

**Cystic
Fibrosis Trust**

Since
1964

**We won't stop
until CF does**

Issue 17

cysticfibrosis.org.uk

CFLife



Then and now

Rob reflects on how CF has changed in his lifetime

Fly on the wall

Celebrating clinical trials

Dealing with diagnosis

How we can support you

Uniting for a life unlimited

It's more than
just inside

It's that time again
so here's your own
CF Week brochure

With this issue: '94
Venture adventures



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Social

-  @cftrust
-  Cystic Fibrosis Trust
-  forum.cysticfibrosis.org.uk
-  cftrust
-  @cftrustuk

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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All magazine correspondence should be sent to:

CF Life Editorial Team
Cystic Fibrosis Trust, 2nd Floor,
One Aldgate, London, EC3N 1RE
magazine@cysticfibrosis.org.uk

Welcome to CF Life

Many of you will already be aware that 2024 marks 60 years of Cystic Fibrosis Trust. In this special edition of CF Life, we reflect on those six decades: the moments of hope and frustration, the challenges and breakthroughs, and the vital discoveries in CF understanding and treatment. You can read about some of those key milestones in the timeline which is included in this issue.

We are delighted to hear from our supporter Rob, who appeared on the cover of the 30th anniversary edition of our magazine as a young boy back in 1994. He speaks to us about how the CF landscape has changed in his lifetime, and his hopes for the future.

Elsewhere in the magazine, we chat to our trustee Neil Priscott about what inspired him to join the Board of Cystic Fibrosis Trust, we discover some top tips for staying active with CF from personal trainer Kieron, and we share an insight into the production of our new diagnosis information resources.

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

The CF Life team

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

Uniting for a life unlimited



“For 60 years, we’ve overcome challenges and celebrated breakthroughs. Always learning and moving forward. And we won’t stop until CF does.”

David Ramsden

**Since
1964**

In case you missed it

Fundraising

We'd like to say a big thank you to Emma Stewart, who organised the Tichborne Team Marathon back in April, raising over £48,000 for the Trust.

Emma set up this event to mark 20 years since she ran her first London Marathon. It consisted of 34 teams of four taking part in 10.5km loops (making up the length of a full marathon between them), with a total of 136 runners.

Emma commented: "2024 came round, and I thought, 'I can't not mark this event'. I'm so proud of everything we've achieved and how much we've raised for Cystic Fibrosis Trust."



Research

Cystic Fibrosis Trust has awarded over £2m to fund four new research grants. The grants will fund projects that target key research priorities identified by people with CF, such as alternatives to current treatment, helping support people with CF as the population is getting older, and supporting reproductive health throughout the lifetimes of women and girls with CF.

"It's great to see Cystic Fibrosis Trust investing in research that matters most to people with cystic fibrosis. The commencement of a Strategic Research Centre to look at the impact of pregnancy and beyond shows how much life has changed for the better for people with CF. And for those who haven't been able to benefit from modulators, it is fantastic to see the Trust put funding into research that aims to provide them with the same life opportunities," commented Zoe Elliott, mum to twins with CF and a member of the QuestionCF project group.



Issac's drawing from his Tree of Life wellbeing workshop

Support

In recent months, we've seen worrying fluctuations in the availability of Creon across the UK. Cystic Fibrosis Trust and CF clinicians, dietitians and pharmacists are working hard to ensure that the impact of shortages of Creon on the health and wellbeing of people with CF is minimised.

We're meeting regularly with Viatrix, the distributor of Creon, and the NHS to ensure that all possible measures are being taken to resolve these issues.

We've written to the Secretary of State for Health, calling for better communication to the community about what is happening, as well as long-term solutions.

We've put together some FAQs on our website (cysticfibrosis.org.uk/creon) to provide the latest information about Creon availability, and what to do if you are experiencing difficulties in accessing Creon.

Young people

We're delighted to share this lovely piece of artwork, created by Isaac, 6, who attended our Tree of Life wellbeing workshop in the summer. Tree of Life was run by a CF child psychologist and those attending were guided through the creation of their unique trees, each part representing important aspects of their life. Here's what Isaac's dad said about his Tree of Life:

"Isaac said he loved doing the picture. The branches of his tree were Daddy, Mummy and Amelia as his family is most important to him. He also has his best friend on there. On the right-hand side he's in a digger as he wants to be a construction man or a policeman (the blue figure). On the left-hand side is Isaac and Daddy playing football – it's his favourite thing at the moment and he's just joined his first football club. He also plays at school. It's an apple tree, so you can see some red apples growing on it."

If you'd like to find out more about our youth programme and how you can get involved, please email cfyouth@cysticfibrosis.org.uk.

Campaigning

Back in June, we shared the fantastic news that landmark long-term deals have been confirmed to make life-changing CF modulator drugs – Kaftrio, Symkevi and Orkambi – available on the NHS. This follows many years of campaigning.

Our Chief Executive David Ramsden commented: **"This is a fantastic moment – ending uncertainty and helping to ensure that everyone who can benefit is able to access these vital medicines – now and in the future.**

"We should not forget, though, that these treatments are not a cure and simply don't work for some people. With the support of our incredible community, clinicians, and researchers a lot has been achieved but we know there is still lots more to do."

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



Mum Shanique and baby Thiago, who has CF

We won't stop

The past few years have been full of ups and downs for the CF community. As we reflect on this, and the past 60 years of the Trust, we also think about the future – what might the next 5 to 10 years look like for people with CF? What are the challenges we might face, and what are the opportunities we don't want to miss? And above all, how we do make sure everyone with CF has the same opportunity for good health and the life they want?

The Information, Support and Programmes team at the Trust is responsible for making sure that the services and resources we provide for the CF community are continually evolving to meet your needs, and that we're helping you in the way you need us to. We do this by listening to those who contact us directly, as well as the feedback we get through our involvement team, and what we hear from CF professionals. It's our job to keep scanning the horizon, and developing our support and information to make sure it has the biggest possible impact.

Here for you

Over the past few years, this has led to the development of new information and support. We launched our first ever employment support programme, Work Forwards, in 2023, supported by the National Lottery Community Fund. This has enabled us to provide tailored support on all aspects of work and employment and there's more to come – over the year ahead we'll be sharing the stories of people with CF in a wide range of jobs and careers and building our information resources for the CF community and for employers.

A major change we've seen over the past few years has been a dramatic increase in the number of people with CF who are becoming parents. In response to this, we've recently piloted our first scheme to support new parents who have CF. This was a local initiative, based in Glasgow and operating in partnership with national parenting charity Home-Start UK, and we are now looking at how we can roll this out further.

We've also relaunched our online community forum when we heard from people affected by CF that you needed a safe, anonymised online space to share experiences and support each other. One of the most heartwarming parts of this new online community has been seeing new parents of babies with CF being supported by older adults with CF.

Some with CF have seen dramatic improvements in health; others are still waiting for the game changing treatments they need and we are committed to being here for everyone.

For those who don't benefit from new treatments, we're focused on making sure you have all you need to stay as well as possible while research continues. This group within the CF community is sometimes known as 'the 10%' – we don't always use this phrase because it isn't completely accurate and sometimes we don't want to 'put people in a box' – but this is a group of people with distinct needs for support, and it's important to recognise that.

There is work going on by key researchers and clinicians to understand who is in this group and to use Registry data to ensure we know how to target support.





Kareem, who featured as part of our CF Week campaign in 2022



Breaking down barriers

When we think about making sure everyone has a bright future with CF, we have to then turn to thinking about what the barriers to this might be, and be very clear that some people face more barriers than others. By identifying these barriers, we can start to address them, helping us move towards equity.

People from ethnic minority backgrounds face additional barriers in accessing services and care that has not been designed around their needs, and in CF, are also less likely than people from white backgrounds to be genetically eligible for modulator treatments like Kaftrio. We've been looking at how we address this in our information and support – by increasing representation in our imagery and the stories we include in our resources, introducing translation services to our Helpline, and building our understanding of the needs of diverse communities.

People from ethnic minority backgrounds face additional barriers in accessing services and care that has not been designed around their needs and are less likely to be genetically eligible for modulator treatments like Kaftrio

In recent years, we've also been focusing specific grant support on low income households through the winter months to protect CF health. All of these actions are small steps, but are about recognising that it is our job as the national CF charity to be relevant, accessible and helpful for all.

As CF changes and we want everyone to have the same opportunity to be well, we have to think about all the things outside of just 'the medical stuff' which can affect how well someone can manage life with CF, and from what we're learning, neurodiversity is a key consideration in this. Through our grants programme, we've often heard from people in the community, particularly parents of children with CF, highlighting the significant challenges that can come with a combination of – for example, autism and CF. This can include extra considerations around hospital stays and procedures, sensory difficulties around types of physiotherapy, or complex issues with food.

Just as everyone with CF is different, everyone who is neurodivergent is different and faces their own set of challenges, but it is clear from the people who've shared their experiences with us that managing CF and neurodiversity can be hard, and people often feel alone. A better understanding of neurodiversity and CF is likely to mean that we need to be able to change and adapt the way we do things to make sure there are no barriers to accessing our support, and it's something many CF professionals are also very interested in considering in terms of how CF care is delivered.

At our study day for CF professionals earlier this year, we held a discussion workshop bringing together good practice and knowledge from CF teams around the UK, and also including the voices of people in the CF community who are neurodivergent, or who care for someone who is neurodivergent.



Support through tough times

Over the past year, the CF community has been through some difficult times: the uncertainty that came through NICE's appraisal of modulator therapies, and the issues with the supply of pancreatic enzyme replacement therapy (such as Creon) to name just two. Our role in the Information and Support team is to keep up to date with these issues, to prepare for the questions we think the CF community will need answers to, and to work with our colleagues across the organisation to find the answers where possible.

We also feed in the information coming from the frontline – calls, emails and messages to our Helpline are often the first place we hear of an issue that is affecting people with CF.

Alongside preparing for the support you might need from us in the future, and responding to key issues that often come up unexpectedly, we also continue to deliver all our core services for people affected by cystic fibrosis – our Helpline, welfare grants, benefits advice, information resources, peer support and youth programme.

Overall, from our data and what we're hearing, it's clear that the CF community needs us more than ever – you need us to be there when you need us, in the right way at the right time, so that you can get on and live your life. Ultimately that's what we want for everyone with CF – the ability to live the life you want. We want you to be able to do that without barriers or challenges – but if you do hit bumps in the road, we want you to know we're here to support you.

“ My Helpline Officer role is a demanding one but it's humbling and always a privilege to be able to support the CF community in a tangible way day to day and see the results of my and our efforts. In terms of my own lived experience with CF, in middle age, I've seen and benefitted from significant advances in treatments and huge developments in knowledge and understanding in my specialist CF team over the years; their unstinting commitment has always been evident.”

Dom, Helpline Officer who has CF





“ Accessing Kaftrio was a game changer for me and turned the clock back around 10 to 15 years in terms of my overall health. This was obviously great, but it did also bring some challenges. I had always preferred to live in the moment and never really thought much about saving for a pension, because as morbid as it sounds, I thought it was never going to be a problem I’d need to worry about.”

Jimmy, Work Forwards Programme Manager who has CF



Work Forwards 



Find out more about the different ways we can support you at cysticfibrosis.org.uk/support.

Growing older with CF

In December 2023 we held a workshop to discuss how growing older with CF may change many aspects of CF care, what we don't know and how research can help us fill in the gaps. The workshop was held as a first step to answer how we manage an ageing population with CF – one of your CF research priorities. Here's a recap of the workshop and what has happened since.

Changing CF care

Living longer has many implications for people with CF and those that support them, including adjustments in how CF clinics are run. For example, it may mean that other specialists outside of the CF team become involved in your care. It is an area that CF teams around the world are actively planning for. **"It is important that we keep our existing skills and expertise in managing CF,"** commented Prof Nick Simmonds, associate director and consultant physician of the Adult CF Centre at Royal Brompton Hospital. **"We also need to develop new treatment guidelines, models of care, and integrated care systems with other specialists."**

"Thank goodness we're growing older with CF," commented Jane who recently celebrated her 60th birthday. **"But we need the security of knowing that the person behind the desk has heard of CF and how CF may interact with their specialism."**

Questions to answer about growing older with CF

As anyone gets older, their risk of developing conditions such as heart disease, cancer and dementia will increase. We don't know how these conditions will affect people living with CF. It is possible that they may be at an increased risk compared to people who don't have CF. More research is needed to understand what growing older means for people with CF, and how any increased risks can be reduced.

We've recently agreed to fund a research study about CF and heart disease, which will be led by Dr Freddy Frost, a researcher based at Liverpool Heart and Chest Hospital. **"To understand more about heart disease in CF we need to know how many people with CF have been affected so far, and work out practical ways to assess an individual's risk of developing it in the future. The research grant from Cystic Fibrosis Trust will help us to test out ways to answer these questions, in order to conduct bigger studies in the future."**



Dr Freddy Frost

Visit cysticfibrosis.org.uk/growingolderwithCF to find out more about research questions around growing older with CF.



“ Thank goodness we’re growing older with CF, but we need the security of knowing that the person behind the desk has heard of CF and how CF may interact with their specialism.”

Jane





Here's to the next 30!

Back in 1994, Rob featured on the cover of the 30th anniversary edition of CF News magazine as a six-year-old. 30 years later and he is on the cover of CF Life in our 60th anniversary year! We chatted to Rob about the changes he's seen in his lifetime, learning resilience as a child, and looking to the future, not the past.

I was diagnosed with CF at four days old. I was very unwell when I was born, which led to me being diagnosed at such a young age. I grew up in Bromley, where the Cystic Fibrosis Trust headquarters were originally based. My parents got involved in lots of fundraising and I featured in the 30th anniversary CF News magazine. One of my earliest memories is being handed a board game by someone from the Trust!

My childhood was normal in many ways, just with lots of hospital visits and stays. It was sometimes difficult to explain to friends why I was taken out of school, or why I was playing in the playground with an IV cannula hanging out my hand. I think I worried a lot about explaining CF to other people when I was younger, but I'm much less cautious now.

I think my advice to a young person with CF today would be to look to the future, not the past. Research, medicine and treatments are always advancing, so each generation will have a different experience to the ones before. I don't think anyone could have predicted when I was a child what my life would look like in 2024.

After university I became a secondary school maths teacher. It was a job I really enjoyed, but the life of a teacher is quite demanding. Incorporating management of my treatments made it harder, and being in a school environment I was exposed to lots of bugs. It meant there was a toll on my health, and one of the reasons I stopped being a teacher was because it wasn't compatible with my health at the time.

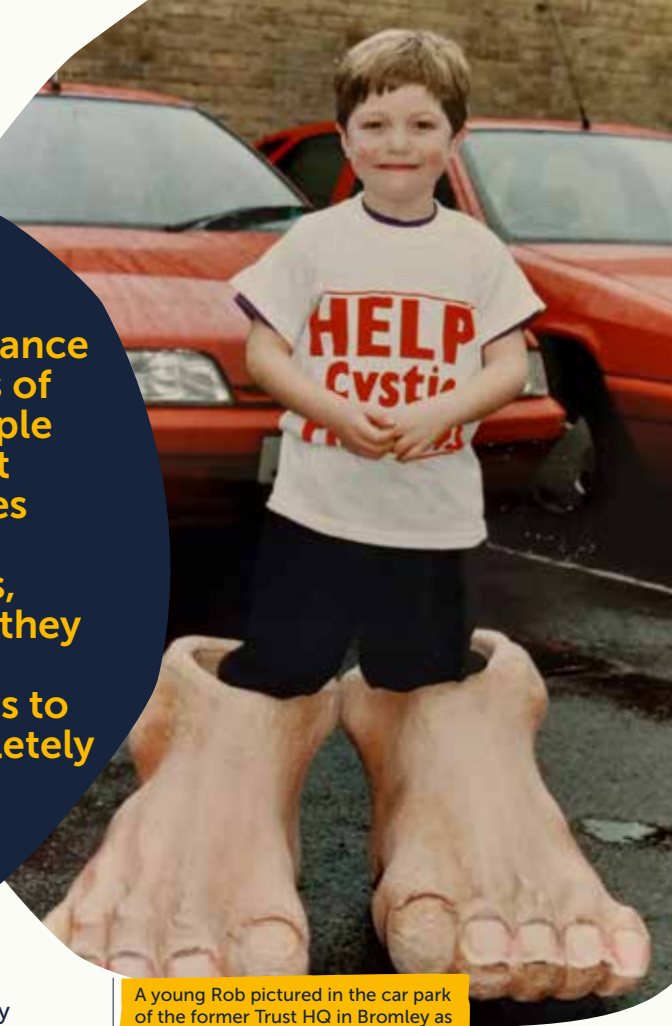
Learning resilience

Through the course of my life, CF has impacted me with lots of smaller setbacks. From one week to the next I don't know if I'm going to be well or unwell. It means there have been lots of bumps in the road. But as people with CF, we learn resilience as children. It's difficult to deal with setbacks sometimes but I know I am capable of facing whatever comes my way.

I think one of the biggest misconceptions about CF is that it only affects the lungs, overshadowing all of the other symptoms and issues. I think the importance of raising awareness of CF today is that people may not know about the dramatic changes brought about by modulator therapies, and even if they do, they may not realise how much further there is to go to beat CF completely and for everyone.

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Rob



A young Rob pictured in the car park of the former Trust HQ in Bromley as part of the 'Big Strides' campaign

Endless possibilities

Since Kaftrio, the outlook is very different for many people with CF and we're all trying to navigate this new landscape. I never used to think of myself as having a limited life, but after starting to take Kaftrio I have realised just how much more I can do now. It has given me a new lease of life and a whole new feeling of what is possible and how long it will be possible for.

There's still a long way to go with CF research and the Trust is as important as ever. While Kaftrio is a miracle for me, it isn't for everyone so it's vitally important that research continues until we find a cure.

Being involved in the Trust's 60th anniversary has made me reflect on just how different the CF landscape is today than in 1994. I'm looking forward to the next 30 years and being involved in the 90th anniversary!

A big thank you to Rob for sharing his story. Visit [cysticfibrosis.org.uk/60](https://www.cysticfibrosis.org.uk/60) to watch our 60th anniversary video featuring Rob. If you have a story that you would like to share, please email magazine@cysticfibrosis.org.uk.

Knowing me, knowing you

Neil Priscott recently joined our board of trustees. He has three siblings with CF: two brothers, John and Stuart, and a sister, Jo, who sadly passed away in 2018. Neil has been fundraising for the Trust all his life. We caught up with Neil to hear more about what it means to be a trustee, his hopes for the future of CF, and why listening to music in a field is his happy place.

Hi Neil, can you tell us about what inspired you to become a trustee?

I've lived my whole life around CF and seen how it has changed and evolved over time. The stage of my career I'm at, I wanted to become a trustee of a charity which means so much to me. I've always raised money for cystic fibrosis – I've done lots of challenges as an adult, and one of my earliest memories is trying to help my mum sell Christmas cards to raise money for cystic fibrosis. My mum still sells cystic fibrosis Christmas cards and she's in her 80s, so it's a lifelong connection.

How did your family feel when you told them the news?

My brother Stuart jokes he has CF and I have the CV! They've been really, really supportive and they are proud. One of the main reasons I wanted to do it was in memory of my sister Jo. She passed away in 2018 at the age of 50. She was a secondary school teacher and lived an incredible and fulfilling life and was the most inspirational person I've ever met in my life. I hope she'd feel pride in me doing this and wanting to help in my own way.



Left-right: Stuart, John, Jo and Neil

It's our 60th anniversary year and there's been so much progress in that time, but the journey's not over yet.

What are your hopes for the future of CF?

CF is not done and ultimately, wouldn't it be amazing if it was? So that's the goal. On a personal level, my two brothers are my best mates and I want many, many more years with my two best mates. If I can have more years with my brothers, for me that's worth fighting for.

Finally, what do you enjoy doing in your spare time?

I love sport, so my passions are Liverpool Football Club, Bath Rugby Club and Gloucestershire County Cricket Club, which is also where I work. But my true happy place is a music gig. In a field or venue listening to a band is where I'm at my happiest.

If you are going through a bereavement and would like to talk to someone about it, call our Helpline on 0300 373 1000, or take a look at our bereavement resources at [cysticfibrosis.org.uk/bereavement](https://www.cysticfibrosis.org.uk/bereavement).

Easy exercise

Personal trainer Kieron Smith, who has CF, shares his top tips to help you stay fit and active from home.



1. Doing something, no matter how small, is better than doing nothing. By committing to do something every day, you'll build the habit of regular exercise and this can bring you impressive results. Even a five-minute stretch can make a difference. Incorporate exercises into your daily routine by stacking them with existing habits. For example, while waiting for the kettle to boil, do some squats or skipping.

2. Incorporate resistance into your exercises whenever possible. You can use household items like cans of food or invest in light dumbbells. Adding resistance helps build muscle strength and can make your workouts more effective.

3. Remember, workouts don't have to be perfect. Setting small, realistic expectations can prevent you from feeling overwhelmed. Even a brief, imperfect workout is better than nothing. The goal is consistency, not perfection. So even if you have 10 minutes, get your favourite music on and find something that you enjoy!



Try this 10 to 30 minute home workout example (aim to do this two to three times a week)

- 30 seconds: Star jumps to get your heart rate up.
- 30 seconds: Squats to strengthen your legs and core.
- 30 seconds: Push-ups (modified on knees if needed) to build upper body strength.
- 30 seconds: Plank to enhance core stability and support better posture.
- 30 seconds: High knees to boost cardiovascular endurance.
- 30 seconds: Lunges (30 seconds each leg) to improve leg strength.
- 30 seconds: Tricep dips (use a sturdy chair) to strengthen your arms.
- 30 seconds: Mountain climbers to work on your core.
- 30 seconds: Bicycle crunches to target your abs and obliques.
- 30 seconds: Bicep curls (using any weights you have) to strengthen your arms.

You can make this easier by taking out some of the exercises or reducing the time of each one. You can make it harder by doing additional rounds of each exercise or adding resistance to some of the exercises.

Find out more about staying active with CF at cysticfibrosis.org.uk/exercise. Remember to speak to your CF team before starting any new exercise.



Don't miss our 60th Anniversary Awards!

To mark our 60th year, we're holding an online awards ceremony on 14 November 2024 to shine a light on some of the incredible people who have made a difference in the lives of those with cystic fibrosis. Our Ambassador Richard Madeley will host the event, which starts at 7pm. You can watch via Zoom. More details to follow at a later date.

Please gather your friends and family together and join us in celebrating the special people who make up the CF community.

To find out more please visit
cysticfibrosis.org.uk/awards

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Celebrating clinical trials

As the Trust celebrates its 60th anniversary, we've been reflecting on how much has changed in clinical trials in that time. In the few years after Cystic Fibrosis Trust was first formed, there was only one CF clinical trial in the UK. Today, the UK leads a wide range of CF clinical trials each year, with more people than ever taking part in trials.

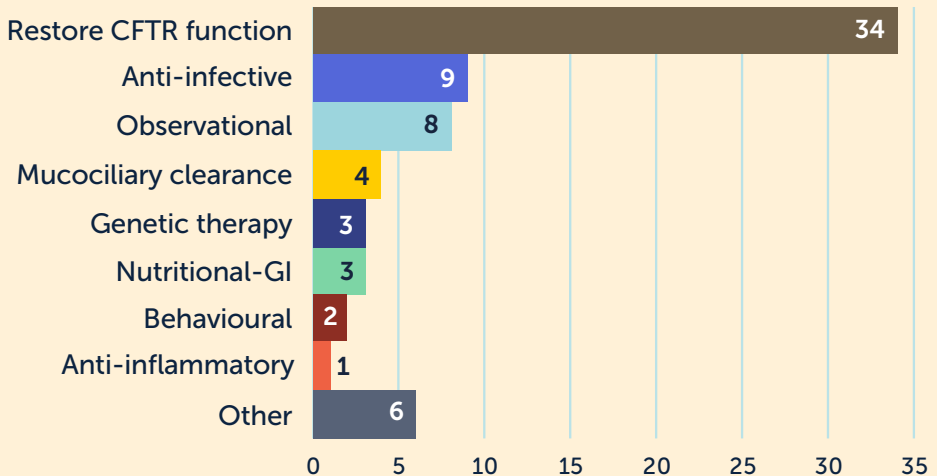


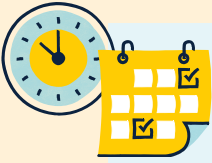
This has been made even more possible through the Clinical Trials Accelerator Platform (CTAP). The Trust launched CTAP in 2017 to help more people with CF access trials. CTAP supports a network of CF centres and works with people who run trials to set up more trials in the UK. Here, we take a look at what we've achieved through CTAP since it began.

Find out more about clinical trials at cysticfibrosis.org.uk/clinicaltrials

We've supported 70 studies

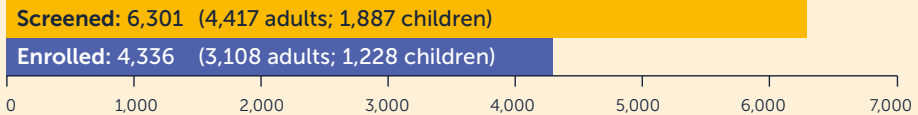
This includes studies that aim to understand and improve all aspects of CF symptoms, as well as studies looking at addressing the underlying cause of CF.





Since CTAP's launch, study set-up times have decreased by **over 70%** – that's more than 11 weeks.

Thousands of you have taken part in a trial



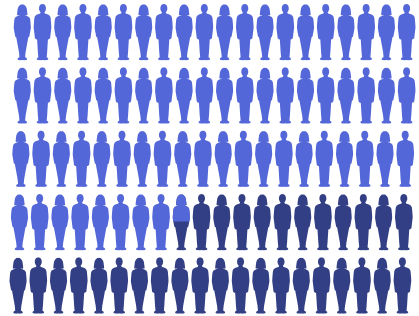
1,000 people have joined the CF BioResource project

The CF BioResource project has recruited hundreds of new participants this year. This exciting project aims to transform the future of CF research by creating a register of people with CF who have agreed to be contacted about research based on their genetic make-up. This will make it easier for future researchers to find the right participants for their studies.

Find out more at cysticfibrosis.org.uk/bioresource

"I have taken part in over 20 trials throughout my life. It's my way of giving back and returning some of the help and support I've had over the years with my CF. I feel I have a responsibility to help the community as they have helped me."

Jane, who has CF and is part of our Involvement Group



More than **1,000** people have enrolled onto the CF BioResource project, including **685** people over the last year.

Branching out

Our work wouldn't be possible without the incredible support of our 39 fundraising branches up and down the country. From Dundee to Dorset, they offer support, organise fundraising events, and advocate on behalf of the CF community. We can't thank them enough! We chatted to Sharon Moore, who is part of the Fakenham fundraising branch, to hear about the motivation behind her fundraising – over £84,000 and counting – and her hopes for a future where we have “seen off CF”.



Sharon (right) receiving another fantastic fundraising donation to Cystic Fibrosis Trust

My cousin Donna was diagnosed with cystic fibrosis (CF) in 1982. Back then very little was known about the condition. There was no internet, so you couldn't just Google it like you can today. There was hardly any research, and we were told that this little baby might not even make the age of 18. At school I remember having to write about something that scared me and I wrote that my cousin won't get better. That is the only time in my life that I got an A in English! The teacher said she cried when she read it.

When Donna turned 18, against the odds, I vowed to raise £1,000 for Cystic Fibrosis Trust. I raised that in two months so decided to keep going for the rest of the year and see how much more I could raise. Then it was £5,000 and £10,000 and suddenly I had the fundraising bug. My total right now stands at £84,333 – so now I want to reach £100,000!

I've been fundraising for the Trust through the Fakenham branch for over 20 years. I've raised money in lots of different ways; from quiz sheets to fashion shows to bingo nights – my motto is 'every penny counts!'.

I know my fundraising has contributed to CF research over the years and that's really important to me because I've seen firsthand what a difference Kaftrio has made to Donna's life."

Sharon

I know my fundraising has contributed to CF research over the years and that's really important to me because I've seen firsthand what a difference Kaftrio has made to Donna's life. She's now 42 and has a 9-year-old son! I asked her how Kaftrio made her feel and she said, 'Like a new woman. I can breathe again. I've got my life back and that's down to you...'

To hear those words made every single minute of fundraising worth it. Helping people with CF in my own way is what I set out to do. But I never thought I'd be able to make a difference to people who've got the condition right now; I thought it would just be the next generation. So it's an amazing feeling to know I've helped Donna and how grateful she is for the work I do with the Fakenham branch. But none of it would have been possible without all the people who have supported me over the past 20 years, especially my Aunt Bridget, Donna's mum.

20 years ago, I remember being part of the Trust's 40th anniversary and now here I am part of the 60th anniversary issue of CF Life. Before the next big milestone, I really hope CF is something we can talk about in the past not the present. I hope there will be a cure and we can see off CF once and for all.

We'd like to say a huge thank you to Sharon and all the wonderful supporters who make up our fundraising branches. If you'd like to find out how you can get involved with your local branch, contact us at events@cysticfibrosis.org.uk.



Remembering those we've lost

Our Book of Remembrance provides a beautiful and lasting memorial to those who we've lost to cystic fibrosis. Our In Memory Officer Susan explains more.

As we mark 60 years of Cystic Fibrosis Trust, I wanted to take a moment to tell you about our Book of Remembrance. The book has four volumes covering the 60 years since we began in 1964. Beautifully bound and inscribed by professional calligraphers, it contains a permanent inscription to remember a loved one.

Relatives and friends can request to add their loved one's name, date of birth and death. The inscription page within each volume documents the advancements that have been made in CF since the previous volume and reflects the situation at the time of each book opening.

Natalie recently had a private viewing to see her brother Sam's entry, and she told us why it was important to her.

"It is important for me to have Sam's name in the book because it lets me know that he's not been forgotten. It's heartwarming to know that he is forever memorialised, even long after my immediate family is gone; he'll still be in this book. I am grateful that the book exists so that he is honoured with all the other brave people that had to deal with cystic fibrosis."

Our Book of Remembrance is kept at the offices of Holy Trinity Church in South Kensington and private viewings can be arranged by appointment. We understand that the location of the book may not be convenient for everyone, so we're pleased to offer to send you a photo of your loved one's entry once it's been included.

Regardless of when your loved one died, we're able to update the relevant volume of the book to include their name, and there's no charge for inclusion. If you're unsure whether a name has already been added, please inform us and we'll be happy to check for you.



"It is important for me to have Sam's name in the book because it lets me know that he's not been forgotten."

Natalie

If you have any questions about our Book of Remembrance or about remembering a loved one, I'd be happy to chat to you. You can reach me on susan.jackson@cysticfibrosis.org.uk.



Dealing with diagnosis

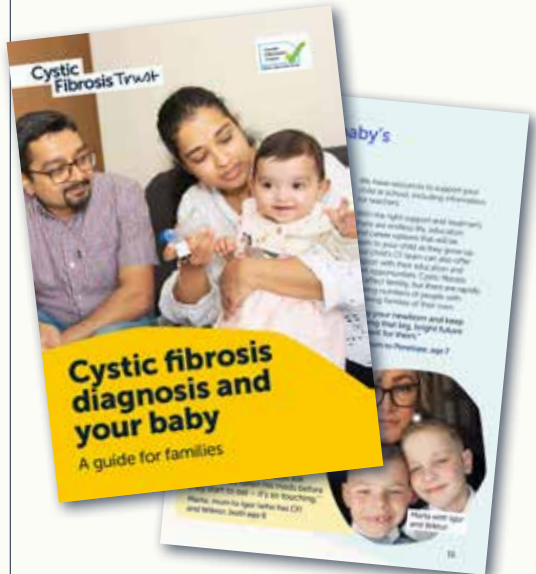
Whether it's a bolt out of the blue or words you'd been expecting, we know that a diagnosis of cystic fibrosis (CF) can bring up a whole range of emotions. It can be difficult to know where to turn but Cystic Fibrosis Trust is here to help. We've recently updated our new diagnosis resources, working with parents and families in the community to create something we hope will be a source of comfort and knowledge in the toughest of times. Alison Taylor, Information Manager at the Trust, explains more.

Newborn screening means that most children with CF today will be diagnosed shortly after birth, and advances in prenatal testing and scanning can also pick up signs of suspected CF before the baby is born

It seems fitting that in Cystic Fibrosis Trust's 60th year, we're launching our updated new diagnosis information booklet – a resource that is often the first introduction to the Trust for parents and carers when their child is diagnosed with CF. The new diagnosis booklet, called *Cystic Fibrosis diagnosis and your baby – A guide for families*, is our most popular information resource – it's often handed to families at the point of diagnosis by their CF teams. In the rapidly changing world of CF, it was time to update it to ensure it reflects what a CF diagnosis means today, and so that it continues to remain useful and valued by families.

Newborn screening means that most children with CF today will be diagnosed shortly after birth, and advances in prenatal testing and scanning can also pick up signs of suspected CF before the baby is born. This early, or more timely, diagnosis means that CF treatment and care can begin without delay, leading to better outcomes for those children affected, showing the significant progress that has been made over the past 60 years.

Alison Taylor,
Information Manager



There is no 'right way' to feel

For many families, when they find out their baby has cystic fibrosis, the news can come as a great shock. The birth of a new baby brings with it a mixture of emotions, which can also be true for parents when they find out their child has CF – they may feel sad, worried or angry, or they might feel relieved that they have a diagnosis if they've been worried about their baby's health. As well as sharing key information and practical tips, this resource offers emotional support; reassuring parents that there is no right way to feel at this time, and that they are not alone.

It's important for us to acknowledge parents' feelings and to encourage them to share their emotions around their child's CF diagnosis if they wish, and for them to feel able to reach out for support. This resource 'holds the hands' of families as they navigate the challenging period around diagnosis; learning about CF, discovering what CF means for their child and family life, and familiarising themselves with a treatment routine, amongst many other things.

Mum, Laura wrote a heartfelt letter to her 'past self', about her son Jack's diagnosis, reflecting on how she felt at the time and how things are today:

Dear Laura (your past self),

You will have just received the diagnosis. Jack is only three weeks old and the words 'cystic fibrosis' are the scariest you've ever heard. Today is the worst day; the hardest, most terrifying day of your life, and I only wish I could lessen the pain you're feeling.

But I can offer hope. Read that sentence again: **today** is the worst day.

A CF diagnosis is not what it used to be. Advances in medicine mean that the outlook for children like Jack is more hopeful than ever. You must believe the doctors when they say this. Since that day, things have got better and better. I'd be lying if I said it was all fun and games, but things have never sunk as low as that first day. There have been days where you've wobbled, or worse just plain crumbled. But reflecting on it all, I realise that none of these bad days were caused by the effect of the condition on Jack's health. He is a joyful, healthy, beautiful and robust little boy (you'll never get tired of being told he's next in line to play for England Rugby because of his size). Thanks, in many ways, to Jack's amazing CF team, a year on, he is thriving...

Soak it all up, life only gets better from here,

Laura (your future self)



*names have been changed.



Involvement

Parents and families have been at the heart of helping us develop the new booklet and other new diagnosis resources every step of the way. We started with focus groups and one-to-one interviews with parents to identify themes and to review the previous booklet, and then they helped shape the content of the new booklet – adding in new sections and reviewing drafts as we rewrote others. They gave feedback on the booklet's design, and shared their personal stories. Families invited us into their homes for photoshoots and filming sessions, shared their top tips and FAQs, wrote blogs, a letter and diary, and even filmed themselves! They've been amazing!

A huge thank you to all the families and cystic fibrosis health professionals who contributed to the new diagnosis resources. They have generously shared their time, stories, experiences, and expertise, and we are extremely grateful to them.

Reflecting the community today

It's vital that our information is representative of different groups of people, and their lives and experiences. During consultations with families, they told us they would like to see "more images of families in the booklet that look like us". We commissioned new photographs of different families and have developed new information for groups such as single parents, and on how to support siblings.

Following our focus groups with parents, we added in content about how to look after your mental health and wellbeing, including tips from parents and where to get support, and on topics that affect families today, like balancing working and having a child with CF.

We've also added parent blogs, videos, families' diagnosis stories, a letter and a diary to complement the booklet.



“Enjoy your newborn and keep planning that big, bright future you want for them.”

Jade, mum to Penelope, age 7

Information and support emails

An addition to our new diagnosis information offer is our series of emails. Parents can sign up for these on our website and will receive regular emails with relevant information about all things CF to help parents and carers navigate the first year following their baby's CF diagnosis. This includes stories from families, and ways that the Trust can support families, such as through online events, the Helpline and financial support services.

Advances in treatments

We also wanted to highlight a message of hope to new parents. In recent years there have been fantastic advances in research, which have led to new and better treatments for CF. There is every reason to feel positive about what the future will bring.

Parent-to-parent support

Parents shared with us the top questions or concerns they had when their child was first diagnosed, and with the help of CF specialist healthcare professionals, we've provided the answers in a Q&A format – to support and reassure parents who'll have so much going around in their heads in those early days and weeks. They also put together a 'top tips' section so that parents can have a head-start on some "CF parenting hacks" which will hopefully make life a little easier! The booklet also shines a light on the invaluable CF Connect peer support service from Cystic Fibrosis Trust, and our online community forum.

All the new diagnosis resources, including the booklet, can be found at cysticfibrosis.org.uk/newdiagnosis

The booklet can also be ordered in print by contacting our Helpline. Call 0300 373 1000, email helpline@cysticfibrosis.org.uk or message us on WhatsApp 07361 582053.

What's on your mind?

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

My child is starting school this year. Do you have any information I can share with the school to help his teacher and school staff understand CF?

Matthew's answer:

Starting school can be an exciting and daunting time for parents, particularly if your child has cystic fibrosis (CF). We have lots of information and resources available at cysticfibrosis.org.uk/parentsandchildren, including real-life examples of how people have managed the transition, with top tips for making the journey as smooth as possible.

We also have videos on our YouTube channel which include interviews with teachers, and we have specific information for teachers on our website too at cysticfibrosis.org.uk/teachers.

You can also complete an Individual Healthcare Plan, (find it at cysticfibrosis.org.uk/ihp) which describes the needs of a child with CF. It outlines how CF affects their daily life, how it is treated and highlights the role of the school in ensuring that the child has a full and safe school experience. This plan should be a dynamic document and updated with any new information or guidance. As a minimum, it should be reviewed on an annual basis. It has been developed with input from the specialist CF nurse and the child's parents and approved by the school.

You might also want to chat to other parents who've been there before. Our online community forum provides a safe and kind space to ask questions. We have a dedicated parents and carers area where you can speak to others. We hope that helps and your child has a safe and happy transition into school life.



If you have any further questions about CF, please feel free to contact our Helpline:

Call 0300 373 1000 or 020 3795 2184, Monday–Friday 10am–4pm

Email helpline@cysticfibrosis.org.uk

Chat with us on Facebook, Twitter or Instagram

Message us on WhatsApp on 07361 582053



Spreading the message about CF

YAG member Chawan recently organised her first Cystic Fibrosis Trust fundraiser, raising an amazing £615. She tells us more about what inspired her fundraising, how it felt to make a difference, and her top tips for other young people wanting to do the same.

My name is Chawan, I'm 14, and last year I organised my first fundraising event at my school in Glasgow. The idea stemmed from watching a family member grow up with cystic fibrosis (CF). I became aware that many people are not familiar with the condition, and I wanted to raise awareness amongst my peers and friends. I did this by putting together raffles for both staff and pupils, organising a stall with many games (for instance guessing how many sweets are in the jar) and having a 'wear yellow' day. There was also a life-size teddy bear that served as a mascot with a CF sash.

My goal was to raise £200 for Cystic Fibrosis Trust and with the support of my friends who helped me run and build the stall, collect donations, and sell raffle tickets, £615 became the final number. To me, this number was huge and made the result even more rewarding! It made me feel that the fundraiser was able to help someone, and I hope the money made a difference. Susan – the fundraiser coordinator from the Trust – supported me throughout the planning process and came into school on the day.



When the event was over, Susan introduced me to the Trust's Youth Advisory Group (YAG), offering me the chance to become a volunteer. YAG is a group of young people who have CF or a family member with the condition. It offers these people a chance to work on projects that make a difference to those living with CF. I have only been a member for a matter of months but am immensely grateful for such an opportunity because I have been able to meet so many people motivated to help others. Seeing this has encouraged me to become involved in their projects and continue spreading the message about CF.

I have already started planning another fundraiser at my school with my headteacher and the Trust for June and hope to expand to a primary school. This time I will focus more on raising awareness with the help of my YAG colleagues. We are figuring out what requires the most attention.

My biggest word of advice for anyone hoping to do anything similar is to talk to people about their plans and take in any suggestions. Lots of people have amazing ideas that can help elevate your event! Often the process can be overwhelming however it is very rewarding. When this happens, I recommend speaking to someone to ensure you aren't managing the stress alone. Also, writing a checklist with all the tasks you need to get done can be very helpful. This way you can keep track of what you have already done and what needs to be sorted next. A checklist makes it easier to set time aside for your tasks.

"I became aware that many people are not familiar with the condition, and I wanted to raise awareness amongst my peers and friends."

Chawan

We're always looking for new people to join YAG, so if you're 14-25 years old and would like to get involved, drop us an email at cfyouth@cysticfibrosis.org.uk.

Find out more about fundraising for the Trust at cysticfibrosis.org.uk/fundraising.

Day in the life

Our supporter Josh is dad to Spencer, 16 months, who has CF. Josh shares Spencer's daily routine featuring 'choc choc', outdoor adventures and lots of cars!

1

We start our day with 20 minutes of physio for Spencer, right after tackling his stinky nappy!



2

Exploring small wonders like this water dam with Spencer keeps him curious, happy, and learning every day!



3

Spencer takes his nebuliser like a champ, but only if there is 'choc choc' (Milkyway Star) in hand for straight after.



4



After Spencer's morning nap, it's time for outdoor adventures – whether it's exploring or riding his trike!

5

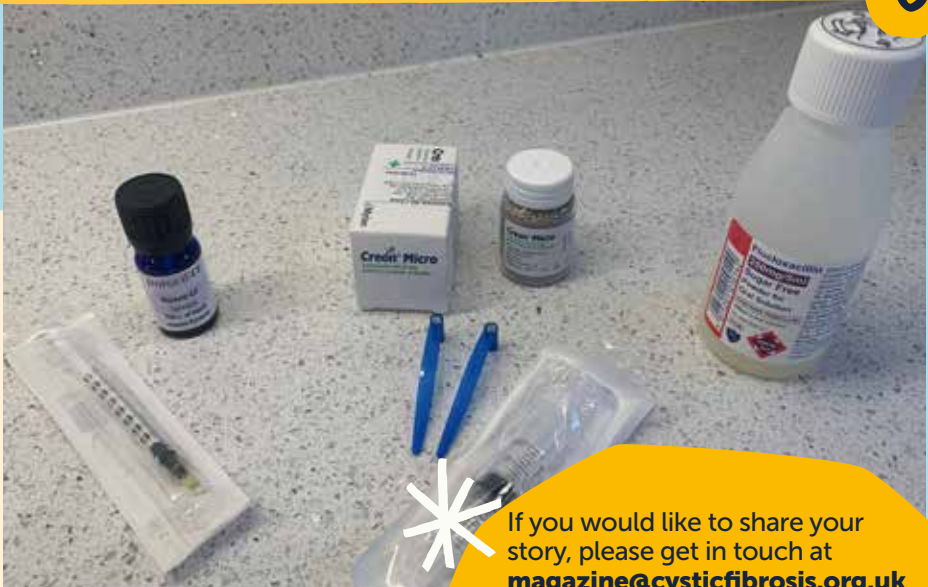


In between 'brum brum' cars and tractor exhibitions, we mix, measure, and give Spencer his meds.



Powering through his daily routine, with 12–15 doses keeping him strong, healthy, and smiling!

6



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

Leave a lasting legacy

Sian's Aunt Vera chose to leave a gift in her Will to Cystic Fibrosis Trust in memory of her daughters Gillian and Christine.

To find out how you can leave a gift in your Will, visit cysticfibrosis.org.uk/freewills or email giftsinwills@cysticfibrosis.org.uk

“My aunt kept a close watch on advances in treatment for CF, which is one of the reasons why she was so keen to leave money after her death to help fund further research into the disease.”

Sian

Sian's Aunt Vera