Cystic Fibrosis Trust

Issue 14
cysticfibrosis.org.uk

CF Life

Pregnancy and CF
A baby boom in the CF community

QuestionCF
Shaping future CF research

Your stories
James Dunmore on fundraising in memory of his sisters

Uniting for a life unlimited

What's inside

Issue 14 – March 2023

If you'd like to give us feedback on this issue, or have ideas for what you'd like to see in the magazine, email us at **magazine@cysticfibrosis.org.uk**

On the cover: Gillian, who features on p30
This page: James Dunmore, who features on p14

Social

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forum.cysticfibrosis.org.uk
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Useful contacts

Donations
020 3795 2177
supportercare@cysticfibrosis.org.uk

Events and fundraising enquiries
020 3795 2176
events@cysticfibrosis.org.uk

Cystic Fibrosis Trust Helpline
0300 373 1000
helpline@cysticfibrosis.org.uk

Our confidential Helpline offers general advice, support and information on any aspect of cystic fibrosis, including help with financial support.

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Welcome to CF Life

In this issue of CF Life, we're really excited to reveal the top 10 refreshed priorities for CF research, as chosen by you, and how we plan to work with the CF community to act on them.

We also explore the increasing number of people with CF becoming parents – as revealed in our recent CF Registry Report – and hear about a first of its kind antenatal clinic set up at the Brompton to support people with CF on their pregnancy journey.

Following the launch of Work Forwards, our new programme of employment support for the CF community, we hear from Gary McNally, Employability Manager at the Trust, about some of the challenges facing people with CF when it comes to work.

And in our new ***What's on your mind?*** column, Matthew from our Helpline team answers some of your pressing questions about CF. This month he covers housing and the support people with CF can access.

Elsewhere in this edition, you can read a moving interview with ***Made in Chelsea*** star James Dunmore, who talks candidly about losing his two sisters to CF and fundraising in their memory.

We hope you enjoy this issue, and please get in touch with your ideas and feedback. We love to hear from all our wonderful supporters.

The CF Life team

Uniting for a life unlimited

In case you missed it

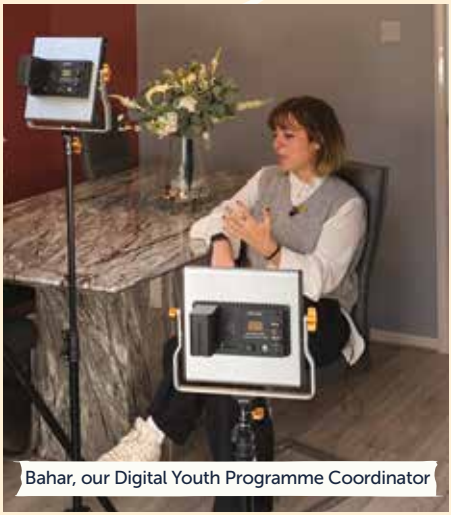
Fundraising

The 20th Anniversary of the Alice Martineau Carols by Candlelight service was held back in December of last year. It raised an incredible £60,000 with over 600 guests in attendance, and even more streaming the service online. The evening's speakers included Mishal Husain, Trudie Goodwin, Zephryn Taitte, and our amazing supporter Charlotte Bones, who has CF.

Charlotte spoke movingly about her life with CF and how doctors advised her that, at age 27, she should prepare for the worst. She also talked about her experiences of the COVID-19 pandemic and a period of severely poor health, which left her in continuous pain. **"CF has never, and will never, get the better of me,"** Charlotte told the audience, and since starting Kaftrio, Charlotte's health has improved greatly. Last year she even took on an epic fundraising trek with her family, many of whom were in the audience, to raise money for the Trust.

On behalf of the Alice Martineau Appeal Committee and the Trust, a big thank you to Charlotte and everyone who joined us and made it a night to remember!

Charlotte



Bahar, our Digital Youth Programme Coordinator

Young people

Back in October 2022, we worked with the BBC on a video about how our gaming workshops have helped children with cystic fibrosis. These workshops are funded by Children in Need's Building Brighter Futures programme, and run by Bahar, our Digital Youth Programme Coordinator. Bahar along with Natalie from our media team, went up to Liverpool for the day with a crew from BBC Sport to film with one of the children, Izzy, who takes part in these workshops, as well as talking to her family about the impact of this experience on her.

It was a great chance to talk to Izzy more about how gaming online has helped her to make friends with other children who have CF, without the risk of cross-infection.

Find out more about our Building Brighter Future workshops on page 32.

Research

At the end of 2022, Vertex Pharmaceuticals announced that they had approval from the Food and Drug Administration (FDA) to begin early phase clinical trials of their mRNA genetic therapy as a treatment for cystic fibrosis. This trial is the result of a collaboration between Vertex and Moderna. mRNA therapies work by adding undamaged protein-making templates for the CFTR protein into cells. This is encouraging news for people with CF who have gene mutations that do not respond to modulator drugs, such as Kaftrio. For more information on clinical trials, visit our Trials Tracker at **cysticfibrosis.org.uk/trialstracker**.

Support

We're delighted to share that following assessment Cystic Fibrosis Trust is now part of the PIF TICK accreditation scheme, run by the Patient Information Forum (PIF), which is the UK's only quality mark for print and online health and care information. This means you can be assured that everything you are reading, watching or listening to from us is evidence-based, understandable, jargon-free, up-to-date and produced to the best possible standard. Our Information Manager, Alison Taylor, said: **"With so much information online, it can be difficult to know what to trust. This quality mark is a quick and easy way for people to be assured our information is reliable and trustworthy."**

Read and download all our information resources at **cysticfibrosis.org.uk/information**.

Campaigning

Over the last year many people within the CF community have been sharing their experiences of the cost of living with cystic fibrosis.

We have always known that having CF, like many other long-term health conditions, means extra costs and lost income. Now, research from University of Bristol in partnership with Cystic Fibrosis Trust provides evidence to quantify this.

Thanks to the insights from people with CF and their families, the researchers have been able to measure the additional spending that is required and the impact on household income caused by living with CF. You can read more about the key findings of the research at **cysticfibrosis.org.uk/costofliving**.

We will continue to raise awareness of the financial challenges facing people with CF, campaign for greater support from Government and strengthen the direct support that we provide to those in our community who need it most.

Together we're shaping the future of CF research

In November of last year, we were excited to announce a refreshed list of CF research priorities, decided by you in several stages throughout 2022.

The James Lind Alliance CF research priority refresh project, or 'QuestionCF' for short, was a partnership between the CF community, the Trust, researchers at the University of Nottingham and the James Lind Alliance (JLA) team at the National Institute for Health and Care Research (NIHR). We're the first group to refresh disease-specific research priorities following the JLA process.

In this article, we recap on the journey to get here, share some of your comments along the way and reflect on how these new priorities will shape future research.

Why is it important to identify research priorities?

Research into cystic fibrosis has the potential to improve the lives of people with CF in lots of different ways. Scientists and clinicians are very committed to working in CF research and a list of research priorities help give focus to their work. In turn this means that we can work together to make the biggest difference to the CF community.

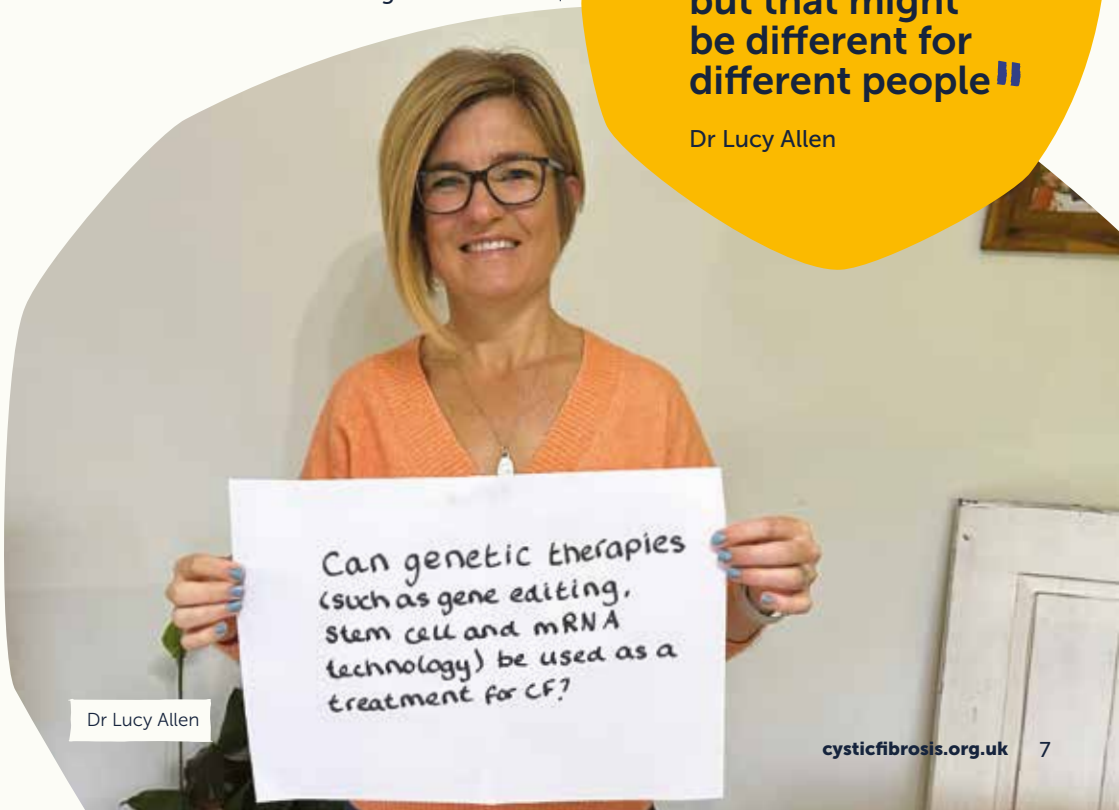
We want to make sure that the research we fund is important and relevant to you. So, the research priorities are important to the Trust in helping us decide which research projects to fund.

Working with the CF community, a research priority list was first drawn up in 2017. But since then, so much has changed for the CF community. That's why last year we wanted to find out which aspects of CF you'd like researchers to focus on right now.

"Everybody's striving for a cure, but that might be different for different people. We also need to think about the immediate needs of people with CF as well as the long-term goals," says Dr Lucy Allen, Director of Research and Healthcare Data at the Trust.

"The research priority refresh project is really important. People have told us exactly how they're feeling right now, and therefore what their research priorities are, whether they are to address immediate health needs or more longer-term priorities."

> **"Everybody's striving for a cure, but that might be different for different people"**
>
> Dr Lucy Allen



Dr Lucy Allen

What are the refreshed CF research priorities?

After an 11-month-long project, consisting of two surveys and one online workshop, people with CF, their loved ones, CF professionals and researchers identified the following topics as their top priorities for CF research.

1. What options are available for those not able to take current CFTR modulators (including rarer mutations, not eligible and unable to tolerate)?

2. What is the best way to diagnose lung infection when there is no sputum eg children and those on modulators?

3. How can we relieve gastro-intestinal symptoms, such as stomach pain, bloating and nausea?*

4. How do we manage an ageing population with CF?

5. Is there a way of reducing the negative effects of antibiotics eg resistance risk and adverse symptoms in people with CF?*

6. What are the long-term effects of medications (including CFTR modulators) in CF?

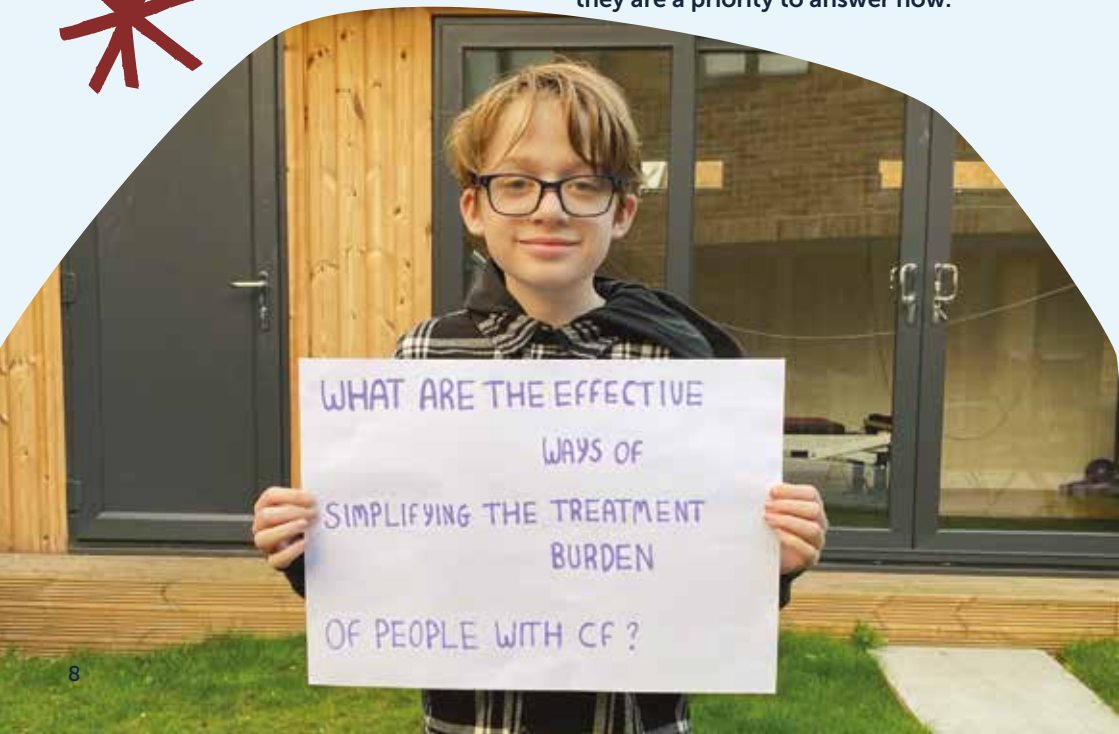
7. What are the effects of modulators on systems outside the lungs such as pancreatic function, liver disease, gastrointestinal, bone density etc?

8. What are the effective ways of simplifying the treatment burden of people with CF?*

9. Can genetic therapies (such as gene editing, stem cell and mRNA technology) be used as a treatment for CF?

10. Is there a way of preventing CF related diabetes (CFRD) in people with CF*

The research priorities marked with * are questions that you told us were priorities in 2017 and you still feel that they are a priority to answer now.



How were the priorities chosen?

Your top 20 research priorities identified in 2017 were the starting point for the project. Survey 1 took place in January to February. 1,600 people from around the world completed an online survey, reviewing the existing 20 research priorities and telling us about your research questions that weren't on the list.

"We're delighted that we were able to reach a wide geographical area with this project," commented Dr Nikki Rowbotham, East Midlands-based paediatrician and researcher. Nikki was a member of the QuestionCF project management group and, together with colleague Sherie Smith, conducted the data analysis of the responses.

"Thanks to our international steering committee we were able to reach people all over the world. With the wonderful help of colleagues in CF Europe we were able to provide translations of the survey in eight European languages".

Over the summer, members of the QuestionCF project management team reviewed all of the answers in detail. After much discussion, a long list of 71 questions was finalised, which we asked people to review in the second survey.

These 71 questions were summary or 'umbrella' questions, where lots of similar questions were grouped together. In some cases, this was many individuals asking the same question, and for some umbrella questions, this was lots of slightly different questions on a related topic.

In the second survey, people were asked to choose their top 10 questions from the list of 71 questions. Then they were asked to choose which question they'd put as their number one priority, which as their second priority and so on.

From everyone's answers to the second survey, a list of the top 17 questions were taken to an online workshop.

The workshop was run online over two days and 22 people took part. There were many different experiences represented at the workshop, including people with CF, family members of people with CF, CF professionals and researchers. Those with CF who took part were of various ages, and had different experiences of CF including those who were on CFTR modulators, those who were not eligible (including people post-transplant) and those unable to tolerate them. Most of the discussions took place in facilitated small groups.

During the surveys, everyone taking part was asked to choose the questions that mattered to them based on their own experiences. The workshop meant that those taking part were able to consider other people's experiences and take them into account when choosing the top 10 priorities.

"Personal stories made a huge difference to my choice of rankings. The small groups in the workshop were a fabulous way to ensure everyone had a say and that their perspectives could be considered. It was a really moving experience to be part of," commented one of the workshop participants afterwards.

Another said, **"I edited my mental list heavily from listening to other's experiences and others said the same from hearing mine."**

At the end of the workshop, a consensus list of the top 10 priorities was identified and shared with the wider CF community.

"The small groups in the workshop were a fabulous way to ensure everyone had a say and that their perspectives could be considered."

Workshop participant

How will these priorities be used?

These research priorities will be used to guide what CF research the Trust and other research funders support in the future.

We'll be talking to CF researchers about how their research studies might answer these questions, and what is the best way to help them get answered. We'll also be sharing the results with other funders of CF research, so we can work together to get as many studies funded as possible.

"The results will drive the research agenda in CF for the next five years. I want my children's future to be that they live their life with the rigour of CF as a dim and distant memory – and I think that community-driven research will get them there," says Zoë, member of the project management committee, whose children have CF.

Thank you

A really big thank you to everyone who took part in the surveys and workshops and helped spread the word about this important project.

If reading this has sparked an interest in having your say in other CF research projects, please get in touch with our Involvement team to find out more via our website: **cysticfibrosis.org.uk/involvement**.

How can I find out more?

You can read more about the CF research priority refresh project at **cysticfibrosis.org.uk/researchpriorities**

Zoë

> **"I want my children's future to be that they live their life with the rigour of CF as a dim and distant memory"**
>
> Zoë

"Our gold dust"

Our UK CF Registry is a vitally important anonymized database for everyone with an interest in CF. We caught up with Dr Jamie Duckers from the All Wales CF Centre based in Cardiff to find out how he uses data from our UK CF Registry in his research.

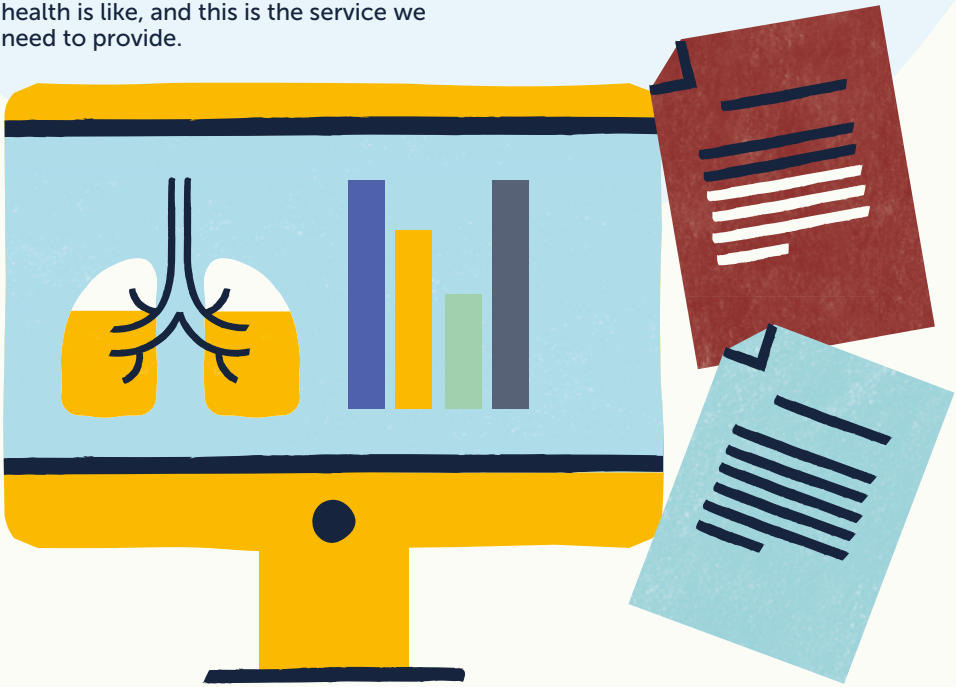
Hi Jamie. Can you tell us why you think the UK CF Registry is so important?

The purpose of the UK CF Registry is to improve the health of people with CF. Non-identifiable data from the Registry is used to help people understand their CF, and help doctors and researchers monitor the safety and benefits of new drugs (including CFTR modulators such as Kaftrio). Data within the Registry helps to drive up standards of care, and it also helps us to work with commissioners to ensure there is enough funding. We can say to them, we know how many people with CF we're looking after, we know what their health is like, and this is the service we need to provide.

I use the headline data from the UK CF Registry annual report to help answer questions people ask me at their clinic appointments – and people can read the report for themselves if they want to too.

What research are you doing with UK CF Registry data?

A lot of women wanted to know about the experiences of people with CF at our clinic who had children. From our clinic data alone we couldn't make any general comments about what they might expect – people's lung functions were different and they had different CF complications.




Dr Jamie Duckers

We did some research with colleagues in the US to analyse data from UK CF Registry and data from the US CF Registry to give a more detailed picture. As a result, we know a lot more about the experience of having a family if you have CF. The UK CF Registry also includes information on men with CF who have had children and we've included that in the analysis too.

This sounds like exciting research! How will it help those with CF planning a family?

People with CF are helping us develop an online decision-making tool for those thinking about starting a family in the UK, adapting it from a US tool. We hope it will give people with CF the answers to their questions, if and when they're ready to ask them.

Conducting this research has also helped us update colleagues in other areas of medicine about how much life has changed for people with CF now.

How is UK CF Registry data being used to support clinical trials?

The UK CF Registry is becoming essential for clinical trials. It may be used in the future to help decide where to set up clinical trials for people with rarer CF gene variants. We can also use the UK CF Registry to be smarter about how we use and collect data from people with CF during clinical trials; for example, as is happening in the CF STORM trial.

The UK CF Registry is like gold dust, we're so lucky to have it. It guides how we help people with CF to manage their condition now, and we can conduct research to answer their questions about the future.

Where can I find out more?

To read more about the UK CF Registry, and all our latest reports, visit **cysticfibrosis.org.uk/registry**.

“My sisters had an incredible zest for life”

James Dunmore, former star of *Made in Chelsea*, sadly lost his two sisters, Lucinda and Jodi, to cystic fibrosis when he was a young boy. Since then, James has raised thousands of pounds for Cystic Fibrosis Trust by climbing Mount Kilimanjaro, and has supported our campaigns for access to life-changing CF drugs on the NHS. We caught up with James to hear more about his memories of his sisters, coping with the grief, and his determination to raise vital awareness and funds in their memory.

James

James's sisters Jodi and Lucinda

Hi James! Thank you for chatting to us. Can you tell us a little bit about yourself?

Howdy, I'm James, I'm 32 years old and I'm most well-known for featuring in ***Made in Chelsea*** some years back. Nowadays, I have a renewable energy company that produces both wind and solar power. I love all things sport, being in the outdoors and animals, especially my two dogs Marley and Kody.

What was your childhood like growing up with cystic fibrosis in the family?

Growing up with my two sisters having CF is all I know, so to me, my childhood felt completely 'normal'. Of course, there were parts that I knew other people didn't have to deal with, such as the vast amounts of medication, physio and hospital visits. But to me, this all felt like everyday life.

CF can take lives far too prematurely, so my parents tried their hardest to ensure we lived life to the fullest and had no regrets. In many ways my parents lived out of their means in order to spoil us and allow us to make amazing memories. So for that, I am eternally grateful.

And tell us about your sisters, Jodi and Lucinda. What are your favourite memories of them?

Above all, my sisters were amazing people. They both shared an unbelievable outlook on life and had an incredible zest for life despite living with CF. Their personalities were incredibly infectious and left lasting impressions on everyone they met. My favourite memories of my sisters are being together as a family, laughing and messing around on holiday with not a care in the world.

They sound like incredible people. How did you and your family cope with the grief when you lost them?

I'm not entirely sure how we coped in the early days if I'm honest. I think just taking every day as it came, remaining close to each other, and being there to support each other is about all you can really do. My parents have always made sure that we speak about my sisters, sharing stories and memories and remembering the good times. As time goes on you evolve to a certain extent, learning how best to cope with the grief and what works for you. And with that, in time, it becomes part of you, shapes how your life goes forward and influences the decisions you make.

What would be your advice to other siblings who have lost a loved one?

I think the most important thing is to keep sharing memories and talking about the loved one. I truly feel this is imperative to learning to cope and it ensures they don't become a taboo subject that must not be spoken about.

I am also a massive believer in turning a negative situation into a positive. Completing challenges or hosting events in their memory is a great way to not only honour your loved one, but is also very cathartic.

You've done lots to raise awareness and funds in their memory. What does this mean to you?

Continuing to raise awareness of CF is really important to me. The amazing strides that have been made in treatments in the time since my sisters passed away is astounding and a true reflection of what is possible with increased awareness and funds.

Looking to the future, what are your hopes for the CF community?

I would of course love to see a cure for CF and believe it's entirely possible in my lifetime. It would also be great to see further advancements in medication and treatments, finding new ways to treat and repair CF lung damage so that everyone with CF can live healthier and longer lives.

Thank you so much for your support, James, and for sharing your story with us.

If you are coping with bereavement and would like to talk to someone, you can call our **Helpline** on **0300 373 1000** or email **helpline@cysticfibrosis.org.uk**.

If you'd like to find out more about how you can remember someone special, please email **inmemory@cysticfibrosis.org.uk**.

Knowing me Knowing you

In our new feature Knowing me, knowing you, we're introducing you to people from across the CF community – from researchers and clinicians, to staff and volunteers here at the Trust. In this issue, we say hello to Gary McNally, Employability Manager at Cystic Fibrosis Trust. We caught up with Gary to hear more about his role, some of the challenges facing people with CF when it comes to work and employment, and our exciting new programme of employment support launching this year.

I have been working in employability information, advice and guidance for about seven years.
I previously worked for a recruiter but was becoming increasingly frustrated by the lack of equality and inclusion in the job market. It ignited my own passion to help people from marginalised communities navigate employment.

I'm the Employability Manager here at Cystic Fibrosis Trust.
I'll be leading a team to deliver our new Work Forwards programme and other employment projects like the Helen Barrett Bright Ideas Awards. We'll be offering bespoke careers guidance and support to people with CF, as well as their carers, to help everyone find success in their chosen career. As well as one-to-one mentoring, there'll be a range of workshops on everything from preparing for an interview, to when and how to disclose your condition to an employer.

I'm hoping the Work Forwards programme will build the confidence of people in the CF community.
I hope it will help people to recognise that they've got something to offer and that there is a space for them.

My top tip when it comes to employment would be to know what your red lines are. Know what you need the job to do for you and what it can't include – for example, if you need your mornings free for physio or need a role you can do at home. I'd encourage you to think about what your needs are before you even think about what job you'd like to do.

Something people might not know about me is that I speak Italian surprisingly well – particularly given I hate the sun!

Gary

To find out more about Work Forwards, visit **cysticfibrosis.org.uk/WorkForwards**, or get in touch with our Helpline at **helpline@cysticfibrosis.org.uk** or **0300 373 1000**.

Easy exercise

We recently launched our first ever Cystic Fibrosis Exercise Practitioner Fellowship. The 12-month fellowship has been awarded to Lucia Diego-Vicente, who is based in the CF team at the Royal Victoria Infirmary in Newcastle-upon-Tyne. Here, Lucia shares some simple exercises for the CF community to try at home.

"These are two examples of exercises you can do almost anywhere: an easy option and a more challenging option. Start with 8 to 10 reps and repeat two or three times with a rest in between sets," explains Lucia.

"Always remember to warm up for around five minutes before you start your exercise. You could try marching on the spot or a light jog. Also add a few forward punches to get your upper body moving. A cool down after exercising is also really important; take three to four minutes to bring your heart rate down and stretch the muscles."

Exercise 1: Squat

- Stand straight with your head up
- Engage your core and torso
- Lower yourself down as if you were sitting in a chair
- Straighten your legs to lift back up
- Repeat

You can modify this exercise by holding on to a wall or chair for support, and not lowering down as far.

Exercise 2: Press up

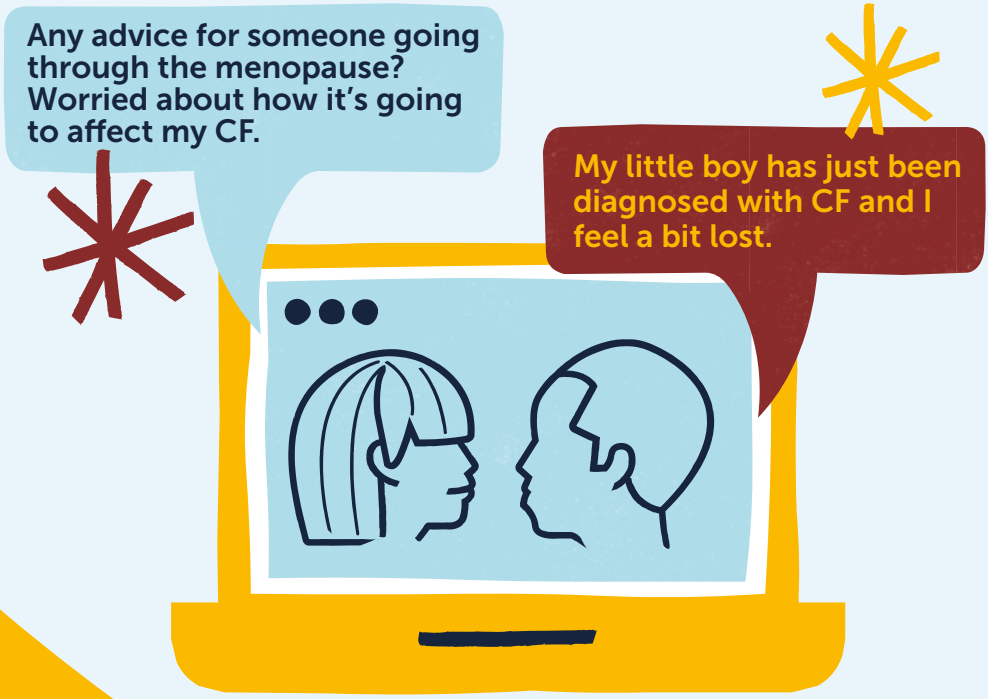
- Place your hands underneath your shoulders
- Keep your arms and legs straight
- Lower your body until your chest nearly touches the floor
- Push yourself up
- Repeat

You can modify this exercise by using a wall rather than the floor. The closer you are to the wall the easier it is.

Staying safe while you exercise: My top tips

- Stay hydrated!
- If you have CF diabetes, monitor your blood sugar levels and carry a glucose snack when exercising in case you have a hypo.
- Try and eat a small snack 30-60 minutes before exercise.
- Always ask for advice when it comes to your PEG or PORT, but avoid heavy lifting unless agreed by your CF team.

Cystic Fibrosis Trust



Introducing our Forum

Connect with others who know what you're going through.

Join our online forum today and chat with others in the CF community. Come together, share experiences, and talk about the topics that matter to you.

Visit **forum.cysticfibrosis.org.uk**

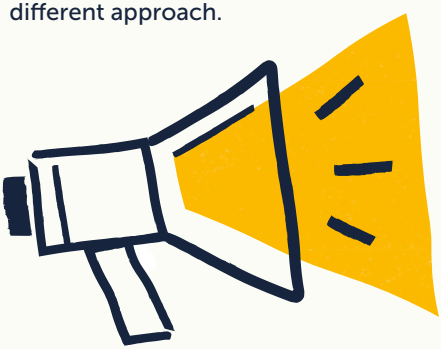
Uniting for a life unlimited

"We are on your side"

April 2023 marks 10 years since Personal Independence Payment, or PIP for short, was first introduced. Sangeeta, Welfare and Rights Advisor at the Trust, shares her reflections on this huge welfare reform that has affected so many people with CF – and includes some of her tips for making your case stronger.

Many of you reading this will have heard of PIP, and some might have experiences of claiming for it. I've worked at the Trust for seven years and it continues to be a big topic in the CF community. In fact, it is the most popular enquiry I receive through our Helpline and the process of applying for PIP often causes a lot of worry for people with CF.

Before I reflect on the past 10 years, and the part the Trust has played in guiding people through the PIP process and campaigning to make the disability benefits system fairer, here's a rundown of what it is. PIP is a benefit which replaced Disability Living Allowance (DLA) for adults over 16 making new claims. Having a long-term disability or illness can make your life more difficult and affect your income. PIP is there to help with additional costs of disability. It is based on a functional assessment, covering 10 daily living activities and two mobility activities. In March 2022, Adult Disability Payment was launched in Scotland to replace PIP. It's based on the same criteria but using a different approach.



Sangeeta

On your side

The rules for claiming PIP are stricter than DLA. We soon started to hear from people with CF who were struggling. We wanted to ensure that our community had the best possible practical support and understanding. The Welfare Advice Service was developed and I was recruited to help families with their claims.

I've worked with the Policy and Public Affairs team at the Trust to attend frequent PIP Working Groups with CF social workers. Together we designed resources that would empower claimants. One issue was that the assessors did not understand CF as it can be an invisible condition. We raised awareness by sharing stories and educating them on CF.

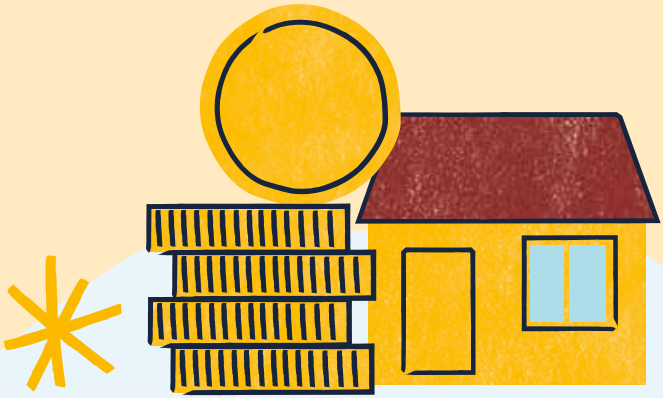
Up until mid-2016, people undergoing assessment for PIP were forced to undertake peak flow assessments and other respiratory function tests. Following complaints from the community, we raised the relevance and safety of these tests with the Department of Work and Pensions (DWP) and they were eventually stopped. We also took a case to the Upper Tribunal in 2020 about the burden of therapy involved with CF and how this should qualify for points in PIP assessments – and won!

More recently, we've responded to Government consultations on the benefits system and fed back your experiences after over 700 of you shared your views.

The future of PIP

Despite these important changes, we know there is still much work to be done to make sure the system is fair for everybody – and we will continue to campaign hard to make sure everyone can access the support they are entitled to. The success rate (the proportion of applications that are awarded PIP) has stayed roughly the same since 2016 at just 40%. But 70% of PIP appeals overall are won.

We are always here to support you to make your claim as strong as possible, by helping you to understand the rules and effectively challenge decisions when things go wrong. We are on your side.



Tips to help you prepare for a PIP assessment

Ask for help
You don't have to go through this alone. Visit **cysticfibrosis.org.uk/PIP**, or contact our Welfare and Rights Advisor via our Helpline to ensure you're clued up on the rules.

Keep a diary
From as early on in the process as you can, keep a diary as CF can affect you differently from day to day.

Be clear about your condition
It can be difficult for people to fully understand what CF is and how it can affect people. You should assume that people assessing your application know little about CF.

Be positive
Remember, you're only asking for what you need to help live your life. Be confident and ask for what you deserve!

Get in touch with our Helpline on **0300 373 1000** or visit **cysticfibrosis.org.uk/costofliving** for more information and support.

10 years of 65 Roses

The past decade has seen incredible advancements in cystic fibrosis care and treatments, changing what it means to live with the condition today. Members of our 65 Roses Giving Club have been on this journey every step of the way; raising over £700,000 towards our mission to ensure everybody with CF can live a life unlimited. As the Club celebrates its 10th anniversary, we speak to some of our members about all that has been achieved during this time – and what still needs to be done so that everybody with CF can access the treatments they need.

"We are learning so much more about cystic fibrosis every year, and people living with CF are living longer than ever before. Becoming a dad, something I never thought could happen to me, has made me realise how important it is to ensure this progress continues and gathers momentum," says Rob Law, patron of our 65 Roses Club and the entrepreneur behind the luggage phenomenon Trunki.

In the 10 years since it launched, Rob and fellow members of the 65 Roses Club have seen the CF landscape change massively. From the introduction of the modulator drug Kaftrio back in 2020, to an increase in the life expectancy for those with CF.

Members of the Club, which is made up of wonderful supporters who donate a minimum of £1,000 a year to fund our vital work, have raised over £700,000 in the past decade, money that has made a huge difference to people with CF and their loved ones. But there is still much work that needs to be done until we can truly achieve a life unlimited for every person with CF – something that is not lost on fellow 65 Roses Club patron Dame Barbara Kelly.

Rob Law

"I have been a supporter of Cystic Fibrosis Trust since its early days, having sadly lost two sons to cystic fibrosis: Hamish, shortly after his birth in 1961 and Jonathan in 1985 at the age of nearly 20," says Barbara. **"When Hamish and Jony were born, the prognosis was dire and there was little support for families like mine, particularly in rural Scotland. It is wonderful that things are different now but we still have a long way to go before we can say that CF has been beaten."**

Our supporter Robert Aitken has been with the 65 Roses Club since the start. He was motivated to get involved because two of his daughters have CF. **"When they were diagnosed in 2002, it felt like really bad news and I wanted to do anything I could to help move things in the right direction,"** Robert explains. **"Being a member gives me an opportunity to keep up to date with the latest news and advancements in CF, attend special events and see first-hand the difference the Trust is making."**

It is thanks to incredible supporters like Robert, Rob, Barbara and all of our 65 Roses members that we can continue to be at the cutting edge of CF research. But we know this is just the start. Incredible progress has been made, but there is still a long way to go until everyone with CF can truly live a life unlimited. Here's to another 10 years of making a difference, together.

How you can get involved

A big thank you to all our 65 Roses Club members, past and present, for their support over the past decade, particularly in these challenging times.

Find out more about how you can join the Club, and what you will receive for your generous gift at **cysticfibrosis.org.uk/65rosesclub**.

Robert Aitken

Lights, camera, ACTION!

Jonathan Phillips, a filmmaker from South Wales, received a Helen Barrett Bright Ideas Award in 2022. Here he talks more about his passion for film, his latest project, and what the Award means to him.

I'm Jonathan, I'm 38 years old and I live in Cardiff with my wife Laura. I was diagnosed with cystic fibrosis a bit later than most, when I was 17. I suffered with a lot of different illnesses and problems as a child, until my lungs started to deteriorate in my teens. After a few cases of pneumonia, I was finally diagnosed with CF.

Jonathan

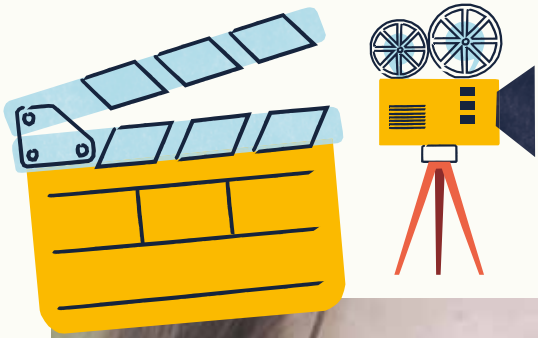
As well as my CF, I've also had two cases of lymphoma which has made my condition a lot more difficult to handle over the years. I'm now 10 years cancer free and finally in a pretty good place in my life. At the same time, the cancer has had a major effect on my general health and who I am as a person. It has taught me to appreciate my life and those around me.

One of the things that has really helped me deal with my CF diagnosis is my love of film. At first writing scripts was little more than a hobby, a form of therapy that kept me sane. Then a few years ago, I started to take it a bit more seriously, and in 2019 my short film, ***She's OK***, was broadcast on BBC Two Wales.

> **"For as long as I can remember, I've loved nothing more than to lose myself in a story, to escape the pain around me and forget about the realities of my existence."**

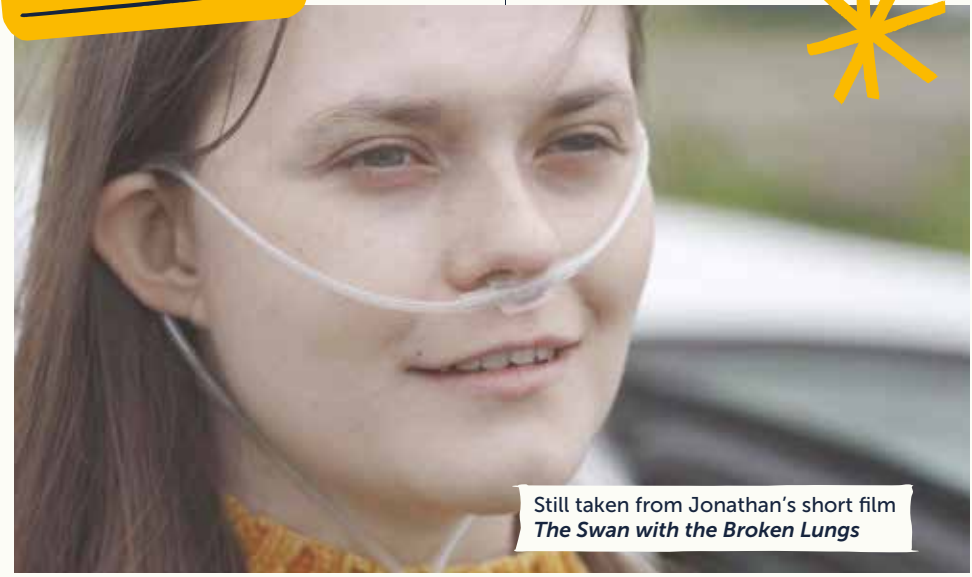
This has given me a desire to want more, which led to my Bright Idea. With the help of the wonderful guys over at Now in a Minute Productions, we've produced another short film, ***The Swan with the Broken Lungs***, which is due to be premiered later this year.

It's a story I have wanted to tell for quite a while now and is based loosely on my experiences of CF. If this film can have any impact whatsoever on helping to spread the awareness of the condition, then I'll be a very happy man. The money I've been awarded from Cystic Fibrosis Trust will go towards production costs, such as paying actors and crew, as well as marketing the film through festivals and a premiere.



My health has always stopped me from being able to really dream and think about enjoying a future. Scriptwriting has helped me see a light at the end of the tunnel and to finally be able to dream. I am so incredibly grateful to the **Helen Barrett Awards** for giving me a chance to do what I love.

Whether you have a creative hobby and need the resources to turn it into a thriving business. Or have already started your business and need some funding and support to help you expand and reach more people. A Helen Barrett Bright Ideas Award can help you turn your dream into a reality. Award winners can receive a grant of up to £5,000 to boost their business idea, as well as access to expert support and guidance. Find out more and apply at **cysticfibrosis.org.uk/brightidea**.



Still taken from Jonathan's short film ***The Swan with the Broken Lungs***

Baby boom

Our latest CF Registry report revealed a rising number of people with CF becoming parents, with over 100 people with CF having a baby in 2021 – nearly double the number from 2020. In this article, we speak to Dr Imogen Felton, consultant in adult CF and respiratory medicine at the Royal Brompton, about a first-of-its-kind antenatal clinic set up at the hospital to support women with CF on their pregnancy journey.

We are in a time where there are more people living with CF in the UK than ever before. As access to new treatments increases across the community, we have seen real progress for people with cystic fibrosis. For many, lives are getting longer and healthier and, in turn, new doors are opening. One area which has seen significant change, is the number of people with CF becoming parents. The latest numbers from our CF Registry report revealed that 103 women had babies in 2021, compared to 56 in the previous year.

One hospital has responded to this rise by setting up a service specifically for people with CF who are pregnant or planning parenthood. The Royal Brompton in London has around 600 adult CF patients, making it one of the largest centres in Europe. In 2021, 27 women with CF at the hospital became pregnant, a fourfold rate rise which continued in 2022. Previously, the CF service only saw seven pregnancies each year.

Gillian, who has CF, with son Frederick

This first-of-its-kind monthly clinic was set up in 2021 and involves a multidisciplinary team of CF specialists, including consultants, psychologists, nurses, dietitians, pharmacists, and physiotherapists, as well as clinical genetic counsellors, physicians specialising in pregnancy, and local midwifery teams, who meet virtually with pregnant women and their partners.

The reproductive and maternal health service includes group virtual meetings, such as exercise classes, and one-to-ones for more personalised advice on having a healthy pregnancy with CF. From conception, right through to delivery and the early days of parenthood, the clinics aim to provide couples affected by CF with the info and support they need during their pregnancy journey.

Dr Imogen Felton started working as an adult CF consultant at Royal Brompton Hospital in 2019 after completing the Trust's Training Fellowship. During this short time, she has seen "seismic changes" in the CF landscape. This, she tells us, was part of the motivation for setting up the clinic.

> **"It is thought that Kaftrio is affecting the reproductive tract, as it is other organs, making it easier for women to become pregnant"**
>
> Dr Imogen Felton

Dr Imogen Felton

"What quickly became apparent to us was an oncoming wave of planned, as well as some unplanned pregnancies, in women who had started taking Kaftrio after it was made available in 2020, and so evidently our service model needed to change rapidly to reflect this," Imogen explains.

"Kaftrio stops the build-up of sticky mucus in the organs that causes many of the symptoms of CF. It is thought that Kaftrio may be impacting female fertility through a combination of direct effects on the reproductive tract, as it is other organs, making it easier for women to become pregnant, as well as the significant overall improvement in lung and nutritional health in women taking the medicine supporting successful conception.

"By early 2021 we knew we needed to focus our efforts by providing a service that was dedicated to understanding and supporting the needs, both clinical and physiological, for those women."

The clinic was started in the midst of the COVID-19 pandemic. Amid all the uncertainty, it was a safe space for people, many of whom were shielding, to connect and reach out to others going through something similar. **"They couldn't attend NCT classes because of the pandemic and for many it was an invaluable opportunity to meet each other virtually and get that emotional peer-to-peer support,"** Imogen explains.

There are guidelines about where pregnant women should receive their care. The success of the clinic at the Royal Brompton has even led to some important changes in these guidelines. **"Previously, all women with CF were recommended to attend specialist obstetric centres for their pregnancy journey, labour and birth. Now, there is more flexibility, and where it is appropriate and feasible, women have been able to receive their care closer to home as per their wishes, through our joint working with local obstetric and midwifery services,"** explains Imogen.

A clinic of this kind might not be feasible for all CF centres, but Imogen believes it does show the importance of more dedicated support as the numbers of pregnancies continues to rise. **"I think dedicating a focussed amount of time to reproductive maternal health is completely appropriate,"** she says.

> **"Previously, all women with CF had to attend specialist obstetric centres for their pregnancy journey, labour and birth. Now, there is more flexibility"**
>
> Dr Imogen Felton

"There are considerations which are very specific and can be complex for people with cystic fibrosis when it comes to parenthood. They might rarely bring it to clinic consultations, but in having a service where we monthly check in, we're able to devote time to have those longer, wider, often deeper conversations and inform them of the rapidly evolving evidence base in this field."

For the many people with CF who have used the service, it's made a big difference to their overall experience. Charlotte, 32, and her husband Iain conceived through IVF in 2021. Their **"little miracle"** Archer arrived in July last year, and Charlotte says she couldn't be more grateful for the support she received throughout her pregnancy.

"It's really important to feel supported through such a big life event, as pregnancy can throw about so many complications and each pregnancy is different. When Archer finally arrived in July 2022 at 37 weeks, I couldn't wait to show the Brompton my little miracle and thank them again for helping me to get him here safely."

If you have cystic fibrosis, or have a partner with CF, and are thinking about having children, it's completely normal to be grappling with lots of different questions about pregnancy. You can find lots more information in our Starting a Family booklet, which you can download or order from our website.

Some people may decide they don't want children, for others it isn't an option as they aren't able to. Cystic fibrosis can be a contributing factor in people deciding not to have children, however others may just not wish to be a parent.

Being told that you can't have the family you wanted, for whatever reason, can be devastating. Your CF team may be able to provide emotional support or direct you to other sources of support. You can also contact our Helpline on **0300 373 1000** or at **helpline@cysticfibrosis.org.uk**

We also recognise that for those who don't benefit from Kaftrio, the journey to becoming a parent might not be straightforward. Our Starting a Family booklet has information and support.

Read about Dr Jamie Duckers' research into CF and pregnancy on page 12.

Gillian and her family

Gillian's story

Gillian lives in Scotland with her husband and one-year-old son Frederick. Gillian was one of the first women in Scotland to have a baby after starting Kaftrio. Here she shares her experiences of pregnancy.

Starting a family was something my husband and I always wanted. But pre-Kaftrio my health was deteriorating and it was a personal choice for us not to try for a family knowing how unwell I was.

I was struggling to even walk up the stairs in my own house. I wasn't really making any plans other than getting through each day. I was having discussions with my consultant about next steps and thinking about lung transplant. It was a great source of sadness for us.

But then I was very lucky to be included on the Kaftrio clinical trial. Within maybe six to seven days of the trial, I started to feel so much better and naturally the thought of children crept back into my mind. But we couldn't try to conceive until Kaftrio was approved, because if you fell pregnant during the trial then you were automatically removed.

When Kaftrio was approved in 2020, I think about an hour later I was on the phone to my consultant to ask his thoughts about whether we could try for a family. And then in December 2021, our little boy Frederick arrived.

I stayed pretty well during pregnancy. I was very closely monitored and I got lots of extra scans. We felt very well-supported by my CF centre in Glasgow.

I think you have this feeling with CF that your body just can't do stuff. I felt so sure we wouldn't get pregnant; that something will happen. But I think it's just because for years before everything just always went wrong.

The feeling of knowing that I was pregnant and feeling my bump growing was just absolutely amazing. It was just life-changing that something that you never ever thought would be for you was actually happening. I've loved being a mum and I just live and breathe Frederick.

What's on your mind?

Our Helpline Manager Matthew answers some of your questions about life with cystic fibrosis.

I rent my home from my local council and there are some serious mould and damp issues which haven't been addressed. My son has cystic fibrosis and I'm worried about the impact this could have on his health. I'm trying to keep on top of it but it's just coming back. The council told me to just open windows. What can I do?

Matthew's answer: Landlords (in your case, your landlord is your local council) are responsible for most of the repairs in your home and must carry out any repairs in a reasonable amount of time.

Timescales can depend on how serious the problem is. Your responsibility as the tenant is to report any issues as soon as possible. You should keep a log and evidence of communication with your landlord.

Landlords have a responsibility to make sure that their properties are 'fit for habitation'.

This means your home is safe for you to live in and well-maintained.

For example, it must be:
- structurally stable
- free from serious disrepair
- free from dampness that could damage the occupant's health
- providing adequate lighting, heating, and ventilation.

Your home may be unfit for habitation when there are significant health and safety issues which mean that it is no longer safe for you to live there. Poor conditions include things that put you and your family at risk of physical harm, anything that means you can't make use of the full home, or, most significantly for people with CF, affect your health.

If you feel that your home is unfit for habitation or needs repair and your landlord is not acting quickly or appropriately, please reach out and get advice. You should also let your CF team know what's happening, especially if your housing conditions are affecting your health. You can contact our Helpline on **0300 373 1000** or **helpline@cysticfibrosis.org.uk** for information and support.

We have also produced a new webpage covering housing issues including rent, homelessness and repairs. You can read it here **cysticfibrosis.org.uk/housing**.

“It’s great to speak to others who know how I feel”

Do you love playing video games with your friends? Reckon you could give Ed Sheeran a run for his money in the singing stakes? Maybe you’re passionate about speaking up on important issues relating to your CF? Our CF Youth Programme is for you! We have loads of social events, workshops and opportunities for young people affected by CF to get involved with. Here’s Jakub and Tilly to tell you more!

For children and young people living with CF there can be a lot to get your head around. Our CF Youth Programme gives young people a space to explore their feelings around CF, to connect and chat with other people going through the same thing, and to have a lot of fun and learn new things too!

Jakub

> “My older brother joins some activities with me and it helps him to understand CF better.”
>
> Jakub


Tilly

> "If I had to describe YAG in three words they would be: inclusive, important and exciting."
>
> Tilly

Tilly's story

Hi, I'm Tilly. I'm 14 and I love reading and acting. I'm part of the Trust's Youth Advisory Group (YAG) and I love it! I love being able to chat with the other members and work on different projects with the Trust. Our latest project is a dictionary for young children with CF.

I think other young people should get involved in YAG because it gives you a time in the week to relax with people who actually understand about the medical part of your life. It's also made me more aware of my own condition, and now I know that others are going through the same thing, not just me. If I had to describe YAG in three words they would be: inclusive, important and exciting.

Jakub's story

I'm Jakub, I'm 10 and I have CF. I love any water activities like swimming and water polo, as well as playing football and gaming.

I really like doing all the youth activities with the Trust, especially the film nights when we can dress up and join online with other children. We have loads of fun together by playing silly games and watching great movies! I also really like joining the gaming nights because it's my only chance to connect with other children with CF and play with new friends. Meeting with other children online is super nice because we all have CF and we can't meet in real life. It's great to speak to children that understand how I feel.

My older brother joins some activities with me and it helps him to understand CF better. I am so happy that the Trust does all that for us. Everyone is so nice and it's really fun being a part of it.

If you, or anyone you know wants to take part in all that CF Youth has to offer, you can get in touch with us at **cfyouth@cysticfibrosis.org.uk**. Follow us on Instagram and Twitter at **@CFTrustYouth**.

Day in the life

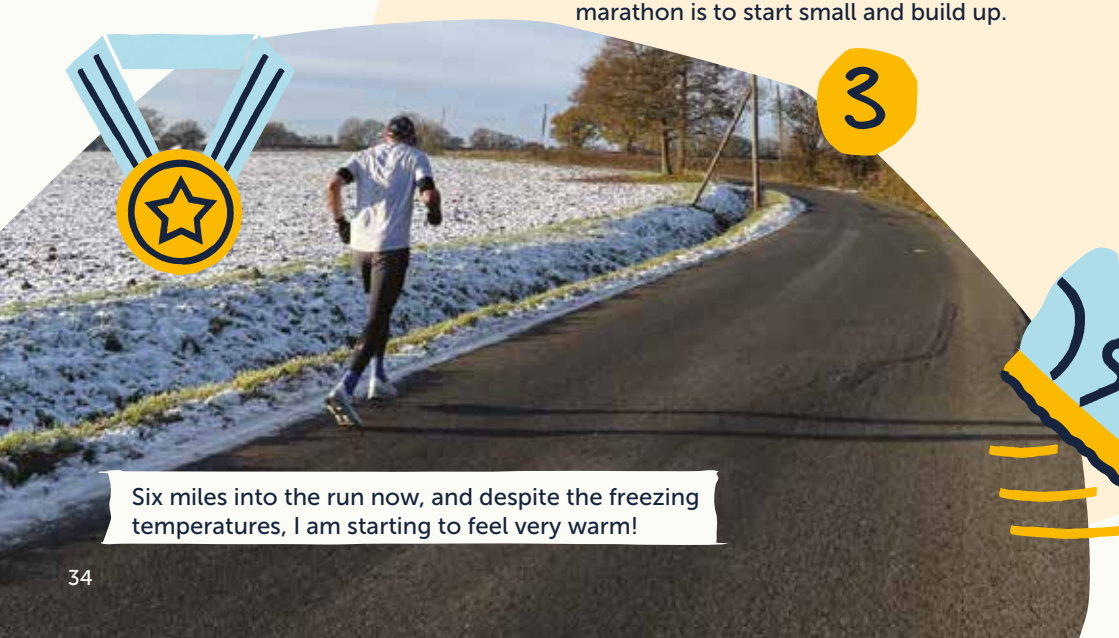
Our amazing supporter Richard, who lives with CF, ran the London Marathon for the Trust last year, and will be pounding the London pavements again at the 2023 event in April. Here he shares a typical Sunday of training, jobs, and spending time with family.

1

Fuelling for a 10-mile run is always important, especially when it's freezing outside!

2

I always make sure I do a proper stretch before a run to warm up my muscles. My top tip for anybody running a marathon is to start small and build up.



3

Six miles into the run now, and despite the freezing temperatures, I am starting to feel very warm!

At time of writing, Christmas is just around the corner and I have my wife's relatives who live in Malta staying with us this year.

4

5

No rest for the wicked as Grumpy the bulldog also needs some exercise! This is a good way for me to walk off any pain from my run earlier .

6

Family is very important to me and so is food! So on a Sunday, I usually invite family over for a roast dinner and we finish the meal with cheese!

If you would like to share your story, please get in touch at **magazine@cysticfibrosis.org.uk**

Cystic Fibrosis Trust

CF Week 2023 is coming!

12–18 June 2023

Save the date for our annual awareness and fundraising week, finishing with the biggest and brightest fundraising day of the year...**Wear Yellow Day!**

Gather your friends, family and colleagues on **Friday 16 June**, either in person or online, for your yellow-themed event. It's never too early to start planning, but remember whether you...

Dress, bake, dance or run... whatever you do, do it in yellow

Visit **cysticfibrosis.org.uk/yellow**

Registered with FUNDRAISING REGULATOR

Uniting for a life unlimited