clinical conference open at the Manchester Conference Centre, under the banner of 'Moving forward together in a new era'.

Day 1 was open to anyone involved in the provision of clinical care at specialist CF centres and clinics across the UK. This multidisciplinary event featured talks and workshops on a wide range of subjects.

At an evening reception at the end of the first day, British high jumper Dalton Grant provided an inspirational talk as guest speaker.

The second day was an invite-only Centre Directors Meeting, aimed at facilitating communication and discussion. It also served as a launching pad for the 2012 UK CF Registry Report.

Opening the conference, Chief Executive Ed Owen spoke of the vital relationship between the Trust and the clinical community, something which has been "hard-wired into what [we] do since our foundation, 50 years ago next year."

Ed also highlighted the need to better engage with the cystic fibrosis community, a "defining part" of the Trust's mission going forwards.

Read the full text of Ed's speech at http://cftrust.blogspot.co.uk.

News in brief

Addressing 'nonsense' mutations

A project led by Professor Smythe, University of Sheffield, is testing a new compound that will help to counteract a group of mutations present in 10% of people with cystic fibrosis.

Class I or 'nonsense' mutations, are detected by a quality control system that stops cells attempting to produce the CFTR protein that is faulty in people with cystic fibrosis.

An oral drug called Ataluren can already compensate for nonsense mutations in vitro but its clinical effect has not been as great as was expected, and it is hoped the compound that Professor Smythe and his team are investigating will enhance the effect of Ataluren.

Find out more at cysticfibrosis.org.uk/smythe.

Campaign success for access to psychology services in Scotland

The Cystic Fibrosis Trust can report some success in its efforts to achieve equal access in Scotland to specialist psychology, after discovering a desperate lack in some regions.

At the end of 2013 the West of Scotland Adult Cystic Fibrosis Unit based in Gartnavel General Hospital gained a specialist clinical psychologist post.

The campaign began after the Trust's psychosocial survey identified a number of areas where a specialist psychologist is badly needed but unavailable due to lack of funding.

Supporters were invited to share stories about when they have either benefited from, or suffered through a lack of, access to psychological support.

Funding increase heralds new era of research and patient involvement

The Trust has followed up the launch of its ambitious research strategy (See 'News', Summer 2013) with two major funding announcements, reflecting its commitment to investing in cutting-edge research and increasing involvement in clinical trials.

In July, Director of Research Janet Allen revealed plans to fund seven projects covering a wide range of cystic fibrosis issues, including cross-infection, emerging superbugs and correcting the basic defect for cystic fibrosis.

Dr Allen commented: "We are delighted to be able to award over half a million pounds to research this year …. [these grants] represent a cross-section of research into cystic fibrosis."

The combined total for the proposed grants represents a 40% increase on the previous year.

In October the Trust invited applications for part-funding for six research coordinators, as part of its strategy to triple the numbers of patients involved in clinical trials over the next five years.

Dr Erika Kennington, Head of Research at the Trust, said: "By placing additional clinical research coordinators into some CF centres, we will be able to reach and recruit more patients for trials, which will strengthen and speed up the recruitment and trial processes."

Read more: The Trust's Patient Engagement Adviser explains the importance of patient involvement in clinical trials – see page 21.

The First Minister, Carwyn Jones seals the Act, overlooked by the Minister for Health & Social Services in Wales.

Wales makes history with transplant opt-out system

In September 2013 the Welsh Assembly became the first UK government to sign into law a system of presumed consent for organ donation.

First Minister Carwyn Jones AM and Mark Drakeford AM, Minister for Health & Social Services, performed the official sealing of the Human Transplantation (Wales) Bill in a ceremony at the Welsh Assembly Government.

Kayleigh Old, the Trust's Public Affairs Officer for Wales, was on hand to witness the historic occasion. The Trust had ongoing engagement during the law-making process, with scrutiny of the Bill, and hopes that this will improve the rate of transplantation for people with cystic fibrosis. Currently one in three people with CF on the waiting list will die before they can receive a lung transplant.

Speaking afterwards, Kayleigh said: "The Cystic Fibrosis Trust has the objective to decrease the number of individuals with cystic fibrosis dying on the transplant list, which is currently 30%. We therefore believe this is a positive move by the Welsh Government; leading to the increased availability of usable lungs and organs for potential successful transplants. We are hopeful the rest of the country will follow suit."

'Pac-Man' vs the superbug

The first of the seven new research projects to start that were funded by the Trust in 2013 is exploring how *Burkholderia cepacia* evades the 'Pac-Man' defence in people with cystic fibrosis, and is seeking to develop a new kind of treatment.

Led by Professor Miguel Valvano, the project looks to establish how cystic fibrosis affects these 'Pac-Man' immune cells (so named because they 'gobble up' bad bacteria) that are infected by the multi-drug resistant bacterium *B. cepacia*, and could lead to more effective treatment for that and other emerging harmful bacteria.

Professor Miguel Valvano is Chair of Microbiology & Infectious Diseases at the Centre for Infection & Immunity, Queen's University Belfast.

Find out more at cysticfibrosis.org.uk/valvano.

EllieVs65Roses:
Ellie, a teenager with cystic fibrosis, has made this video to share her story of living with the condition. http://bit.ly/Ellie65

Marking the Trust's 50th

Keen battle re-enactor: Jonathon Farrow was born in the same year as the Trust, when most people with cystic fibrosis didn't live past five years old.

2014 is the Cystic Fibrosis Trust's 50th year. But rather than celebrating its 50th anniversary, the Trust is using it as a springboard to redouble its efforts to beat cystic fibrosis for good.

A 50th anniversary should be a golden opportunity for people to let their hair down and have a really good time.

But the Trust didn't send out invitations to its friends and supporters for a celebration to mark the five decades that have passed since the charity was formed early in 1964.

Trust Chief Executive Ed Owen and his team like a good celebration as much as anyone but they didn't think that this was the right time. "When many people with cystic fibrosis still don't live to see their 40th birthday, we thought it was wholly inappropriate to be celebrating our 50th," says Ed.

"The next few years will be crucial if the organisation is to complete the task it set out to perform half a century ago – to finally beat cystic fibrosis, that is, to ensure that everyone born with this common inherited condition can enjoy a full, healthy and active life. Our first priority is keep our eyes on the ball – not to go to one."

To this end, the Trust is using its 50th to launch a new campaign – 'Cystic Fibrosis is no party' – to encourage the whole cystic fibrosis community to unite behind this common goal. It is asking people, be they people with cystic fibrosis and their friends and family, clinicians or researchers, to blow up a balloon and share their experience of cystic fibrosis.

But that doesn't mean that Ed's team will be denying themselves the quiet satisfaction of reflecting on the progress made so far.

"It is important that we mark the achievements made," Ed says. "You cannot underestimate what has been done and, of course, we know the Trust has played an important role in that work. If you had talked to

doctors 50 years ago they would have struggled to believe what is possible now. Cystic fibrosis was a condition that caused people to be struck down far too young. Then, few survived to reach double figures, now people can live to 50, 60 years or more and that is extraordinary progress."

This progress has been captured on an interactive timeline on the Trust's website, which was launched at the start of 2014 (see box, page 14). It documents the efforts of medical staff who developed the treatments that have improved both the length and quality of life enjoyed by people born with cystic fibrosis. It also recognises the efforts of those scientists whose fundamental research revolutionised our understanding of what causes the disease and paved the way to these new therapies.

"It also reflects the many families affected by cystic fibrosis who haven't been willing just to accept their lot – they wanted something better," says Ed. It is their commitment, dedication and inspiration that has helped drive forward those changes."

These include people with cystic fibrosis who were dealing with their condition on their own, well before the Trust was formed to help them. They therefore have a clear insight into how life has changed for their community – people like Peter Thaxter aged 63 from Hampshire, Bedfordshire resident Linda Madden, who is 60 years old, and Jonathan Farrow, from Kent, born in the same year as the Trust.

Peter says that the important differences between then and now are the effectiveness of the treatments available and the quality of the information available to patients. "We know so much more about the disease now than when I was a child. So when you go to the medical staff with your problems they seem to have so many more answers." The introduction of specialist CF units at the major regional hospitals has been another huge factor in improving the quality of care. For years Peter would have to travel to the Royal Brompton Hospital in west London for his regular medical checks. But since the unit at Southampton began treating adults as well as children around 12 years ago, expert staff and facilities have been available practically on his doorstep.

One major step forward as far as all three are concerned has been the development of enteric-coated tablets for the pancreatic enzymes they need to take with their food. Previously, this was only available as a powder that had to be sprinkled on to the meal – "It tasted pretty awful," says Peter.

"I tried to keep it to myself and even my friends were often unaware that I had cystic fibrosis."
– Linda Madden

"Yes, it was horrendous," Jonathan recalls. "And it made your food disintegrate in front of your very eyes. But that has had one lasting effect, even now that I take the enzymes as tablets, I still bolt my food down as quickly as I can."

Another disadvantage of the old enzymes for people with cystic fibrosis was that using them drew attention to their condition. Like many young people with a rare condition that is not widely understood by the general public, the trio were self-conscious about having cystic fibrosis and would prefer to undergo treatment away from prying eyes and intrusive questions. "I tried to keep it to myself and even my friends were often unaware that I had cystic fibrosis. If anybody asked why I had a cough, I would say that I'd got bronchitis. It was only when my lungs started to get worse and I had a transplant about 10 years ago that many people knew," Linda says.

"The one thing that I perhaps missed out on was in not going on holidays with my school friends because I didn't want other people to see me taking my medicines. But apart from that I was like any other teenager, always out at pubs, clubs, discos and parties," she adds. All three were probably fortunate in having been born with a mutation that did not cause severe respiratory disease when they were young. But they still had to deal with the effects of the condition on their digestive system, and so they ▸

How you can help

The Cystic Fibrosis Trust has launched a campaign in its 50th year to unite the whole cystic fibrosis community behind a single cause: to beat cystic fibrosis for good.

It wants all of its supporters, including all readers of this magazine, to blow up a balloon – online, that is, so no extra puff required – then add a short note telling your fellow No Party goers why you're committed to beating cystic fibrosis, and what you'll be bringing to the No Party campaign. You'll also be able to discover other people's stories and experiences too.

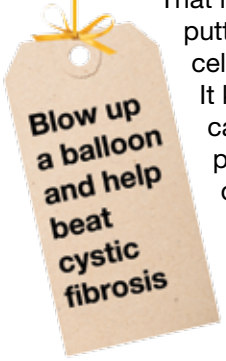
To blow up your balloon today, visit www.cysticfibrosis.org.uk/no-party.

needed the resilience to cope with periods of ill health and the discipline to keep taking their doctors' advice during periods when they felt perfectly well.

Each has been able to enjoy a lengthy and successful career. Peter worked in the computer industry and at the offices of the Forestry Commission until he retired two years ago and he still works part time running a software company. Linda worked in a range of different jobs including managing her own taxi-cab business as well as bringing up her son Stephen, now 31. Meanwhile, Jonathan is manager of two companies: one making scale models of buildings for architects and another providing computer services and IT support.

They have also been healthy enough to enjoy their hobbies: Peter is still able to enjoy long walks with his dogs, Jonathan enjoys archery and martial arts and uses both in the historical re-enactment events that fill his summer weekends. Linda has a lifelong passion for horse riding and later took up athletics at a level that won her medals in the National Transplant Patient Games.

"You do have to be careful in making sure that you take your medicines and do your physiotherapy exercises. That does interfere with your life because it takes so much longer to get out of the house every morning. So you can't ignore the fact that you have cystic fibrosis but you mustn't let it take over your life," says Peter.



"We have achieved some extraordinary things but we can't relax when our ultimate goal – beating cystic fibrosis – is within reach."

Of course, all three grew up at a time when medical staff were less aware of the dangers of cross-infection between people with CF and so they were given the opportunities to mix with other patients. Jonathan hopes that the next few years will see medical advances that eliminate those dangers. "You live with cystic fibrosis half in your body and half in your head. There has been wonderful progress in dealing with the bodily side but people do need contact with others that are just like them. We need to have a strategy that keeps people safe while allowing those social benefits."

That is why the Trust won't be putting out the bunting in celebration of its 50th birthday. It knows that as well as causing chronic health and premature death, the condition denies people some of the simple pleasures that others take for granted.

"So this anniversary year is all about saying, yes, we are proud of the achievements that we have witnessed over the past few years but the job is not done..."

We have to use this year as an opportunity to re-energise the CF community and remobilise it to become even more ambitious about what we can achieve over the next few years," says Ed Owen.

"We are living through an era of extraordinary opportunities in which we can expect to see big improvements in life expectancy and quality of life for people with cystic fibrosis. We are now seeing the potential for transformative treatments that target the basic genetic defect that causes the disease, and that should spur us all to even greater things. So, yes, we have come a long way in those 50 years and we have achieved some extraordinary things, but we can't relax when our ultimate goal – beating cystic fibrosis – is within reach."

50 years of progress

The Trust has launched an interactive timeline on its website documenting the fantastic progress that has been made in the treatment and care of people with cystic fibrosis since the Trust was founded in 1964. It contains hundreds of stories, photos and videos detailing the efforts of its supporters, research breakthroughs, and the improvements in care over the years. **Explore the timeline at cysticfibrosis.org.uk/50timeline**.

Getting active

Where eagles dare… we fundraise!

Jessica Bone took to the skies for the Cystic Fibrosis Trust in September, leaping out of a plane to raise vital funds to support our work.

The 20-year-old secretary and auxiliary nurse was inspired to take on the challenge by two friends who both have cystic fibrosis.

Jessica says: "The ups and downs of my friends with cystic fibrosis have demonstrated to me that I need to live life to the full, make the most of my health and do something that scares you, something amazing. I thought a skydive would be an excellent way to raise money as it is also a personal challenge.

"My friend, Kate Hennessy had a double lung transplant last August, and she does what she can every day to make sure the legacy her organ donor has left behind isn't wasted. My other friend with CF has just come back from travelling – they show that cystic fibrosis affects everyone differently, but that you need to make the most of the life and time you have. They are both a massive inspiration."

By plucking up the courage to take the plunge, Jessica had an incredible experience and discovered how supportive people can be. She says: "The skydive was beyond amazing. I'm proud not only of myself but also the many who sponsored me over £850 for an incredibly worthwhile charity and they have my heartfelt thanks."

The sky's the limit: Jessica Bone was inspired by two friends with cystic fibrosis to take on a sky dive for the Trust.

Fundraising skydives take place all over the country throughout the year. Visit cysticfibrosis.org.uk/skydive for more information.

Spice Girl Mel C (@MelanieCMusic) tweets in support of the Trust: "Good timing @nickwlee Good morning! Here's another member of #TeamNorth #GNR raising money with @JustTextGiving @cftrust" http://bit.ly/MelCGNR

Tackling adherence to transform lives

New approaches to adherence are focusing on engaging young people with their care through play.

Many inherited diseases can be cured or maybe kept in check with a simple course of treatment. But cystic fibrosis isn't curable, at least not yet, and to maintain good health, someone with the condition will have to undergo lengthy physiotherapy sessions every day and take large numbers of different pills and dietary supplements.

So it is not surprising that those who have to carry this unwelcome burden will sometimes want to put it down, and forget for a moment that they were born with a serious, life-shortening condition. Whether it's a conscious decision or simple absent-mindedness, skipping part of the essential treatment is likely to have the same effects. Medical staff call this 'non-adherence' and it puts their patient at risk of suffering a severe infection or a sudden deterioration in their lung function.

However, there is hope that the next generation of people with cystic fibrosis will carry a lighter load. This isn't just through the introduction of more effective medicines, but also through developing ingenious and practical technology designed to make life easier for people with the condition, or their families.

Usually these efforts are directed at helping two age groups in which non-adherence can be a particular problem: very young children and teenagers.

"It really is awful – you get crying, screaming matches, tantrums ... every parent of a toddler with cystic fibrosis has experienced it." – David Day

Everyone with cystic fibrosis finds it a chore to do the breathing exercises needed to clear their lungs of sticky mucus. But some are less willing than others to suffer in silence: "It really is awful – you get crying, screaming matches, tantrums… every parent of a toddler with cystic fibrosis has experienced it. You have to spend a lot of time trying to persuade your child to do these exercises because they hate it – it's BORING," recalls David Day, father of Alicia, who is now aged seven.

But David was fortunate in having the knowledge and energy to make a difference. A lecturer in the Computer Sciences Department at the University of Derby, he worked with his wife Ruth and colleagues Andreas Oikonomou and Dan Hartescu on developing a suite of computer games designed to motivate small children to do their daily breathing exercises. 'Breezy Games' consists of a tube connected to a computer into which the child blows to control the movements of characters or shapes on the screen.

Initially the team developed prototype versions of three games, – 'Flower Garden', 'Dragon Cave' and 'Pirates'– , intended for children aged between 4 and 12 years old. These were sent to a group of families who volunteered to try them out, with very positive results.

Meanwhile, David and team worked on making the games more effective through changes that more closely replicate what the child has do in their normal physiotherapy. "In

Blown Away: one of the winning designs from the 2013 24-hour Design Challenge at the University of Sheffield.

one game the child has to blow to make a dragon figure leap from ledge to ledge. At first they could do this with lots of short puffs. But they now have to do one long continuous blow which is much better at clearing the mucus," he explains.

The next step is to apply for the CE mark which guarantees the safety of toys and games in Europe; he hopes he can start marketing the product shortly after. Breezy Games will be sold as a toy rather than a medical device as it is intended to supplement rather than replace standard physiotherapy treatment, he explains.

If the product is successful, the team plans to develop a steady stream of new games to ensure that the child retains their interest. "All computer games start to lose their appeal after a while and I would reckon that we would need to give them something new every couple of months." says David. "Even so, Alicia will still play with the original games every now and again, but she won't want to use them every day."

In the meantime, David's team plans to work with staff at the local CF centre to find ways to develop the concept further. One idea that they will be exploring is to record the way the child uses the game to see if it provides useful information on their health. "It seems likely that it could be used to monitor any changes in, say, forced expiratory volume. Gathering and recording that sort of information would be quite straightforward, you just have to make sure that you are measuring the right things."

A similar invention intended to help older children emerged from an event at the University of Sheffield in July 2013. The 24-hour Design Challenge brought together a team of professional designers, medical staff and patients to develop the concept for a new technology that would help people deal with a chronic medical condition. This year cystic fibrosis and motor neurone disease were chosen and two teams were assembled for each condition to see what they could come up with when put under the pressure of a really tight deadline.

One team, led by John Bateson from the London College of Communication, developed an iPhone app that reminds teenagers to do their breathing exercises. Called 'Blown Away', the technology creates the image of a layer of sand on the screen. This effectively immobilises the screen and if the owner wants to use the phone, they have to blow into the microphone socket to get rid of the 'sand'.

Lorraine Barnes, who has two boys with cystic fibrosis, was recruited as the team's 'design partner' to give a first-hand account of the problems of dealing with the condition. Knowing how much time a typical teenager spends on their phone, she thinks that it will be useful to have the app as a regular reminder of the need to do their physiotherapy. Her 18-year-old son loves his phone but he isn't keen on doing everything he is told. "He will take regular medication when he eats, because he can see a direct benefit of this, but he doesn't want to do exercises, probably because he's a stubborn teenager," she says.

Matt Dexter, a researcher from the university's Healthcare Design Department, was responsible for organising the event. He was impressed that people from different backgrounds came together to come up with practical solutions to the difficulties faced by people with cystic fibrosis. "We don't think what they created is just another phone app, it's a tool that will allow people to manage their condition better," says Matt. "In this case it is as easy to do the blowing exercise as to not do them. They can do what they need to even when they have forgotten to bring their Acapella™ machine, the technology that they normally use for their physiotherapy."

The second cystic fibrosis team at the event looked at ways to improve adherence during that tricky transitional period around the age of 16, when a child is learning to take responsibility for looking after themselves rather than relying ▸

Learning to bear it: Geoff the Bear is designed to help children understand cystic fibrosis and establish good care habits.

entirely on their parents. Dr Kathryn Holden is a clinical psychologist at Sheffield Children's Hospital who specialises in dealing with the problems facing this age group, and advised the team which came up with the idea for an educational toy called 'Geoff the Bear'.

"If you can help them to understand their condition and establish good habits when they are still very small then it is much easier..."

Kathryn agrees that a soft toy is a little young for a teenager who wants to be treated like an adult: "The idea is to get to them at a much earlier stage. If you can help them to understand their condition and establish good habits when they are still very small then it is much easier further down the line to get them to do the things that will help them to stay healthy."

During the frantic race to make a prototype toy within the designated 24-hour period the team members all pitched in to sew small fabric models of the lungs, liver and other organs. These fit inside the bear and can be taken out and shown to the child to explain how the disease affects different parts of the body. "Children find it difficult to understand a concept when it must seem very abstract to them.

This gives us something to show what we mean. It is an interactive approach and we find that children learn through play. We have also produced literature that explains what is happening inside them, written in child-friendly language and with cartoons and simple illustrations."

Geoff the Bear also makes use of the child's need to care for others. They can project their feelings on to the toy and can use it to practice what they have learned about managing their own disease. The team also came up with the idea of giving the bear a passport in which the child can collect stickers every time he receives 'treatment'. "This is something that we have found works when a child is not adhering to what he or she has been asked to do," says Kathryn, "it can give them the encouragement that they need."

Months after the event, the various members of both the teams – designers, doctors, dieticians and parents – still keep in touch and are giving up their own free time to try and take the projects on to the next stage. They have taken the advice of teams at CF centres around the country on how to improve their design and hope to raise the funding needed to turn them into a commercial product.

Teen speak

Technology can also help young people with cystic fibrosis share the burden that they carry.

Many readers will have already seen the short film '...the rest is up to me', produced by the Trust, in which six teenagers speak with frankness, insight and optimism about the effect that their disease has had on their lives. They describe their efforts to explain to healthy peers what CF is and what they have to do to keep it under control. Their treatments combine to put a lot of responsibility on young shoulders and so they encourage others with the same condition to join up on the Trust's internet discussion forum. As one of them explains, "It is good to know that you are not alone."

Watch '...the rest is up to me' at http://bit.ly/cfteens. Visit the Trust's forum at http://forum.cysticfibrosis.org.uk.

Day in the life

Kayleigh Old balances living with cystic fibrosis with her full-time role at the Trust as Public Affairs Officer for Wales.

I often say and think that cystic fibrosis does not define me. Well it doesn't, but it does take a lot of strength and determination to not let it get to me; there is a lot of one-sided compromise!

As well as having cystic fibrosis, I work full time as the Trust's Public Affairs Officer for Wales. My role involves engaging with the Welsh Assembly, parents, patients and clinicians.

My day-to-day role varies from meeting with Assembly Members, including the Minister for Health & Social Services, to discuss CF services, or with other charities with a common goal to gain optimal access to care for patients, to responding to consultations, as well as lobbying and campaigning for optimal CF care.

Recently, I have worked with families of people with cystic fibrosis, on the medications appraisal review in Wales. It was really great to work with them as it combined my knowledge of the process and their experiences of access to medications. These views and experiences will feed into the medications review recommendations for rarer conditions.

As a lot of my work is based around governmental work, I have had to learn lots about how the Welsh Assembly works and how to engage effectively with decision makers. This job has been a breath of fresh air and has been so interesting. There's a lot to keep you on your toes! I can't wait to learn more, and I strive to be better in my job.

"I want to make sure I make some impact, even if small, for those living with cystic fibrosis."

Having cystic fibrosis and a full time job means I have to be very organised with my treatments, and planning for nights away. I do hate it when cystic fibrosis gets in the way and when I need a hospital stay – I have to cancel work meetings and my social life. Getting the treatment as quickly as possible means I can then get on with my life a lot sooner. My way of thinking is that everyone gets ill sometimes – I'm just a bit stubborn in accepting that I'm not feeling great sometimes!

My personal experiences and those of others in the cystic fibrosis community have made me very focused in my job. I want to make sure I make some impact, even if small, for those living with cystic fibrosis.

Read more about Kayleigh's work and find your Public Affairs Officer at cysticfibrosis.org.uk/pao.

Trials and tribulations

Clinical trials should not be a tribulation. In fact it has never been so important that clinical trials get the staff and patients they need to succeed.

"This is the most exciting time for the cystic fibrosis community in the nearly 25 years that I have been involved in the field. More clinical trials of new treatments have begun in the past three to five years than in the whole of the previous 20."

So says Professor Stuart Elborn of Queens University, Belfast, one of the country's leading researchers in cystic fibrosis. As a scientist, he is keen to see this progress maintained with even more trials in the next few years to drive forward our understanding of the disease – and as a clinician he is desperate for the trials to succeed and give him more effective treatments for his patients. Professor Elborn, Director of the University Hospital's Centre for Infection & Immunity, wants as many patients to get involved in trials as possible. This will ensure that the trial organisers can get statistically reliable results when studying the safety and effectiveness of a new treatment or a novel formulation of an existing compound.

Volunteering to take part in these clinical trials is good for the patients concerned, who will get access to the very latest treatments before they become widely available. They also get the emotional benefits of doing something positive to help themselves and others like them, along with the reassurance that they will receive excellent care while their doctors assess the effects of the new treatment.

Taking part in a trial is also good for the hospital as it provides income that will help it maintain and improve its medical services. In return, hospitals have to provide access to the right sort of patients or the multinational drug companies who fund the work will go elsewhere – the companies require a fixed number of patients and they can find them at any clinic anywhere in the world.

Who the right patients are depends entirely on which scientific questions the study has set out to answer. Most clinical trials need to find a specific group of patients – those with a particular genetic mutation of cystic fibrosis or whose disease symptoms fall within a precise range. If a hospital wants to include its patients in a trial they must have an efficient way of identifying which of their patients would be suitable and be able to contact them to get them to agree to take part – or in the case of a paediatric trial, to get the parents on board. Sometimes this process has to be carried out surprisingly quickly – the company organising one recent trial found all the patients they needed within two weeks of announcing the study.

The UK CF Registry contains the medical details of around 99% of the people in the UK with the condition so Britain should be the ideal place to test any new treatments. The database was set up to allow specialist CF centres to monitor the quality of care they provided for their patients while simultaneously protecting the patients' anonymity. But it is also important for ensuring clear and effective communication between the three partners in any clinical trial: the companies, medical staff and patients.

Britain already contributes to a significant number of clinical trials through the major CF centres in Belfast, Birmingham, Leeds, London and Nottingham, which belong to the European Cystic Fibrosis Society's research network. However, there are CF centres all over the UK looking after patients who would be keen to have the opportunity to take part in trials and currently don't often get asked. The problem smaller centres face is that the medical staff are too busy looking after their patients. They don't have the spare time and resources to take on the massive amount of effort, and particularly the paperwork associated with a clinical trial. ▸

Why we should all think about clinical studies

Oli Rayner has cystic fibrosis and is working with the Cystic Fibrosis Trust as Special Adviser on Research & Patient Involvement. He believes passionately that everyone with cystic fibrosis should get involved with clinical trials, for the benefit of all.

Clinical studies (also known as clinical trials or clinical research) are vital to the development of new and better treatments. Studies that compare the clinical effectiveness of existing treatment options are just as important as those involving new drugs, yet many important studies fail due to a lack of volunteers. Only 1 in 10 people with cystic fibrosis has participated in a clinical study.

Many people have pre-conceived ideas about clinical studies and wrongly associate them with danger and human guinea pigs. In fact there are many different kinds of clinical studies. Some early stage ones are certainly dangerous, but others are carried out at a much later stage in the development process or even after the drug has been on the market for many years. In these later stage studies, there is often little difference between the study and normal clinical care in terms of risk.

By the time new drugs are tested on patients, they have already been through laboratory/pre-clinical testing and testing on healthy human volunteers. Those that get past these hurdles have relatively predictable side effects and safety profiles It is typically only at this later stage that they are tested in cystic fibrosis patients.

People volunteer for different reasons. Common ones include:

- Playing a part in advancing knowledge of cystic fibrosis.
- Taking a more active role in managing their own healthcare.
- Learning more about what treatments work for them.
- Being able to help those newly diagnosed with cystic fibrosis.
- Having the opportunity to improve the quality of life for people with cystic fibrosis.
- Potentially gaining access to new treatments before they are widely available.
- Moving the cystic fibrosis community a step closer to better treatments.

At the same time, taking part in a clinical study is a personal decision and it is important to be aware of your rights.

- You are free to decide not to participate after looking at all the information.
- Whether or not you participate will not affect the routine care you receive.
- You can ask as many questions as you want before deciding.
- You must give informed consent before taking part.
- Your identity and medical information will be kept private.
- You can stop taking part at any time without giving a reason.

People with cystic fibrosis should think about clinical trials because we have unique power over the progress of developing treatments.

This bureaucracy is onerous but necessary if the organisers are to collect the information they need while also guaranteeing the safety of those taking part.

That is why the Trust has established a fund worth over £330,000 for the appointment of research coordinators at some of the larger UK CF centres outside the existing European network. These coordinators will be appropriately trained allied health professionals who are able to manage the patients entered into the trial all the way through the trial and oversee the paperwork involved in running the trial. Half the costs of these appointments will come from the host centre's own resources, and within a couple of years the coordinators should be paying for themselves in the fees earned from managing clinical trials through both public and private funding.

"It is a chicken and egg situation: the CF centres need money to appoint a coordinator, but without having that person already available they are not going to receive the funding. So what the Trust is doing is to 'pump prime' the process and set the wheels in motion," Professor Elborn explains.

The Trust also has plans to build expertise internally to provide additional centralised resource to help CF centres deliver more clinical trials in the UK. This person will work at the Trust's headquarters and liaise with those responsible for organising trials both in the UK and abroad to ensure that such costly and complicated medical research is done more efficiently.

Professor Elborn hopes that the new coordinators will be just the start and that there will be funding available in future to greatly expand the network. The coordinators could work from any of the existing CF centres around the country but the centre would need to be looking after at least 150 patients and the most appropriate sites will be those able to manage both paediatric and adult patients or two such clinics in close proximity.

Historically, cystic fibrosis was considered to be primarily a childhood disease but the increasing numbers of people with the condition surviving well into middle age has meant that the age range of patients wanted for these studies has increased. Usually clinical trials in cystic fibrosis have been restricted to those aged six years or over, as that is the point when doctors can reliably measure the effects of treatment on a child's lung function.

However, methods are now being developed to analyse the benefits of a new treatment in those who are too young to understand a request to blow into a machine. Being able to do studies with babies and toddlers that are necessary to prove the safety and effectiveness of treatments offers great opportunities for helping them to grow up with healthier lungs.

Combining these advances in medical science with greater resources to organise and carry out clinical trials should mean that more patients with cystic fibrosis in the UK who wants to contribute to this wave of new research will have their chance. Dr Erika Kennington, Head of Research at the Trust is confident that the momentum achieved over the past few years will continue. "We hope that we will be able to triple the numbers of patients that are enrolled in clinical trials in the UK over the next five years."

For details of cystic fibrosis clinical trials currently running in the UK, visit cysticfibrosis.org.uk/uktrials.

Out in the community

We Three Kings: Dave Bagnall, Philip Barrett and Feargal Mostyn-Williams rode from Cambridge to Oslo to raise money for the Trust.

While most of us were basking in that rarest of British idylls, a genuinely hot summer, a group of choral scholars from King's College, Cambridge, were getting ready to swap cassocks for cycle clips, with an epic fundraising adventure.

Dave Bagnall, Philip Barrett and Feargal Mostyn-Williams, ably supported by Bryony Watson, Rebecca Martin and Dan D'Souza, set off on 21 August on a 1,200-mile odyssey that would take them from King's College Chapel in Cambridge through Holland, Germany, Denmark, and Sweden, before finishing up at the Royal Palace in the Norwegian capital Oslo.

The team was inspired to set up a fundraising challenge by their friend, and King's graduate, Alex Stobbs, whose courageous battle not to let cystic fibrosis stand in his way has formed the subject of two documentaries for Channel 4.

Writing on the team's blog, Dan said: "The real motivation for the trip stems from a true passion among our peer group for the brilliant work of the Cystic Fibrosis Trust. Being friends with Alex Stobbs and spending so much time together on tours and in the chapel allowed us to see what a struggle it was for sufferers of cystic fibrosis and what a positive impact the Trust brings to their friends and family."

"There was no greater rush during the ride than seeing the total donated rise higher."

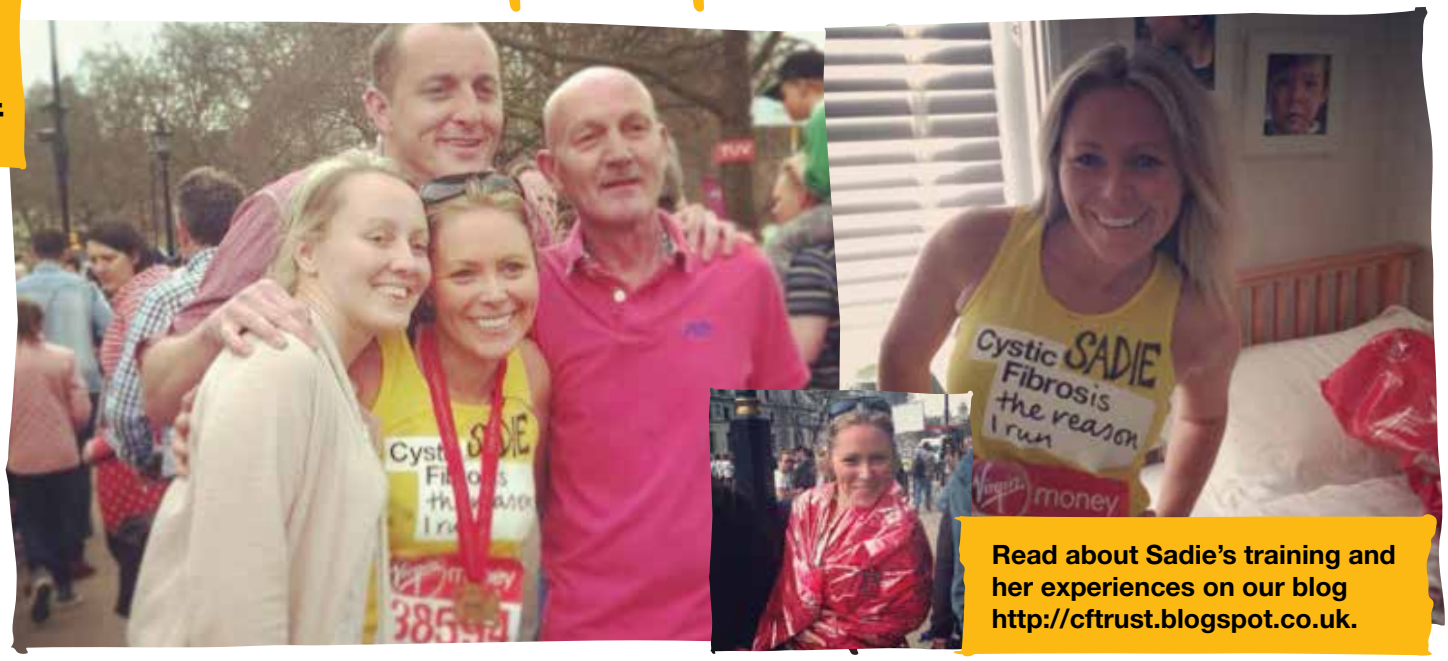
The costs of the trip were covered by Cantab Capital Partners, so the 'Kings' were able to give all of the money donated straight to the Cystic Fibrosis Trust, which will help it keep on making a daily difference to the lives of everyone affected by cystic fibrosis, and one day beat cystic fibrosis for good.

One of the team's masterstrokes in their fundraising effort was to offer to sing a concert for the largest donor. There aren't many who get their own concert from a group of King's choral scholars!

The team raised more than £12,600, including Gift Aid, which is a fantastic achievement to crown their incredible journey.

Supporters played a big part in keeping the cyclists going when things got hard. As they recalled in their thank-you message: "There was no greater rush during the ride than seeing the total donated rise higher and higher. Every penny donated and every message spurred us along, helped those wheels spin, helped us through the early starts and late finishes. To see target after target crumble before our eyes was a humbling experience."

Two-point perspective



Read about Sadie's training and her experiences on our blog http://cftrust.blogspot.co.uk.

Sadie Barclay took on the London Marathon in 2013, despite having cystic fibrosis and a childhood hatred of exercise. That changed when she found how much exercise could help with her daily physio routine. CF specialist physiotherapist Sarah Rand admires Sadie's achievement, and highlights the importance of exercise for people with cystic fibrosis.

If anyone suggested in my teens that I would not only run a marathon but want to, without Gary Barlow waiting for me at the end, I'd have consigned them to the 'We Used To Be Friends' list. I never needed to as I was so obviously not a lover of running.

My loathing for conventional physiotherapy, combined with my determined nature meant that if I wanted to get out of being tipped upside, pummelled and bored to within an inch of my life, I needed to find an alternative to keep my lungs fit and clear. So I found sport – anything to avoid the dreaded draining position. I got into cycling, swimming, aerobics, the gym, yoga and my childhood hate… running. My lung function increased, infections decreased significantly and holistically I felt stronger than ever. Ironically there was one sport I craved more than the others… yes, pounding pavements became my panacea and so it began… a marathon on the bucket list. Running for the Cystic Fibrosis Trust was never going to be an altruistic mission, my cousin (24) received a successful double lung transplant last year and my brother (24), and sister (29) and other cousin (14) also have cystic fibrosis.

The training was an arduous challenge. I took a mental image of myself running 26.2 miles and used it to plan what I needed to get there. Training is much more than just about running because your entire body and mind need to be strong. Cycling, swimming, weights, yoga, antioxidant benefits from red wine and extortionate amounts of laughter featured heavily in the plan.

The day itself was nothing short of magical. The atmosphere, your name being hollered by strangers willing you on. The force of one intent – to cross that line – but everyone driven by their own reasons to be there. Goosebump-inducing. That feeling enhanced by clocking loved ones as I went around the course. When I finished, my legs seized up completely and the realisation that I had ran the entire distance sunk in, followed by an immediate urge to find my family. The only time I have ever been carried into a drinking establishment rather than out of it!

Yes, I picked up injuries and encountered tough times along the way, but I truly believe that all of the wonderful messages of support that I received wrapped me up with a super power for the day. Now I'm the proud owner of a London Marathon medal and a foil coat. Love conquers all they say – yeah it does.

To sign up for a running event – from fun runs to marathons – visit cystic.fibrosis.org.uk/events.

Expert comment

Sarah Rand
Specialist CF physiotherapist, Great Ormond Street Hospital for Children, London

Exercise is a vital component of managing cystic fibrosis. Aerobic fitness is associated with prolonged survival and quality of life. Most studies that have investigated the potential of exercise programmes in cystic fibrosis have assessed the effects of aerobic training (for example cycling, running, swimming – endurance activities). Some studies have compared endurance exercise versus strength exercise and sprint training. These studies have shown that a combination of different exercises is the best approach.

Sadie's achievement is incredible. I'm sure the secret to her success lies not only in her determination but also her varied training routine. She incorporated cycling, swimming, yoga and weights, which is exactly what we would recommend for anyone training for a marathon, but also for individuals with cystic fibrosis as part of their regular exercise programme.

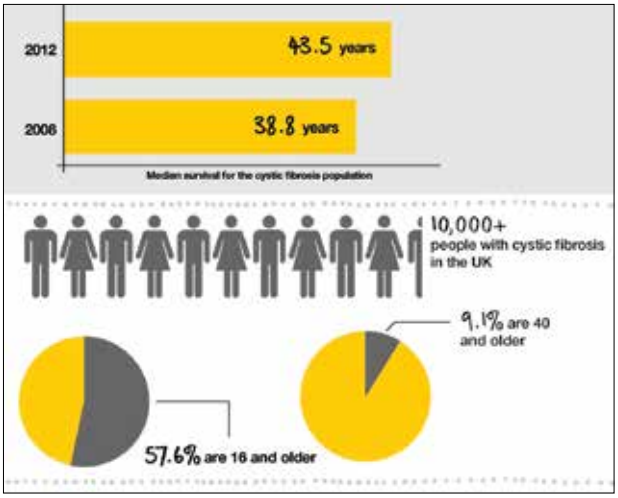
We still don't have enough evidence to suggest an exercise session can replace an airway clearance session. However, the incorporation of airway clearance techniques into an exercise session may be adequate for some people. Always speak with your CF centre for advice.

Will Sadie keep running now she has achieved her goal? Keeping up a regular exercise routine without a goal can be challenging. Having a 'buddy' to train with and doing activities you enjoy, as well as setting realistic goals can be helpful.

The incorporation of exercise and physical activity into cystic fibrosis routines is well established and should be encouraged for people of all ages.

Facebook feedback

We published a graphic highlighting some of the latest statistics from the 2012 UK Cystic Fibrosis Registry Report on our facebook page. Here is a small selection of the comments it received.



"I have cf i am 46 i have a 23 year old daughter after my transplant 8 years ago i went to college for 4 years and have just married my soul mate life is good. X"

"I've just found out my 5 week old daughter has cf and finding it very hard to come to terms with but this gives me a lot of hope."

"My son has CF. He has just turned 7. He plays sport 6 days out of 7. To date he has been very well. But that is no excuse to take it easy. Most out there know it takes a lot of effort to keep on top of CF. with the support of the CF Trust we can push that 43.5 even higher each year."

621 1,000

"@kieran_stanley My new #CysticFibrosis tattoo! @CFAware cftrust pic.twitter.com/yKBotGFbTE" http://bit.ly/KStattoo

Just ask

Jackie Rice runs the Trust's helpline, offering general advice, support and information on any aspect of living with cystic fibrosis, including help with financial support. The helpline is often the first contact members of our community will have with the Trust.

We asked Jackie to share some common enquiries the helpline receives, to give an insight into how we can offer help and support to those affected by cystic fibrosis.

Question: I'm a new parent, and my baby girl has just been diagnosed with cystic fibrosis. I'm not aware of any history of cystic fibrosis in the family, and I don't know what to do. Can you help?

Answer: That's okay, you are not alone. Many people receive a diagnosis out of the blue, and it can be very scary. We have an information pack specifically for parents like you who have just received a diagnosis, which I can send you now. If you have any more questions when you've read through the literature, just give us a call back, even if you just want a listening ear.

Jackie says: This caller was very upset when she called, which is perfectly natural when someone has just been told their child has cystic fibrosis, especially if they weren't expecting the diagnosis. The first thing I did was to reassure the caller, told her to take her time, and offered to call her back if she preferred. When she calmed down we had a chat, and I told her about our 'new diagnosis' pack, and reassured her that the helpline would be there for her whenever she needed, even if she just wanted someone to chat to again.

Question: I am receiving Disability Living Allowance, and it needs to be renewed. They have decided to reduce my benefit from Middle to Low rate, but my circumstances have changed and I now need to take more medication. I didn't know who to turn to for advice, so I thought I'd try the helpline.

Answer: Don't worry, you are not the only caller who has had to go through a similar situation. The forms they use for benefit assessments are not specifically designed for people with cystic fibrosis, and most of the information on there doesn't fit with your condition. Why don't you contact the benefits people and appeal against their decision? If you'd like I could help you by writing a supporting letter?

Jackie says: This kind of situation is quite common these days, and it can be worrying. I took the gentleman's email address and sent him our 'Care Needs' form to complete, which I can then use to write a letter of support backing his appeal. As well as the form itself, it was important that the caller had someone to listen to him, especially since he felt like there was nowhere to turn.

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–Friday 9am–5pm

*We will respond to emails within three working days.

"@timwotton: Ten years of marriage, a fine son and pretty good health. Find out how in my cystic fibrosis blog - 'Right beside me' http://timwotton.wordpress.com/2013/07/26/right-beside-me/ … http://bit.ly/TimW10

cysticfibrosis.org.uk/legacy

Cystic Fibrosis

why we believe in a better future

10%+

of our income is from gifts in wills.

Put your family first when you make your will – then please consider helping future generations.

Gifts in wills to the Cystic Fibrosis Trust of any size help fund our investment in cutting-edge research to one day beat cystic fibrosis for good.

For more information about legacy giving contact Michael Clark 0208 290 8051; michael.clark@cysticfibrosis.org.uk, or visit cysticfibrosis.org.uk/legacy.

Cystic Fibrosis why we're connecting

245,000

posts and counting on our online forum

To reduce the risk of cross-infection, people with cystic fibrosis must avoid meeting each other face to face.

The Cystic Fibrosis Trust forum gives them the chance to meet others online, discuss the latest treatments and research or simply share their experiences.

Join the conversation at **forum.cysticfibrosis.org.uk**