Issue 4: Spring 2015

is

The magazine of the Cystic Fibrosis Trust

From grassroots to corridors of power

The future of care

Body and soul

Cystic Fibrosis why we're here

is

Regulars

News

Features

Welcome

Hello again. Spring is in the air (I hope – I am writing this on a grey January day, because that's how publishing works!), a time of change and optimism, and we hope that the latest issue of 'is' will give you plenty to get excited about.

In our features, we talk political change with the Cystic Fibrosis Trust Manifesto (see page 14), we look at a bold new vision to change the way we think about care with SmartCareCF (see page 20), and we ignore taboo to look at how something as universal as sex and relationships gain a new layer of complexity when you throw a lifelong condition like cystic fibrosis into the mix (see page 24).

There are also some big events to look forward to in the coming months, not least the Big Balloon Bonanza (see page 19) and the return of CF Week in June, when we'll be raising awareness up and down the country about cystic fibrosis, and the Trust's work.

Henry Fogarty
Editor

Sophie, Mahesh and Stephanie were among the five recipients of the Sir John Batten Memorial Studentships who presented at the UK Cystic Fibrosis Conference.

30

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Genotype campaign is all about you

In January the Trust launched 'Genotype Matters', an awareness campaign to highlight the importance for people with cystic fibrosis to know their specific mutation (or genotype).

The campaign seeks to empower individuals to take a proactive role in their care and understand more about their particular symptoms.

There are over 1,400 mutations of the faulty CFTR gene that causes cystic fibrosis, and as more and more medicines treat specific genotypes, it is increasingly important that people with cystic fibrosis know theirs, so they can access and benefit from the right treatments for them.

Dr Janet Allen, Director of Research & Care at the Cystic Fibrosis Trust, said: "It is vital that people know their genotype, so that they can understand their symptoms, access the right treatments as they come to market, and take part in relevant clinical trials."

People with cystic fibrosis who don't know their genotype should ask at their next CF centre visit. If it is unknown, the Trust will pay for a blood test to find out.

Using a new website launched by the Trust, people can enter their genotype and receive information about their cystic fibrosis that's personal to them.

Find out more at genotypematters.org.

A royal visit: HRH Prince of Wales chats to Nicholas Mason, a patient at the Royal Brompton adult CF centre on his first official engagement as Patron of the Trust in December.

Cystic fibrosis is no joke: 'The Breath Before' film was shown at the start of the British Comedy Awards 2014 at which the Trust was the official charity partner.

News in brief

Co-funded study targets dehydration

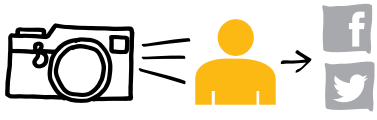
The Trust has joined forces with children's charity Action Medical Research to fund a £150,000 laboratory trial into a new inhaled treatment to protect the lungs of people with cystic fibrosis from becoming dehydrated. This is believed to be a major cause of the build-up of sticky mucus which allows harmful bacteria to flourish.

The trial will investigate how best to formulate the medicine and the safety and effectiveness of using a synthetic molecule to switch off a gene called ENaC. The hope is that this will ease breathing and reduce chest infections in people with cystic fibrosis.

Save the date

Remember to save the date for our Wear Yellow Wednesday on 1 July!

Ask family, friends and colleagues to dust off their favourite yellow outfits and join our annual fundraising day, and don't forget to send us your pictures with the hashtag **#cfyelfie** so that we can share the fun.



It's good to be connected

A new scheme being piloted by the Cystic Fibrosis Trust will train volunteers from the cystic fibrosis community to offer telephone support to parents and families, as well as people with CF themselves. CF Connect will offer volunteers a chance to share their experiences and lend a listening ear.

The pilot project will train a small group of parents from Oxfordshire and the West Midlands to provide support to parents and carers experiencing a new diagnosis of CF in their family.

Later this year, the Trust plans to recruit and train CF Connect volunteers nationwide and will start to expand the support to cover areas such as 'starting school', 'transition to adulthood', 'going into higher education or employment' and 'transplants', with an additional service for young people.

Becky Kilgariff, Support Service Manager at the Trust, said: "We are delighted to be launching our pilot for CF Connect. Callers to the Helpline often tell us they want to speak to someone who has 'been there', but the risks posed by cross-infection can make this difficult."

CF Connect will be available by contacting the Helpline on 0300 373 1000 or helpline@cysticfibrosis.org.uk.

If you are interested in volunteering to provide CF Connect support please email volunteering@cysticfibrosis.org.uk.

Training the specialists of the future

In July 2014, the Cystic Fibrosis Trust announced the award of two clinical training fellowships, to the Royal Brompton Hospital and the Wythenshawe Hospital, after reinstating its fellowship programme earlier in the year.

First awarded in 2005, these fellowships are a popular and effective way of ensuring that respiratory physicians are offered specialist training in cystic fibrosis healthcare management. The fellowships add an element of research to the training programme to encourage the fellows to undertake a clinical research project alongside their training programme.

Dr Janet Allen, Director of Research & Care at the Trust, said: "The healthcare management of people with cystic fibrosis is complex. These fellowships offer the opportunity for respiratory physicians to be equipped with the required skills to run a CF centre and so ensure the next generation of specialists."

Dr Caroline Elston undertook a Trust fellowship in 2006/7

Dr Caroline Elston, Clinical Lead for King's College Adult Cystic Fibrosis Centre, took up a fellowship post at the Royal Brompton in 2006/7, launching her career in cystic fibrosis. She said: "The fellowship was the ideal opportunity for me to consolidate my clinical experience and was specifically designed for future CF consultants, offering a mixture of clinical training, research and managerial experience."

Spreading Christmas cheer: celebrity readers including Damien Lewis and Jeremy Vine, and the Winchester College Chapel choir, made the 12th annual Carols by Candlelight a success.

The enterprising youth of today...

Three people with cystic fibrosis who have set up wedding floristry, graphic design and window cleaning businesses were the recipients of grants from the first ever Helen Barrett Young Entrepreneurs Award scheme.

The scheme gives budding entrepreneurs with cystic fibrosis a helping hand, with up to £2,000 to help develop or kick-start their business, and pairs them with a mentor.

Angela Searle was thrilled to receive £2,000 to help with her wedding floristry business, 'Blooming Marvellous'. She said: "I still can't believe it! I have only been up and running for six months so I am quite a new business and this money will really help with boosting my business. Not to mention the support of a mentor which you get assigned to help your business grow."

Three of the 16 applicants in 2014 were awarded a grant and all will receive expert mentoring through the scheme, which was kindly sponsored by Action 4 Employment (A4e), and set up in memory of a young lady with cystic fibrosis who ran her own successful gym. Helen Barrett grew up determined not to let her ambitions and dreams be limited by cystic fibrosis. Sadly, Helen died a week before her 32nd birthday after fighting a long and difficult battle with the condition.

Look out for details for the 2015 scheme coming soon.

Trust invests in volunteers

The Trust was awarded the Investing in Volunteers (IIV) accreditation by the National Council for Voluntary Organisations in October, reflecting its commitment to best practice and standards around volunteer involvement. In recent years the Trust has greatly increased the number of volunteer opportunities.

James Atkins, Volunteer & Development Manager at the Trust said: "We are thrilled that we have been awarded Investing in Volunteers accreditation. Our volunteers are fantastic – throughout the UK they are going the extra mile to help beat cystic fibrosis for good. Without them, we simply wouldn't be able to carry out the essential work that we do."

For more information about volunteering for the Trust, visit cysticfibrosis.org.uk/volunteer

Volunteer & Development Manager James Atkins and some of the Trust's growing number of volunteers receive the Investors in Volunteers award.

New-look grants

If you're facing financial strains because of CF – perhaps struggling with the costs of setting up home, or travelling for assessment for transplant – the Trust could help through its new grants system.

Dividing applications into emergency and health and wellbeing grants, the new system is more responsive and reflects the needs of the cystic fibrosis community today. While emergency payments will usually be arranged within a week, an independent panel will meet every two months to consider health and wellbeing applications, giving applicants confidence that their application will be dealt with fairly and impartially.

Emergency grants are divided into transplant grants, small grants for emergency needs such as essential household repairs, and grants to help towards the cost of a funeral for a loved one with cystic fibrosis.

Health and wellbeing grants help pay for goods or services that support health and quality of life, such as exercise equipment, washing machines, or gym fees or travel insurance costs.

Trevor Man, Welfare Grants Assistant, said: "The new grant system will be able to respond more rapidly to emergency needs and it will be easier for people to apply in emergency situations. The introduction of health and wellbeing grants allows us to provide financial support to help people affected by CF improve their quality of life and their long-term health."

Find out more at cysticfibrosis.org.uk/grants, or email trevor.man@cysticfibrosis.org.uk.

The meaning of life: a new sculpture by Julian Bull highlights the burden of treatment endured by people with cystic fibrosis.

The Tree of Life

A new freestanding steel sculpture by artist Julian Bull transforms the daily burden of care faced by people with cystic fibrosis into a positive artistic statement.

Measuring 215x155cm, 'Tree of Life' depicts a tree with flowers, fruit and seed pods, using everyday CF medicine and equipment such as a Tobi Podhaler, syringes and tablets.

Julian, whose wife Jane has cystic fibrosis, says: "It has often been said that trees are the lungs of the world providing oxygen for us all. The aim of the piece is to convey renewal, life and hope to those with CF as well to create something of beauty from the drudgery of daily treatment regimes."

The tree of life concept appears in science, religion and mythology, and references the interconnection and cyclic nature of all things. The concept can also be applied to the wonder of the human body and its interconnected systems.

In 2014 Julian marked his wife's 50th birthday with a sculpture using cystic fibrosis medication to spell out '50 Years'.

The artist is currently working on a third CF-related piece, commissioned by the Trustees of the Birmingham Heartlands Adult CF Centre and involving participation from patients, families and medical staff.

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.

UK CF Conference leads the way

Collaboration and innovation took centre stage at the first ever UK Cystic Fibrosis Conference, organised by the Trust at the Renaissance Hotel, Manchester, in September 2014.

Bringing together leading figures in cystic fibrosis research and care, the conference saw keynote speeches from Preston Campbell III, Executive Vice President of the Cystic Fibrosis Foundation in the US, and Tim Kelsey, National Director for Patients and Information for NHS England.

Resounding themes from the day included the vital need to put people with cystic fibrosis at the heart of every issue, excitement about some of the new treatments and evolutions in care on the horizon, and practical optimism that the Trust's vision to beat cystic fibrosis for good is a realistic, achievable and essential goal. For the first time ever the cystic fibrosis community were able to stream the entire day online.

Opening the event, Trust Chief Executive Ed Owen said: "The active involvement of people with cystic fibrosis – their voice and experience – is a vital component of how we will beat it for good. Today, [our] commitment to beat cystic fibrosis is one drawn not simply from hope but from a genuine belief of what is possible."

In 2015 the UK CF Conference will be a two-day event, taking place on 22–23 September.

September saw the inaugural UK Cystic Fibrosis Conference.

A shaggy dog story: Keath Armstrong and his three Siberian huskies raised over £3,000 from their 318-mile sledge journey from Manchester to Bournemouth.

Partnerships ballooning at the Trust

Nationwide raised £10,000 for the Cystic Fibrosis Trust in 2014 with events including a virtual balloon race, which saw 1,500 staff members race balloons around the world. The overall winner 'travelled' over 900 miles to the middle of the Atlantic.

Stephen Uden, Head of Corporate Citizenship at Nationwide, said: "We have found the Cystic Fibrosis Trust to be a pleasure to work with, full of good ideas, creative and able to turn things around quickly." Nationwide is one of a wide range of companies which have together raised over £10m for the Trust and much of this has been raised because members of the CF community have helped to build relationships with the companies they work for.

The Trust's Philanthropy & Strategic Partnerships team builds relationships with companies from a variety of sectors. In 2015, partner companies will be providing support through many great activities, including Nationwide, which is continuing to support the Trust with its Scotland to Swindon cycling challenge in May.

Kieran Cornwell, Senior Strategic Partnerships Manager at the Trust, said: "We're grateful to everyone who nominated the Trust to be a charity of the year partner of their company, or asked their employer to support us."

If you work for a company that supports charity partners, please contact Kieran Cornwell, Senior Strategic Partnership Manager (kieran.cornwell@cysticfibrosis.org.uk 020 8290 8064).

Sign up now for the Trust's own big balloon race bonanza (see page 19).

Corporate friends: Nationwide launched their partnership with the Cystic Fibrosis Trust with a virtual balloon race.

Getting strategic about genes and data

The Trust has announced two new £750,000 Strategic Research Centres that will enable scientists and researchers around the world to work together to tackle specific problems within the field of cystic fibrosis.

Dr David Sheppard is leading one of the teams receiving a new SRC grant.

One project, led by Dr David Sheppard at the University of Bristol, aims to promote the development of new drugs to treat the F508del genotype, the most common mutation of the faulty cystic fibrosis gene. The other, led by Professor Di Bilton and colleagues from the Royal Brompton Hospital, will explore harnessing data to improve the lives of people with cystic fibrosis.

Dr Janet Allen, Director of Research & Care, said: "SRCs provide a platform for international collaboration and inspire the brightest and best young scientists to focus their research in cystic fibrosis. They are also a chance to bring academics from different disciplines, such as epidemiology and chemistry, with much-needed skillsets, into cystic fibrosis research."

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

The picket line: Protestors at King's College Hospital call for better adult CF inpatient facilities in December.

Enough is enough!

After years of broken promises from King's College Hospital, the Cystic Fibrosis Trust launched the 'Enough is enough' campaign in November, demanding a commitment by the end of March 2015 to deliver adequate adult inpatient facilities for people with cystic fibrosis.

The Trust pledged £432,000 in 2010 towards the development of inpatient facilities with adequate en suite accommodation, and work was due to start in April 2011. However, the money remains unspent, and the Trust's offer will soon expire.

Following the launch of the campaign the Trust cautiously welcomed the hospital's decision to move the adult CF unit to a temporary home where patients no longer have to share bathrooms. However, despite over 2,600 signatures on the campaign petition, the hospital has refused to say when work will begin on a new permanent home for the unit. The Trust has vowed to continue its campaign for a permanent home for patients on an expanded and refurbished ward.

James Barrow, Head of Public Affairs at the Trust, said: "Many people with cystic fibrosis view hospital as their second home and they have a right to be treated in facilities that minimise the risk of cross-infection and enable them to continue life as normally as possible."

Find out more at cysticfibrosis.org.uk/kingscampaign

News in brief

Change at the top

The Trust has welcomed four new Trustees: Dr Andrew Jones, Consultant Physician and Honorary Reader at the Manchester Adult Cystic Fibrosis Centre, Hannah Begbie, a literary and performance agent, Louise King, a platform analyst, and Michael Winehouse, a fundraising events coordinator. Louise and Michael bring first-hand experience of living with cystic fibrosis, and Hannah brings a parent's perspective.

The Finance Committee has also welcomed two new members, Trustee David Turner QC, and Chartered Accountant Stephen Mullen, both of whom have children with cystic fibrosis.

The Board has recently bid farewell to Peter Sharp, Martyn Rose and Professor Stuart Elborn CBE, who stood down after serving the maximum two terms.

CF Week 6–14 June 2015

Save the date. The Cystic Fibrosis Trust's annual week of awareness and fundraising returns in June 2015!

Cystic Fibrosis saying thanks

sayingthanks.co.uk

The Trust brought its 50th anniversary year to a close with a month-long campaign to say thank you to all those who have supported the fight to beat cystic fibrosis.

The campaign also gave supporters a chance to acknowledge those people who have made a difference to their lives. Here are some of their thank you messages.

Andrew Ward is saying thanks to Helen Beswick (partner) for being my best friend/partner in crime. Love you. X

For being an incredible ambassador for the Cystic Fibrosis Trust, as well as a tireless fundraiser with the CFTwo Group. You're an inspiration to everyone you meet and the reason I'm proud to be a part of the fight to beat CF.

Vicky Bratherton is saying thanks to Ashley Harris-Moore (fundraiser and friend) for being my inspiration.

Thanks to the staff at Warrington Hospital.

Joyce Roberts is saying thanks to Dr Bedford and staff (at the chill) for making visits to clinic so child friendly.

A massive thank you to all the staff at the Aberdeen CF clinic who make sure my daughter Lois is well looked after.

Graeme Wilson is saying thanks to Aberdeen CF Clinic (all staff) for taking care of my daughter Lois.

A huge massive thank you to everyone that helps out with, performs at, or donates prizes/time/money to RAVE2RAISE to help raise funds for the Cystic Fibrosis Trust...!

Paul Buckingham is saying thanks to RAVE2RAISE (event) for raising money for the Cystic Fibrosis Trust.

For being there and being a true inspiration.

Lou Trenchard is saying thanks to Greg Phillips (university friend) for being one of my best friends.

I want to say thank you to Llandough CF Adult Team for everything they've done for me and for being such super stars!!

Lucy Taylor is saying thanks to CF Adult Team in Llandough Hospital (nurses and doctors) because they're simply amazing!!

Rory Watling is saying thanks to All that took part in the HAN-DEL-BAR challenge (working for Capita) for raising money and awareness for CF.

Catherine Fletcher is saying thanks to Marie Greenan, Maddie Killick, Rachel Braithwaite (best pals) for climbing a mountain and eating gross food for Ida.

Thank you for everything you have done and continue to do for my daughter lauren sayers, we know how incredibly lucky we are to be in your expert hands :-) xx

Deborah Sayers is saying thanks to Bristol Children's and Bristol Royal Infirmary (CF clinics) for keeping my daughter well over the last 19 years.

Carol Hunt is saying thanks to Felicity Dunn (fundraiser) for raising over £13k at the Dragon Boat Festival

I'm saying thank you because without this person, life for my children would be so much different and because she keeps us all strong.

David Wood is saying thanks to Katie Wood (wife) for keeping our kids happy & healthy.

Watch the our thank you video by going to youtube.com/cftrust. Don't forget you can also view other videos from Trust initiatives and events at youtube.com/cftrust.

From grassroots to corridors of power

Dr Ian Ketchell, Director of the All Wales Adult CF Centre in Wales, and Mark Drakeford, Minister for Health and Social Services in Wales, at our event 'Cystic Fibrosis and Celebrating the Patient Voice' held in the Welsh Assembly in November.

Hazel Morgan, parent of a child with cystic fibrosis, speaking at a Trust event at the Welsh Assembly giving her perspective of having a child with the condition and the daily impact it has on her child.

With the General Election just around the corner, the Trust has released its own manifesto, building on the momentum of an exciting year of campaigning and presenting some of the key issues it will be fighting for in the year to come.

Whichever party is elected in May will carry with it the hopes and expectations of the cystic fibrosis community. More than any previous administration, the next government must think about the opportunities available to transform the lives of those born with the most common life-limiting genetic disease in Britain.

The Cystic Fibrosis Trust has launched its own manifesto, with nine points it will be campaigning on in the upcoming year. Supporters have a key role to play supplying the 10th point (see our manifesto – centre spread, overleaf).

Parliamentary Officer Darren O'Keefe explains how the Trust is influencing policy across the UK: "The Public Affairs team raises awareness at the highest level, building relationships with politicians and policy makers to influence policy and promote understanding of cystic fibrosis."

The All-Party Parliamentary Group on Cystic Fibrosis (see box, page 17) created by the Trust last year provides a political channel for the Trust to exert pressure on decision makers. This group of supportive MPs and peers from all main political parties also provides a high-level forum for discussion on the issues that matter to the CF community.

Since health policy in the regions is largely a responsibility of the devolved administrations, the Trust has also focused on working with politicians in Edinburgh, Cardiff and Belfast. With Public Affairs Officers representing it in each nation, the Trust can campaign on local issues and deliver the major UK-wide initiatives that have been a feature of its work over the past year.

Darren sums it up: "It's fair to say that, alongside our vital research and support work, we are now a formidable campaigning organisation with an official political presence."

Transplantation

When the Hope for More campaign was launched in March 2014, the Trust recruited more than 4,700 supporters to email politicians across the UK, highlighting the unacceptable current situation where less than 25% of donated lungs are used and one in three people with CF on the transplant list will die before their operation.

As a result of Hope for More, NHS Blood and Transplant announced a review of the current arrangements for organ allocation, which should lead to a fair national lung allocation system. ▸

Cystic Fibrosis Trust

Manifesto

Have your say!

Submit your ideas for the tenth action point.

Cystic Fibrosis a fight we must win

Campaigning for change

1

Increase the number of successful lung transplants for people with cystic fibrosis

It is unacceptable that one in three people with cystic fibrosis on the waiting list for a lung transplant will die before they can receive one. The first step to correcting this shocking situation is to make the most of the donor lungs that are available now. Through education and innovation we can save more lives.

2

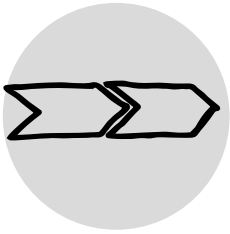
Increase NHS capacity to appraise drugs for rare conditions

The NHS is failing patients because it does not have capacity to adequately appraise new treatments for people with rare conditions. For example, the current Highly Specialised Technology route used by NICE in England only has capacity to appraise three drugs a year, meaning patients are waiting unnecessarily for potentially life-changing treatment.

3

Streamline European licensing and UK appraisal systems

It takes twice as long to licence new medicines in the UK as it does in the US. This must change. We welcome the Life Sciences Minister's commitment to making Britain the best place in the world to get quicker access for patients to innovative medicines and we will work with the Government to make this a reality.



4

Urge industry and Government to work together to ensure equal access to new medicines

All stakeholders, from patients to the pharmaceutical industry, must work collaboratively to ensure patients can benefit from safe and effective treatments as quickly as possible, wherever they live in the UK.

5

Ensure the government invests now to beat cystic fibrosis

Innovative medicines are being developed that will transform the future of cystic fibrosis. All UK governments must ensure that this innovation is rewarded at a fair price by adopting appropriate systems of appraisal for rare diseases such as cystic fibrosis. Without this investment, we stand to forfeit a brighter future for cystic fibrosis.

6

Invest in specialist CF centres

As we demonstrated with campaigns for the Wythenshawe Hospital and the adult CF unit at King's College Hospital, we will not stand by while specialist services and CF centres are under threat, whether it be political, financial, or through poor administration within a hospital or Trust.

7

Protect standards of care

We will continue to campaign to ensure that cystic fibrosis remains a nationally commissioned service, and fight against a return to the days of a 'postcode lottery', so that patients receive the same high level of care wherever they live.

8

Press for change on prescription charges

It is unfair that adult cystic fibrosis patients in England have to pay for their prescription charges. This is because the exempt list was drawn up over 40 years ago, in 1968, when most children with cystic fibrosis did not live until adulthood.

9

Ensure Personal Independent Payment (PIP) works for people with cystic fibrosis

We will continue to press the Government to make sure that people with cystic fibrosis are given the right level of financial support for the challenges they face in everyday life.

10

We need you to submit your ideas for the tenth point of our manifesto.

Have your say!

Our manifesto currently has nine points which we will be campaigning on in the upcoming year.

Now it's over to you: tell us on Facebook and Twitter what issues you want us to fight for, and the most popular theme will become the tenth action point in our manifesto.

facebook.com/cftrust
twitter.com/cftrust

cysticfibrosis.org.uk

"As a result of Hope for More, NHS Blood and Transplant announced a review of the current arrangements for organ allocation which should lead to a fair national lung allocation system."

The campaign also brought together politicians from across the UK's political spectrum to campaign for a soft opt-out system of organ donation.

Rebecca Barr, whose 20-year-old sister Charlene died four years ago while waiting for a lung transplant, spoke movingly of the impact on families at an event at the Northern Ireland parliament in October. She urged politicians to make the soft opt-out system for organ donation being pioneered in Wales a reality across the UK.

"If that system had been in place in Northern Ireland when Charlene needed her operation there is every chance that she would be alive today. But we can make sure that in future people with CF who need lung transplants will get that opportunity," she said.

Welsh Health Minister Mark Drakeford AM, who introduced the soft opt-out system to Wales earlier this year, with Anne McTaggart MSP (right), who is progressing legislation in Scotland, and Jo-Anne Dobson MLA, Northern Ireland (left).

Access to medicines

In November the focus shifted to the life-changing but costly new medicines in development and the need to ensure they are available to those who could benefit from them. The Trust held events in Edinburgh and Cardiff and offered advice and support to the efforts of both Parliaments to develop a better system for appraising so-called 'orphan' drugs, those for conditions affecting very small numbers of patients.

"...the Trust is fighting to ensure that budget pressures do not cause unacceptable changes to NHS care."

The Trust is now working to influence the review into innovative medicines announced by Life Sciences Minister George Freeman MP, aimed at speeding up the process for licensing in the UK.

"We must find a way to make sure people with cystic fibrosis get access to the best available treatment at a price that is affordable to the NHS and will not have a negative impact on CF care,"says Darren O'Keefe.

With the austerity measures likely to continue into the next Parliament, the Trust is fighting to ensure that budget pressures do not cause unacceptable changes to NHS care. ▸

Quality of care

The Trust has been vigilant in issues affecting regional CF centres like those at King's College Hospital in London (see page 11), where facilities for inpatients were not fit for purpose, and Wythenshawe Hospital in Manchester, which was part of a wider review of specialist services. It remains concerned that the current national system for commissioning cystic fibrosis services could be replaced by local arrangements with different priorities.

Darren warns that the CF community will not tolerate changes that weaken the vital services provided under the current arrangements: "All patients with cystic fibrosis must receive the care to which they are entitled. We must maintain the current national commissioning system that ensures that service providers can be held accountable for delivering the highest quality specialised treatment."

Quality of care is one of the three key areas that make up the Trust's manifesto.

Crossing the divide: Jason McCartney leads the new All-Party Parliamentary Group on cystic fibrosis.

All-Party Parliamentary Group

Jason McCartney, Conservative MP for Colne Valley in West Yorkshire, chairs the new All-Party Parliamentary Group (APPG) on Cystic Fibrosis and is a long-standing supporter of the Trust's work.

He said: "The new APPG will work with the Cystic Fibrosis Trust to provide a forum in Parliament for Members to represent their affected constituents and to work with the broader CF community. The APPG will raise awareness among Parliamentarians of the key issues faced by people with cystic fibrosis and provide a powerful voice in Parliament.

"It will build upon recent breakthroughs in CF treatment by discussing urgent problems such as transplantation and the appraisal of new drugs. The ultimate aim of the APPG is to beat cystic fibrosis for good."

To have your say on the Trust's additional manifesto priority follow us on social media. You can find us at: Twitter.com/cftrust and facebook.com/cftrust.

Getting active

A Hertfordshire schoolgirl ran 100k in a month for her auntie with cystic fibrosis.

Twelve-year-old Hannah Brazil from Sawbridgeworth created her own challenge to run 100k during October, raising money for the Cystic Fibrosis Trust. Hannah was inspired to take up a fundraising challenge by her auntie Claire, who has cystic fibrosis.

Hannah had to fit running around her day-to-day life; after school and at weekends, in all weathers. She set a route of 3.3k and ran every day for 31 days. Hannah says: "It was a tough challenge to set for myself. By the end of the month I had got use to running every day but I felt a huge sense of achievement when I realised I was coming to the end."

Most of us wouldn't dream of venturing out on a running challenge in the cold month of October, but for Hannah her determination enabled her to complete 100k! Hannah's least favourite part was running in bad weather, but she explains: "My friends were all very supportive and sponsored me as well."

"By the end of the month I had got used to running every day." – Hannah

Hannah summed up her experience: "My favourite part of the challenge was when I calculated how much money I had raised – over £300!" Hannah's dad Ian says he is extremely proud of Hannah and explains that "she came up with the idea and calculated the route herself. Hannah's auntie Claire is getting married next year and Hannah is looking forward to being a bridesmaid at the wedding."

On the run: Inspired by her aunt Claire, 12-year-old Hannah ran 100k in a month to raise money for the Trust.

Be inspired by Hannah, 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/balloon

Cystic Fibrosis a race we must win

Get set for the Big Balloon Bonanza!

Buy a virtual balloon, set it on an online race across the globe, and you could win one of our fantastic prizes; from an iPad mini to a hot air balloon ride for two, or even a three-night London hotel stay.

Every balloon will support our work and help to fund vital research.

Please support our mission to get over 10,000 balloons in the sky – one to support every person in the UK living with cystic fibrosis.

Visit cysticfibrosis.org.uk/balloon to design your balloon today.

Entry deadline: 12 noon 21 March
Race week: 21–28 March
£5 per balloon

The future of care

If you don't like the game, change the rules.

"In a nutshell, my challenge is to stay as healthy and strong as possible while supporting myself and living my life," says Kayleigh Old, who after 28 years living with cystic fibrosis, knows a thing or two about the constant battle to stay healthy and keep out of hospital.

Living with cystic fibrosis means a huge burden of care, in sickness and in health. But what if we did things differently? What happens when we change the way we think about care itself?

This is the idea behind SmartCareCF, a collaboration that aims to transform future care, which the Cystic Fibrosis Trust wants to develop in a unique public-private partnership.

This new model seeks to take the popular rhetoric about 'patient-centred care' and make good, care that is tailored to the individual and focuses on wellbeing, not illness.

SmartCareCF challenges us to think differently about the way care is delivered.

The battle to stay healthy: 28-year-old Kayleigh faces several hospital visits a year and a demanding daily treatment regime with no guarantee of catching an infection before it hits.

The vision for SmartCareCF is one in which we harness today's 'smart technology and devices' to draw together and stream daily information that gives the individual control over their care and provides valuable trend data to their CF centre.

To enable this, the Trust is establishing a consortium to develop fully the concept and potential of SmartCareCF. "This will need to draw on expertise that others can bring to the table to make it a success," says Dr Janet Allen, Director of Research & Care at the Trust, "including the real experts: people with CF and their carers."

The consortium will bring together CF teams, regional NHS hospitals, academic centres, drug companies, diagnostic manufacturers, IT specialists and the CF community, to create the infrastructure needed to make this vision a reality.

Dr Allen states: "This bold vision sees people with cystic fibrosis empowered to keep healthy and out of hospital.

"This new model looks to take the popular rhetoric about 'patient-centred care' and make good, care that is tailored to the individual and focuses on wellbeing, not illness."

"As the full potential of SmartCareCF develops, we will be able to identify and evaluate better ways of detecting any problems earlier than is currently possible and potentially intervene earlier. Any developments here will need careful evaluation and the use of fancy tools such as the development of machine learning-based algorithms."

"Even if I stay as healthy as possible, I still have to go to hospital at least five times a year, which isn't easy when you're working full time." – Kayleigh Old

The new system of care offers a wide range of advantages, including the safe elimination of routine hospital visits when the patient is well, cutting down on the risk of cross-infection and reducing the burden of time off work or school for the patient.

Kayleigh adds: "Even if I stay as healthy as possible, I still have to go to hospital at least five times a year, which isn't easy when you're working full time. And of course, there's no guarantee that any potential infection will show on the day rather than between visits. I don't know what SmartCareCF will become, but anything that could give me more control over my life and less time in hospital would make a big difference."

This new model of care will provide complete physiological data to empower the individual and support the multidisciplinary team. Data generated at home by bluetooth devices can be securely and safely stored in the 'cloud' and downloaded both to the individual and (with the patient's consent) the multidisciplinary healthcare team at the CF centre.

"At the moment, people with cystic fibrosis have to go every two or three months, irrespective of how they are feeling and for the 70 per cent of adult patients that have jobs or are in full-time education, that can mean they have to take a whole day off just to be told everything is OK," explains ▸

Professor Andres Floto, Research Director and Honorary Consultant at the Cambridge Centre for Lung Infection. “But there is also the risk of cross-infection that exists for people with CF visiting the same unit.”

“Anything that could give me more control over my life and less time in hospital would make a big difference.”

Professor Andres Floto.

To begin laying the foundations for what might be possible, Professor Floto is leading a six-month Pilot Study, which is being funded by the Trust through the support of the Freemasons’ Grand Charity and will involve a number of CF centres.

Future features of SmartCareCF could include the possibility of remote clinical assessment through secure video conferencing and clinic review, and allow the patient and their CF team to see the impact of new treatments while the individual is at home. “We need to take this step by step, and make sure that we introduce changes in a safe way,” explains Dr Allen. “So this initial study will be non-interventional, at first. Patients will still attend their regular appointments at their CF centre – all we are doing is assessing remote monitoring of data by the patient at home and comparing it with what we normally measure in clinic.”

Ed Owen, Chief Executive of the Cystic Fibrosis Trust, warns that it is easy to misunderstand what the project is trying to achieve: “Our focus is to develop SmartCareCF to drive improved standards of care and quality of life through care that is tailored to each individual. We realise that it will not suit everyone and there are times in anyone’s life when face-to-face visits to the clinic are essential.

This is not about replacing the important relationship between patient and healthcare professionals. Rather it is about using technology in a smart way to improve that relationship.”

If this sounds aspirational, it is. The technology exists, it’s a matter of what can be done with it. The initial study will help to inform the road ahead and the consortium will, for the first time, bring together everyone involved in care to design and deliver a truly integrated approach centred around the individual.

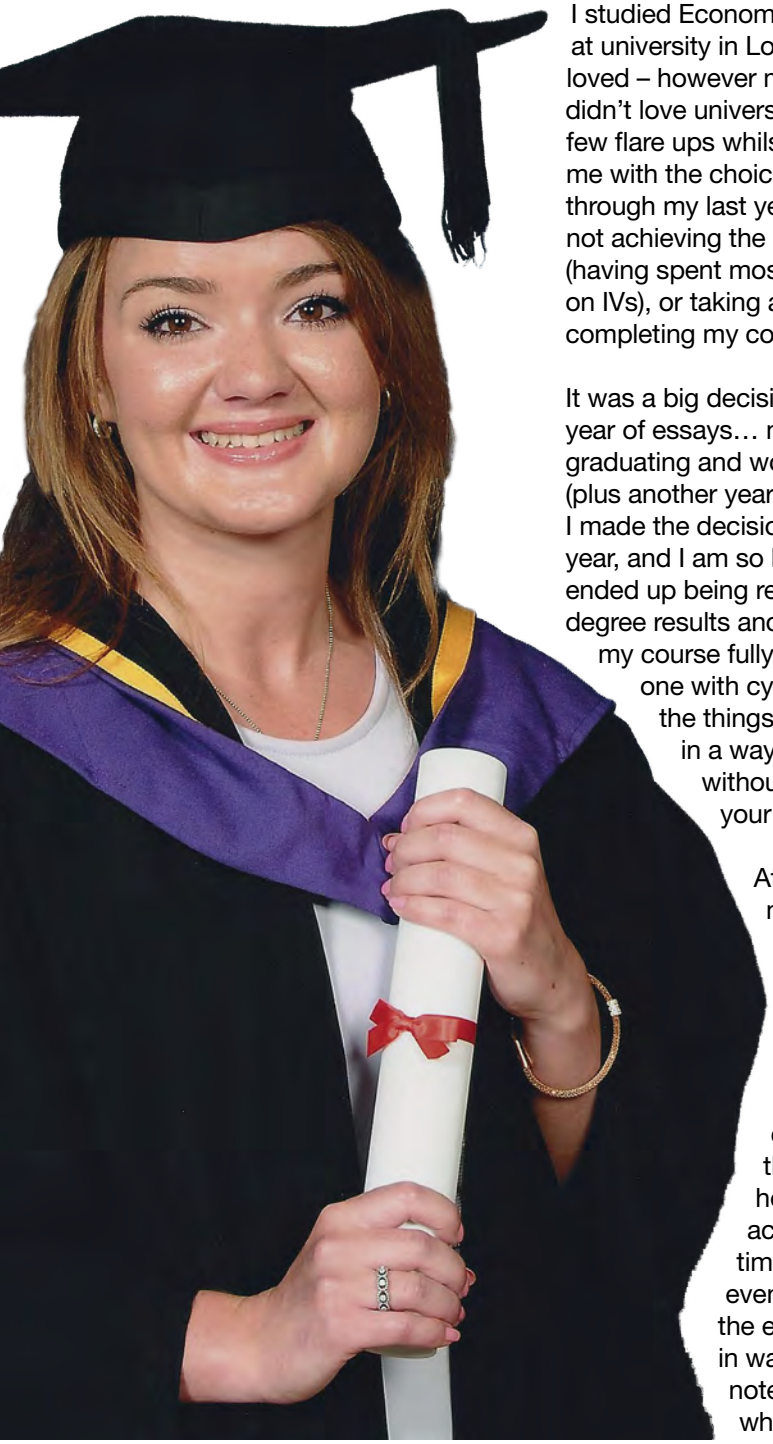
Ed concludes: “We don’t know exactly what SmartCareCF will look like, but as long as we keep an open mind, the potential for this technology to improve the lives of people with CF is enormous.”

How hi-tech are you?

We’re keen to hear how you use fitness and health monitoring technology at home and the difference it makes to your life. Tell us about your wellbeing gadgets and smartphone apps by emailing HealthTech@cysticfibrosis.org.uk.

Day in the life

Jemma Wood is a 22-year-old with cystic fibrosis, who has just graduated from university and has started her post-university adult life in London. She is currently in a graduate management consulting scheme at a major London firm.



I studied Economics and Geography at university in London, which I loved – however my cystic fibrosis didn't love university so much. I had a few flare ups whilst at uni, which left me with the choice of either rushing through my last year, and probably not achieving the results I wanted (having spent most of my final term on IVs), or taking an extra year and completing my course properly.

It was a big decision for me… another year of essays… my friends were graduating and wouldn't be around… (plus another year of debt!). However I made the decision to take an extra year, and I am so happy I did so. I ended up being really proud of my degree results and that I completed my course fully. My advice for any one with cystic fibrosis is to do the things you want to do, but in a way that works for you, without compromising your health.

At university I made the most of the Disability & Wellbeing office –they were amazing and I wouldn't have been able to complete my course without them! They helped me with accommodation, extra time in exams (they even gave me a heater if the exam room I was in was too cold!), and note-takers for lectures when I was ill.

My university also had a dedicated Disability & Employment consultant who was brilliant in showing me how employers are looking for a diverse set of employees, that employers will make reasonable adjustments and helping me decide how and when to disclose my cystic fibrosis. I'm sure most schools/colleges and universities will have similar departments who can give you the confidence about going into the workplace with cystic fibrosis!

I like to think that living with cystic fibrosis has its positives; it makes us good at time management, and determined, "get on with it"-style workers – attributes employers love to see.

The biggest challenge I have encountered since starting work is being disciplined. I have to keep to my daily medication, physio, nebuliser, and exercise routine (that I'm sure you are all familiar with). I have also had to learn when to say no at work, to make sure I get home at a decent time, and to take the rest and sleep time I need each day – or I will very quickly not make it into work the next day!

This is hard as it makes me conscious that people might not consider me as good at my job. However my team know me, and my condition, and trust that when I need to go, or need to work from home, I'm saying it because I need to.

Being this regimented does mean I feel that I am missing out sometimes, but I am determined to keep my cystic fibrosis at bay for as long as possible!

Body and soul

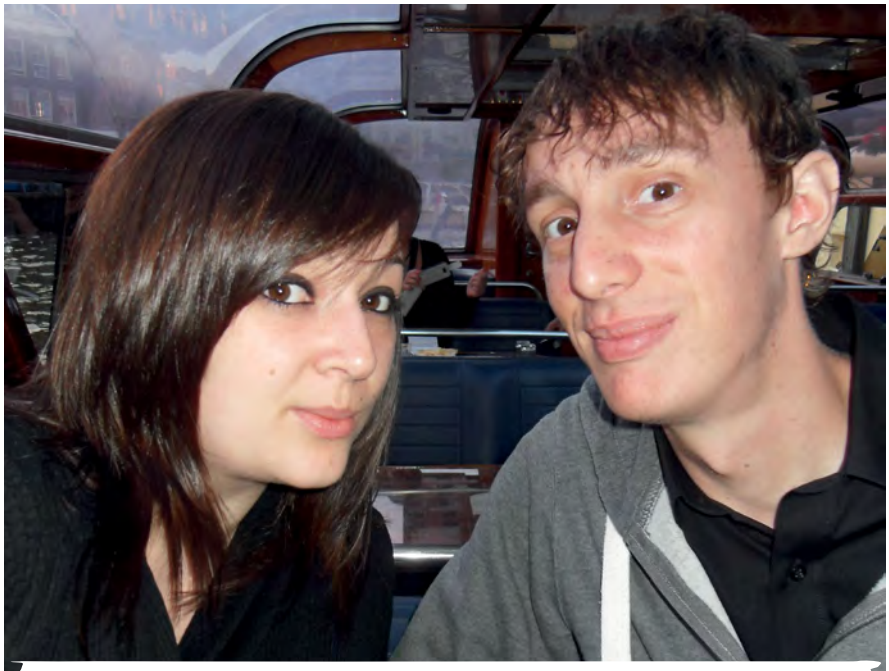
Sex and relationships can get tricky. So what happens when you add in the small matter of a lifelong and often demanding condition like cystic fibrosis? Thank you to everyone who shared their stories with us.

If you're navigating a life with cystic fibrosis, you're on pretty intimate terms with your doctor. Still, if there's one thing no one feels comfortable speaking to their doctor about, it's their sex life.

It's also not as though a sex advice column ever tackled the topic of getting jiggy with cystic fibrosis either. When did you last read a "What positions are best when negotiating my peg?" letter?

So what better way to break the taboo than get the CF community to share their experiences? It turns out more rather than less are facing the same travails, even behind the bedroom door.

"I told him I wanted a tattoo saying 'just breathe' on my ribs. Of course, he asked me why and I explained that I had cystic fibrosis."



You can get through anything: Carly and Chris won't let CF stand in their way.

Opening up

As if feeling attracted to someone, falling in love, and navigating a relationship wasn't fraught enough, when you have CF, there's the added complication of when and how to tell a new or potential partner.

For Emily, cutting to the chase was best. "When I first met my girlfriend Paris, I told her I had CF quite quickly. I tend to tell people straight away so they know what they are letting themselves in for, but she didn't seem too bothered by it."

Lara, meanwhile, looked for a different way in. "My partner has a tribal tattoo on his arm, and to strike up a conversation with him, I told him I wanted a tattoo saying 'just breathe' on my ribs. Of course, he asked me why and I explained that I had cystic fibrosis."

But for others it's altogether a more anxious process. As Rachel explains, "I dread the day I have to tell a new partner and have put it off for months at a time. With regards to my current partner, he outed me on the topic while I was trying to play down a recent hospital admission with a broken rib. Turns out he'd known for a good couple of months and had been waiting for me to tell him. My holding him at arms length had been par for the course for our relationship until the spring of this year and we had been together for more than two years before I let him visit me in hospital."

Checking what your partner understands by your condition is also important. As Emily explains, "When I told Paris I had CF, she did ask a lot of questions, most of them I didn't even know the answer to. She also did the one thing I asked her not to and looked everything up on Google, and found out all sorts of horrible things about life expectancy and illness. That meant it took her a while to understand that not everyone with CF was the same." ▸

Getting down to it

Once the CF declaration is out of the way, you can start laughing, arguing and finding out what dodgy tunes are on someone's Spotify playlists. And embark on one of the most fun parts of a relationship – the sex.

In good health, it seems a happy sex life is par for the course. It can even function as a primary source of exercise. "Aside from the fact my girlfriend's kitchen has become a bit of a pharmacy, our sex life has never really been affected by my condition," says Emily.

"Given that I told my partner immediately about my condition, he just 'gets' it if I'm having a bad day"

Having a naturally high sex drive, being sexually adventurous or enjoying casual encounters are as much a part of life for people with CF as for anyone else.

They can just be more difficult to navigate. As Rachel recalls, "I once had a one-night stand where someone referred to me as Frankenstein. Luckily I have thicker skin than that and now I bear it as a nickname and a tattoo."

And while everyone struggles with sexual confidence, CF can bring additional challenges. Not being able to maintain weight or exercise regularly can affect body confidence, as can scars, and the coughing bouts. "I hate it when I have to stop midway and cough," says Rachel, "and I hate that I can't just lie there with my partner in post-orgasmic bliss because I will need to cough afterwards."

So while sex can be feast or famine, taking advantage of the good health periods and being understanding in the not-so-good ones seem to be key for couples that keep the flame going.

As Carly explains, "If Chris and I don't have sex as much as we'd like, we have to be reassured that it's not because we don't want to, more that it's a struggle for breath for him most of the time."

After sex, the support

But given that sex is just one part of the relationship picture, ultimately empathy is what carries couples through. In fact, hospital admissions, periods apart, and the need to conserve energy may take a toll on the relationship in the bedroom, but weathering those challenges only deepens the emotional connection.

As Lara puts it, "Given that I told my partner immediately about my condition, he just 'gets' it if I'm having a bad day because I've messed up my Creon somewhere, and he's come to every hospital appointment whenever he can."

"I hate it when I have to stop mid-way and cough and I hate that I can't just lie there with my partner."

And it's not just the person with CF that benefits. As Carly explains, "It is incredibly hard living 100 miles apart and only seeing each other every two weeks, around work, treatments, physio, hospital appointments and admissions, but when you love someone as much as I love him, you can get through anything."

Call our helpline

If you have any questions or concerns about these or any other aspect of living with cystic fibrosis and you'd like to chat to a friendly, knowledgeable person, contact our confidential helpline on 0300 373 1000 Monday to Friday, 9am–5pm or helpline@cysticfibrosis.org.uk.

*Some of the names featured in this article have been changed by request.

Out in the community

The All Beans No Monkeys team and Ocean Reunion team appeared together on Channel 5's 'The Wright Stuff'.

This year, two teams of friends will be going above and beyond, when they take on the 2015 Talisker Whisky Atlantic Challenge to raise money to beat cystic fibrosis.

These would-be mariners will attempt to row over 3,000 nautical miles across the world's second largest ocean, facing 50ft waves, gale force winds, bruises, burns and sleep deprivation. It may not come as a surprise to learn that more people have been into space than rowed the Atlantic.

The All Beans No Monkeys team of Stuart Markland (31), James Timbs-Harrison (32), Liam Browning (30) and James Kendall (29), all met at university in Newcastle.

For Stuart, cystic fibrosis is a very important issue. Speaking after the crew's maiden training voyage, he said: "My nephew suffers from cystic fibrosis. He obviously has his struggles on a daily basis, and we hope to raise awareness and hopefully also some money.

"It did feel fantastic to finally be on board our boat – or our new home from home may better describe it. It's certainly going to be cosy on board, with not too much space!"

> "When we think of the work that the Trust does – and the people they help – we know it's a very small token of our appreciation"

By coincidence, joining them in the Challenge and also raising money for the Trust will be the Ocean Reunion team, comprising old friends Jack Mayhew (25) and 24-year-olds Angus Collins, Joe Barnett and Angus Barton, who is taking part despite often suffering from sea sickness and admitting to being a terrible swimmer with a fear of sharks!

Angus Collins, whose uncle is the defending world record holder in transatlantic rowing, said: "More people have climbed Mount Everest than rowed the Atlantic. It's a huge challenge for all of us but when we think of the work that the Cystic Fibrosis Trust does – and the people they help – we know it's a very small token of our appreciation."

In December the teams appeared together on Channel 5's 'The Wright Stuff'.

The teams will set off on 15 December, and row around the clock in shifts, with pairs toiling two hours on, two hours off. The course record is 39 days, although the average is 60.

Find out more and sponsor the teams at:
www.allbeansnomonkeys.com/.
www.oceanreunion.co.uk/.

Two-point perspective

Journalist Jo Willacy talks to bestselling author Jill Mansell about her new novel, 'Three Amazing Things About You', which deals with cystic fibrosis and transplantation.

Journalist Jo Willacy.

The main character in Jill Mansell's latest book Hallie, is 28, has cystic fibrosis and never expected to live this long. She's just been called because a new pair of lungs have become available. She's scared, and excited.

Three things about me:
1. I'm 42, have cystic fibrosis and also never expected to live this long.

2. My sister, Kate, also had cystic fibrosis. She never received a new pair of lungs and died aged 28.

3. I'm excited that CF is now making it into the storylines of best-selling books.

Growing up in the '70s, that's not something I could ever have imagined happening. Cystic fibrosis was little known then – I still remember the wonderful response from an elderly lady who, when hearing of our condition, whispered back, "Ooh, cystitis. Nasty. I've had that several times!"

I was fascinated to know what had inspired Jill's book.

Best-selling author Jill Mansell explores the emotional side of cystic fibrosis and transplantation in her latest novel.

Q: Why did you want to feature a main character with cystic fibrosis?

A: I've just finished my 27th book so I'm always looking for new ideas. It occurred to me I'd never known of a novel featuring a heroine with cystic fibrosis. I'd seen people with CF being interviewed on TV and, it sounds ridiculous but, I was always struck how amazing they were, despite having a life-limiting illness.

Q: You used (Cystic Fibrosis Trust Engagement Director) Oli Lewington's autobiography 'Smile Through It' to help you research your book. How did you hear about Oli's story?

A: I read a lot of blogs by people with cystic fibrosis. Initially I thought I should contact a girl with CF, because girls are more likely to be interested in reading my book. But Oli's blog stood out; it was so brilliantly written. I couldn't have written my book without his. He was very helpful when I made email contact, too, answering any questions I had. Once I'd written the book, I remember Oli's wife popping up on Twitter saying she couldn't believe he'd been having email conversations with her favourite author and had never bothered to tell her!

Q: Why is transplant on your radar?

A: I'm passionate about all organ donations and have been on the donor list since I was 18. It seems so ridiculous that organs are wasted. I worked in a hospital for years as an EEG technician and part of my work involved testing for brain death before organ donation. When people used to hear about my work I'd get comments like, "Nobody's ever having my organs… they wouldn't make sure I was dead, they'd just turn off the machine, cut me open and use my organs." There are so many misconceptions.

I've already had lots of responses from readers saying it's really changed their views. I'm thrilled. I've heard so many stories of families being in such shock after a death that they say no to organ donation, but then regret it afterwards, whereas anybody who says yes and has given permission never regrets it – it becomes such a comfort to them.

Q: What's your opinion on soft opt-out?

A: I'm hugely in favour of anything that gets people to have a transplant if they need it, so I definitely agree with the opt-out system.

Q: Are you nervous about the response you may get from the cystic fibrosis community?

A: I was very careful not to write anything that could be considered offensive and, so far, all I've had is good responses. Although I deal with serious issues in my books, the tone is fairly light. If I'd made it too medical, it would have put people off. That sounds harsh, but I'd rather people learn a little about CF from my book than nothing at all.

Three Amazing Things About Jill

1. When writing her book, Jill tried to imagine what breathing with poor lung function might feel like by covering her mouth with a cloth. "It was horrible, quite shocking," she says.

2. She's been on the bone marrow donor list for years and a few years ago was shortlisted as a possible donor. Sadly, after further blood tests she wasn't 100% suitable.

3. She loves working from her bed and writes her books by hand – her next book is 600 handwritten pages in five ringbinders!

Follow Jill on Twitter @JillMansel

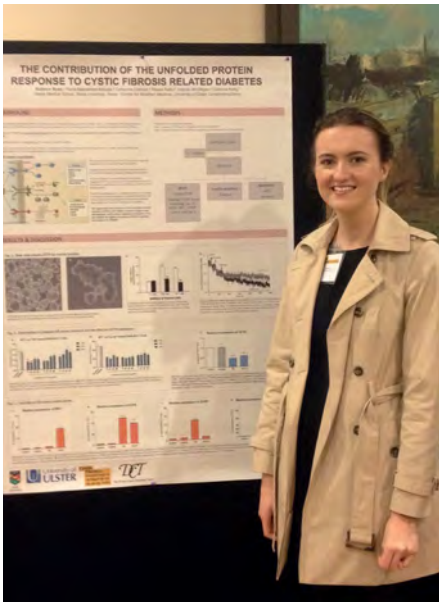
Don't forget you can find highlights of the latest news on our Twitter feed. Stay connected with the Trust at twitter.com/cftrust. **Follow us on Twitter @cftrust.**

In the lab

The Cystic Fibrosis Trust unveiled an exciting annual scheme in summer 2014 funded by D'Oly Carte Charitable Trust, to engage top medical students in cystic fibrosis research.

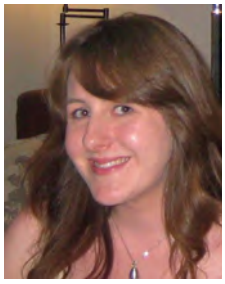
Set up in memory of Sir John Batten, physician to the Queen and founding president of the Cystic Fibrosis Trust, a new six- to eight-week programme gave five successful students an opportunity to combine clinical practice with a research programme. The students were also invited to present their work at the 2014 UK Cystic Fibrosis Conference (see page 9).

How did they get on?



"The studentship programme was a good opportunity to follow in my mother's footsteps as a researcher. After being involved in the Keele University Medical Research Committee last year, I was looking to further my involvement in research."
– Kate Ryan, 20, Keele University, who was awarded first prize for her research into cystic fibrosis-related diabetes (CFRD) by assisting with another student's PhD project.

"If you are unsure about applying for a studentship, I would definitely say go for it! It is an important opportunity to decide whether or not research is the right career for you and in my case it has certainly confirmed my interests. Being able to present my research at the conference enabled me to put my work into context on a more personal level with people who have cystic fibrosis."
– Sophie Herbert, 20, University of Bristol.



"The studentship offered invaluable experience in cystic fibrosis research. After learning about cystic fibrosis in my first two years at university and, during a hospital placement, meeting lots of people who have it, this was an incredibly interesting experience, especially with my plans to work in a hospital environment and consider going into research."
– Stephanie Murdock, 22, Queen's University Belfast.

"This studentship was my first exposure to the research environment and it has been an invaluable experience for me. The highlight was being able to attend the UK CF Conference. I felt privileged to be in an audience with such distinguished researchers and clinicians who are shaping the scientific landscape. It was an honour and an exhilarating experience to present my project to such an audience and win third prize."
– Mahesh Pillai, 21, University College London

"I wanted to develop my research skills before completing my fourth and fifth year of studying medicine. The studentship was a great opportunity to do this and I feel I have gained a lot from the experience. Although I am not completely decided on my career path, cystic fibrosis is definitely a potential area."
– Hollie Wilson, 21, Queen's University Belfast.

Janet Allen, Director of Research & Care at the Cystic Fibrosis Trust, says: "The summer studentships were a great success in attracting some of the brightest and best medical students in the UK and I hope that they will now consider a future clinical career in cystic fibrosis. It's this new generation of medical professionals that can help make a difference in beating cystic fibrosis for good."

cysticfibrosis.org.uk/corporate

Cystic Fibrosis beatable, but we need your help

Workplace partnerships are essential if we are to deliver vital change. Can a company that you or a family member or friend works for help us beat cystic fibrosis?

With your help we can get there quicker. Our Strategic Partnerships team works closely with all of our partners to make sure that everyone gets maximum benefit from the relationship.

For more information contact Kieran Cornwell, Senior Strategic Partnerships Manager on 020 8290 8064 or email kieran.cornwell@cysticfibrosis.org.uk

genotypematters.org

Cystic Fibrosis as individual as you are

Get the treatment that's the right fit for you.

When it comes to cystic fibrosis treatment, there's no 'one size fits all'. As we move into the era of personalised medicine, over the coming years we will be seeing more treatments that are tailored to you.

But in order to access these personalised medicines, you need to know your genotype.

To discover yours, talk to the staff at your CF centre at your next visit. Knowing your genotype may mean you can access new drugs that could transform your quality of life.

Your genotype could already be on record. But if it isn't, then the Cystic Fibrosis Trust will cover the costs of a simple test to reveal yours.

Visit genotypematters.org

Know your genotype.

#genotypematters

ONE SIZE FITS ALL