Cystic Fibrosis Trust

CFLife

Issue 18
cysticfibrosis.org.uk

Your stories
Zanib shares her transplant journey

In focus
Explaining CF to friends and family

60th Anniversay Awards
Meet our amazing winners

Uniting for a life unlimited

Cystic Fibrosis Trust

Whatever you're dealing with, you don't have to face it alone. We're here for everyone affected by CF in the UK.

Here are just some of the ways we can support you.

- Benefits advice
- Welfare grants
- Information resources
- Peer support
- Student support
- Events for young people
- Help with work and employment

To find out more, contact our friendly Helpline team by phone, email, WhatsApp or on our social media channels.

helpline@cysticfibrosis.org.uk
Phone 0300 373 1000
Whatsapp 07361 582053
(Mon–Fri, 10am–4pm)

Uniting for a life unlimited

What's inside

Issue 18 – April 2025

On the cover: Zanib, who features on p16
On this page: Bottom; Claire, who features on p19
Top; Aiden, who features on p38

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.

ISSN 2513-8391

All magazine correspondence should be sent to our new address:

CF Life Editorial Team
Cystic Fibrosis Trust, 33 Creechurch Lane, London, EC3A 5EB.

magazine@cysticfibrosis.org.uk

Uniting for a life *unlimited*

Welcome to CF Life

In this issue of CF Life, we're delighted to introduce the winners of our 60th anniversary awards. From researchers and health professionals to fundraisers and campaigners, every one of them makes an incredible difference to the CF community.

Elsewhere in this issue, we find out more about our new Translational Innovation Hub on lung health and infection in CF and meet some of the researchers involved. We also share some top tips for talking about CF to friends and family, as we know it can sometimes be tricky to find the right words.

In our What's on your mind? column, Matthew from our Helpline team answers some of your pressing questions. This month, he shares tips for going on holiday when you have CF. Plus, we chat to Zanib about her experience of having a double lung transplant.

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

CF News

Support

Having a warm, dry home is vital for people with CF to stay well, but because of increasing energy costs over the past few years, people with CF and parents of children with CF are having to make impossible choices between heating their homes and eating properly. This winter we have given 550 Winter Support Fund grants to low income households at most risk of going without warmth or food. We've also been offering further help from our welfare team, checking they are getting all the financial support they are entitled to, and offering suggestions of other sources of help and support.

Campaigning

The vanzacaftor triple therapy is a new, once-daily modulator therapy made by Vertex. It is made up of tezacaftor, one of the modulators used in Kaftrio, as well as two new modulators called vanzacaftor and deutivacaftor. The Medicines and Healthcare products Regulatory Agency (MHRA) has approved the new triple modulator drug, Alyftrek (deutivacaftor/tezacaftor/vanzacaftor), saying it is safe and effective for eligible people with one or more F508del mutations or another mutation in the CFTR gene that is responsive to Alyftrek, in people six years and over. The vanzacaftor triple therapy is also being assessed by the National Institute for Health and Care Excellence (NICE), to determine its clinical and cost-effectiveness. We expect this process to conclude during the summer of 2025.

What's on

Together, let's build new connections, have fun and #Game4CysticFibrosis. Anything you raise through gaming can make a real difference to everyone living with CF. Whether you want to host a games night with friends or jump online and stream your adventures, we are all part of the quest for a brighter future.

Anyone can take part, at any time. Your game, your rules. Head on over to our website to accept your mission and gain access to exclusive merchandise. See **cysticfibrosis.org.uk/game4cf**

GAME
4 CYSTIC FIBROSIS

What's on

Sign up to our brand new event for 2025! Walk, Jog or Run for CF at Harewood House estate on July 12 and help bring us closer to the next research breakthrough. Choose from either a 5k or 10k route and explore the exclusive grounds of the beautiful estate. Sign up today and be part of this new event for 2025 at **cysticfibrosis.org.uk/harewoodhouse**

Harewood House
Walk Jog Run for CF

Research

We fund many early career researchers (ECRs) and we hope that they will continue to be active in CF research throughout their careers. In October last year we held a one-day conference to empower them to work together in the future.

Throughout the day they shared their latest results, were able to put their research in context of the wider field of CF research, and network with each other. **"It was great to see an event just for ECRs – it was intimate, comfortable and not intimidating, and a nice way us to come together,"** one participant commented.

Professor Jo Fothergill presenting at our ECR conference 2024

Sophie Pierce (second from right) and members of Team Cruising Free

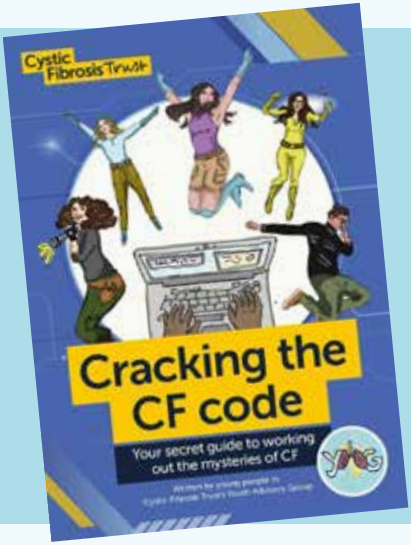
Fundraising

In February, our Trustee Sophie Pierce set out on her epic challenge to row the Atlantic Ocean. Sophie is taking on the 3,200 mile journey along with her crewmates Polly, Miyah, and Janine, who are all fellow members of Neyland Rowing Club. Sophie is aiming to be the first person with cystic fibrosis to row an ocean, and Janine at 70 the oldest woman. They are raising money for three charities, Cystic Fibrosis Trust, Emily's Entourage and Paul Sartori Hospice at Home.

To see their progress and sponsor the team see **gofundme.com/f/team-cruising-free-atlantic-row-2025**

Young people

We are excited to announce that our new resource for children, **Cracking the CF Code**, is out now! This is a very special resource, because it was completely written by young people in our Youth Advisory Group (YAG). YAG use their knowledge and experiences to explain tricky medical words and concepts to 6–9-year-olds. YAG are very proud of their work and are so excited to share it with the world! You can also order a copy on our website.



Richard Madeley hosting our 60th awards ceremony

And the award goes to...

Back in November, we held our 60th anniversary awards, shining a light on some of the incredible people who make up the CF community. Hosted by our celebrity ambassador Richard Madeley, it was a special evening celebrating outstanding achievements in healthcare, research, advocacy and fundraising. Here we meet our seven winners.

Professor Alan Smyth, Outstanding Researcher

Alan is a member of Cochrane Cystic Fibrosis group, which is an enthusiastic team of people who are interested in producing systematic reviews of interventions in the care of people with CF and their families. Alan also played a pivotal role in our James Lind Alliance Research Priority Refresh project, which identified the most important research priorities for people living with CF,

On winning the award, Alan said: **"I am absolutely delighted to receive this award. It is a privilege to work in partnership with clinicians and patients to bring about practical improvements in the care of people with cystic fibrosis through research!"**

Lorraine Barnes, Outstanding Fundraiser

Lorraine has been a passionate and dedicated fundraiser for Cystic Fibrosis Trust for 20 years. From charity balls to coffee mornings, wing walking to abseiling, her fundraising knows no bounds!

Lorraine dedicated her award to her two sons who have CF: **"While this award is deeply meaningful to me, it is not just a reflection of my efforts. It is a tribute to my two incredible sons, who inspire me every single day. Living with CF is not easy; my sons have faced challenges that many of us can only imagine, but their resilience and courage remind me of the strength of the human spirit."**

Anastasia Grainger, Outstanding Young Fundraiser

At just seven years old, Anastasia is a tour de force when it comes to fundraising. One of her many amazing achievements was organising a Halloween party just two days after she was discharged from hospital where she had been receiving IV antibiotic treatment, raising an incredible £3,500.

"The other nominees in my category had amazing stories too so I was really surprised and shocked to win but very happy," Anastasia said. **"What I love most about fundraising is bringing an idea to life and seeing everyone enjoy themselves for a good cause. I also enjoy finding out how much we've raised and letting my CF team and Cystic Fibrosis Trust know the amount."**

Marie Clegg, Outstanding Adult CF care

Marie has clearly made quite the impression on her patients. One nominator described her as **"an amazing lady who always goes out of her way to put her patients and their families at ease, always making sure they have everything they need."** On winning the award, Marie said: **"To be honoured this way by my patients makes me feel so proud and that all of the hard work and dedication is truly appreciated by the people I care for."**

Yasmin Hussaini, Outstanding Paediatric CF care

Not only is Yasmin an excellent nurse, she also organises parents' events, giving up her own time to bring CF parents together. She arranges annual education events with guest speakers and CF role models talking about topics that parents might want to find out more about.

Talking about what she loves most about her job, Yasmin said: **"I get to work with amazing children and parents. I love watching the children grow up and I love watching the parents become knowledgeable about CF and confident in managing their child's care. I also get to work with a great CF team who are supportive, encouraging and good fun."**

Rosie Nation, Outstanding Advocate Award

Rosie is mum to four-year-old Reuben, though Rosie's efforts extend beyond her role as a parent. She has worked tirelessly to raise awareness of cystic fibrosis, from sharing her own personal story to actively engaging with the media and collaborating with politicians. Rosie also campaigned relentlessly to challenge NICE's appraisal process for modulator therapies.

On her campaigning work, Rosie said: **"When the draft NICE guidance concluded that the CF medication was not cost-effective, I knew I had to take time away from work, and use my strengths and connections to give all my energy to changing that outcome.**

"I made sure parents understood the situation and how they could positively contribute. I worked with other CF parents to gather more evidence. I worked with health economists to put that information into a persuasive language for NICE. Together the CF community secured access to modulator therapies for our children. Aside from the infinite pride I have for my son, I have never been more proud of anything in my whole life."

Tilly Green, Outstanding Young Advocate

Tilly, who is a member of our Youth Advisory Group, has been raising awareness of CF from an early age. From speaking at her school when she was just 5 to campaigning for Orkambi and talking on local radio and in national press, she has made an incredible difference for the CF community.

On the importance of raising awareness, Tilly said: **"Because CF is an invisible condition, I am constantly debating whether I should explain what it is to people. Is it even worth it? And, on the rare chance they have heard of CF, they believe that the life expectancy is half of what it is today. That's the worst part. The only way we can stop that happening is by raising awareness, which is what I've really enjoyed doing for many years and intend to keep doing for many more!"**

"Our awards were a great opportunity to highlight incredible achievements in research, CF care, advocacy and fundraising. A huge thank you to everyone – we couldn't do it without you!

David Ramsden, Chief Executive of Cystic Fibrosis Trust

A huge well done to all our winners and nominees! Thank you for everything you do for the CF community.

New innovations in CF lung health

We recently launched the new Translational Innovation Hub Network for Lung Health and Infection in CF, a £15 million research partnership between Cystic Fibrosis Trust and LifeArc which will fund four Innovation Hubs at universities across the UK.

Over the next five years, researchers will work to address challenges around developing new treatment approaches for lung infections, detecting and treating exacerbations or 'flare-ups', and developing new ways to diagnose infections. The Network builds on the success of the original Innovation Hub led by Professor Andres Floto, which was funded in partnership between Cystic Fibrosis Trust and the University of Cambridge.

This research is vitally important because detecting and treating lung infections is still a big challenge in CF, as highlighted by the CF community in the JLA Research Priorities Refresh exercise. Our ultimate aim is to fast-track new research and treatments to improve health and quality of life for people with CF.

"These new hubs give me hope because improving research into the cause of exacerbations and the development of potential new treatments takes away a lot of my fears around what my health is going to look like in the future."

Sarah, who has CF

You can learn more about each of the Innovation Hub programmes on our website at **cysticfibrosis.org.uk/innovation-hubs**. We'll be keeping you updated on our website and social media, so look out for the different ways you could get involved.

Let's introduce the incredible lead researchers behind each Innovation Hub – and share their ultimate ambitions to make a difference for the CF community!

Hub: FLARE-CF
Leader: Professor Andres Floto, University of Cambridge
Ambition: To create a test that can be used by people with CF at home, to decide how and when to treat infections.

Professor Andres Floto

Professor Jo Fothergill

Hub: CF-TRAILFINDER
Leader: Professor Jo Fothergill, University of Liverpool
Ambition: To optimise treatments for exacerbations and develop phage therapy in the UK as an alternative to antibiotics.

Hub: PRECISION
Leader: Professor Jane Davies, Imperial College London
Ambition: To develop predictive tests for lung infections in order to inform doctors about the best way to treat them.

Professor Jane Davies

Professor Alex Horsley

Hub: PULSE-CF
Leader: Professor Alex Horsley, University of Manchester
Ambition: To test ways to prevent exacerbations in the future, taking into account events that may trigger them for individuals with CF.

“Whenever I accomplish something, I think of my donor and hope they would be proud”

Adjusting to life after an organ transplant can bring new opportunities, but also new challenges. This can be complex to navigate, both practically and emotionally. We spoke to Zanib, who has CF and had a lung transplant in 2020, to hear about her experience, how she's adjusting to life post-transplant and her hopes for the future.

Around the age of 27, the possibility of a lung transplant became reality for me. I had gone to college and university and hoped to pursue a career in pharmacy when my lung function started to decline and I needed frequent IVs. As this progressed, the subject of a lung transplant was raised (this usually happens when you have a two-year window where they can predict that your lung function could decline drastically). It was scary to even think about a transplant.

I had to wait about two years for my transplant. Being an ethnic minority put me at more of a disadvantage because you have to have more vigorous tests – your blood group and tissue all have to be a perfect match. I'm quite petite too, which made finding a match harder. Initially I was quite reluctant; going from knowing your own body so well to the unknown and having someone else's lungs is scary. While deciding whether to undergo the transplant, I heard so many different stories – unfortunately a lot of them were from people who had complications, which scared me. With the right support, I was able to make an informed decision that was right for me.

I had my transplant in January 2020, then in March the whole country went into lockdown. I'd just been given this new lease of life and then I became isolated. That was very scary because so little was known about COVID-19 at the time and I was also trying to adapt to this new way of life I had.

> **"The level of care that I need now is very different and that was something else I had to learn quite quickly."**

Life post-transplant

After the transplant there was the added worry of rejection, which can occur at any time – either initially, which is acute rejection, or chronic rejection, which is over a long period of time, a bit like how CF declines.

Having grown up with CF I was pretty much an expert on my own condition, but post-transplant there was a whole host of other symptoms and complications to get my head around. It takes time to learn what is the new normal for your body.

The level of care that I need now is very different and that was something else I had to learn quite quickly. Pre-transplant I had a very strict routine: wake up, do my nebs, do my physio, nebs again, then set out my day. I was on regular IVs, and I couldn't do a lot of things for myself. Post-transplant, I'm very much able to do a lot more for myself, but there are still limitations.

A common misconception around transplant is that you just swap your damaged CF lungs for healthy lungs and job's a good'un. Unfortunately that isn't the case. It's not just your lungs, all the organs in your body are impacted by CF, and every patient is different.

My donor

Upon learning I needed a transplant, one of my first thoughts was that my new lease of life would come about because someone else had died, and that was quite disheartening. But this is a blessing, and whenever I accomplish something, I think of my donor and hope they would be proud. I did get in touch with my donor's family and received an emotional letter in response.

It was quite touching and motivated me to make the most of the second chance I have. I would say to my younger self that your health is the most important thing in life so cherish it. Life is too short and you should make the most of it. Don't let anyone ever put you down from achieving your dreams and aspirations.

You can find out more about CF and transplant on our website at **cysticfibrosis.org.uk/transplant**. We have information resources for adults and children with CF, as well as their friends and family, to help them understand what it might mean for their loved one. We also have resources to help people with CF to adjust to life after transplant at **cysticfibrosis.org.uk/lifeaftertransplant**

Knowing me, knowing you

Claire is a former CF nurse who now works as Patient and Public Involvement and Engagement (PPIE) Partnership Manager here at Cystic Fibrosis Trust. We caught up with Claire to hear more about how she works with the CF community and the changes she's seen in CF care.

Hi Claire, can you tell us about your role at the Trust?
I use community insights to develop partnerships with other organisations who may have similar objectives or community needs. In particular, we are interested in partnerships with charities and industry (such as pharmaceutical or biotech companies). We can offer industry paid-for services that include coordination of PPIE activity, access to funding streams and research networks, valuable data through the UK CF Registry and support in setting up trials through the Clinical Trials Accelerator Platform.

Why is community involvement so important?
When you hear the challenges people with CF are facing in managing their condition you truly begin to understand why you need researchers to be in the lab, why you need services and resources to support the emotional and physical wellbeing of those with CF, and why you need medications and treatment to be accessible to all. The **why** is the most critical thing to understand, but this understanding also helps to inform the **how**. The power of lived experience cannot be underestimated.

What do you love most about what you do?
The relationships I get to build are the best thing about my role and hearing from those who live with CF on a daily basis is my motivation. People share some of their most sensitive and challenging experiences, but I know they are doing so in the hope it will benefit others.

Can you tell us about your previous role as a CF nurse?
My last nursing job before joining the Trust was working as a specialist nurse in an adult cystic fibrosis team. I was in the role for some landmark changes in care and treatment and witnessing the impact of this was just incredible, but it also made me realise how much there is still to be done. It was a huge wrench for me to leave nursing. This role allows me to work with the CF community in a different way.

Tell us something people might not know about you?
When I was 26, I spent several months in Africa, travelling and doing some volunteer nursing. I met some inspiring people and learned a lot!

Find out how you can join our involvement group at **cysticfibrosis.org.uk/involvement**

Easy exercise

We've been working closely with a team of specialist CF physiotherapists and people with CF to create a series of eight physiotherapy videos.

Physiotherapy is an essential part of managing cystic fibrosis. It covers lots of aspects of your health including airway clearance, exercise, postural work, pelvic floor health and inhaled therapies.

Airway clearance techniques are an important tool for people with CF to help keep their chests clear and prevent infections. Whether you complete airway clearance every day or only when unwell, it's important that you do it well.

The videos will guide you through important airway clearance and physiotherapy techniques which can be used as a reminder or refresher whenever needed. These videos are designed to work alongside the detailed factsheets already on our website at **cysticfibrosis.org.uk/resources**

Here's what we cover:

- **Autogenic drainage** and the **Active Cycle of Breathing Techniques (ACBT)**
- **PEP** (Positive Expiratory Pressure) **and OPEP** (Oscillating Positive Expiratory Pressure)
- **Bubble PEP**, a fun and playful way to make airway clearance more enjoyable
- **Percussion**, a hands-on technique to help loosen mucus in infants
- **Pelvic floor health**, because coughing can sometimes put pressure on this area and cause leaks
- **Posture**, as certain postures can impact lung function

If you have questions, please speak to your CF specialist physiotherapist. You can find the videos at **cysticfibrosis.org.uk/physiovideos**

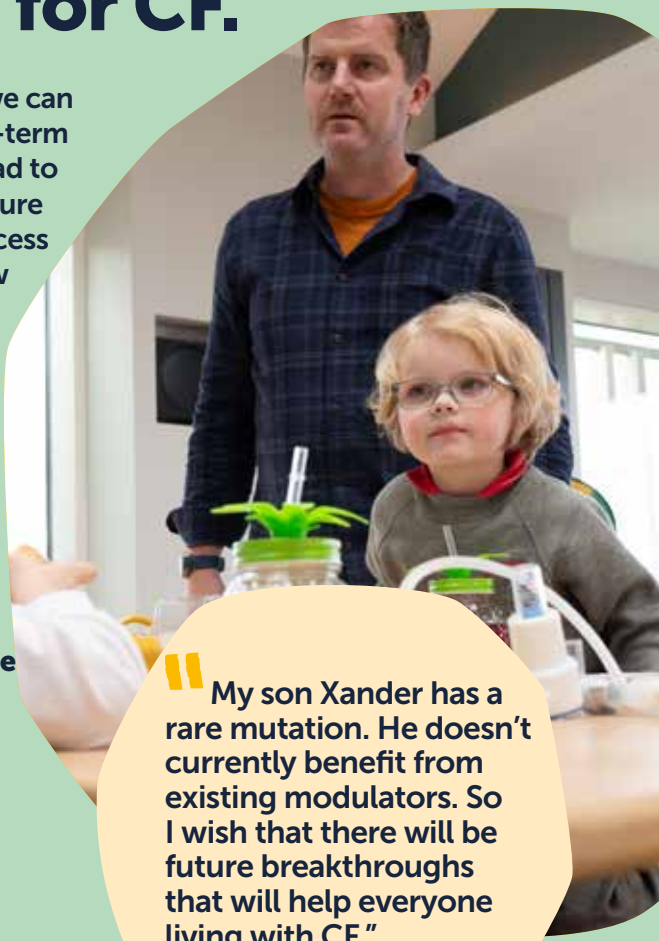
Cystic Fibrosis Trust

Regular gifts help to fund ground-breaking research into new treatments for CF.

Consistent donations mean we can invest in more complex, long-term research projects. This can lead to breakthroughs which will ensure that everyone with CF can access life-saving medicines and new treatments.

Whatever your gift, you will change lives and help us come closer to the day when everyone can lead a life without limits.

If you would like to support with a regular gift visit **cysticfibrosis.org.uk/donate**



"My son Xander has a rare mutation. He doesn't currently benefit from existing modulators. So I wish that there will be future breakthroughs that will help everyone living with CF."

Duane, Dad to Xander

Registered with FUNDRAISING REGULATOR

Uniting for a life unlimited

Team Ewan

Dream team

Colleen and Mike, whose son Ewan has CF, are part of Team Ewan, which has raised an incredible £70,000 for the Trust over the years. They opened up to us about dealing with diagnosis, fundraising, and their hopes for Ewan's future.

Tell us a little about Ewan.

Well let's be honest, he's six, so mostly he's an expert in everything. He's lively, smart, loves to play – mostly Lego and Hot Wheels. His favourite things are probably eating (fruit and sweets), his cousins and my Xbox.

How did you deal with Ewan's diagnosis?

It was rough. Ewan had a suspected bowel obstruction and CF was mentioned. A lady introduced herself as being from the CF team and the penny dropped. What followed was the steepest of learning curves.

We pretty much lived in the hospital for the next seven weeks due to other complications. It was exhausting, but we dealt with it by just doing it – there wasn't another choice.

How does CF affect him day-to-day?

It's always there in the background but he's currently doing quite well. What affects him most day-to-day is just doing all the CF-related things that take him away from being a kid; he doesn't love physio and is on nebulisers twice a day, on top of lots of tablets.

> "We want the best for Ewan and everyone with CF. Without the funding, Cystic Fibrosis Trust can't do what it's doing."

Why did you start fundraising for the Trust?

We already fundraised for various charities, but none close to home. Ewan's dad Mike often signs up for the Great North Swim and swimming for the Trust quickly became an obvious choice.

Tell us about Team Ewan and how you've raised money for the Trust.

Initially it was just family, then we had a wave of people wanting to help, so Team Ewan was created, with people all over the country taking part in events: from coffee mornings and raffles to the Great North Swim (from 250m to 10km), the Great North Run (with some people carrying a 12ft replica of the Tyne Bridge), and Ewan's 2.6 challenge (when he was two years old). The highlight is the Team Ewan Charity Ball, which we have held four times and brings in 150+ supporters all in their finery. All that comes to a fundraising total of over £70,000 to date.

What advice would you give to other parents with children with CF?

We could say loads here: stick to information from the Trust; beware of social media; talk to your CF team; wear sunscreen (music credit: Baz Luhrmann). While that's sound advice, you're doing fine – keep doing that!

Why would you encourage others to fundraise with the Trust?

We want the best for Ewan and everyone with CF. Without the funding, Cystic Fibrosis Trust can't do what it's doing. We were invited to the Trust's 60th anniversary event, and it was clear to us that there are very smart people working on this so we're gonna have their back while they do.

What are your hopes for Ewan's future?

Oooooh, astronaut, actor, Olympian, international man of mystery – whatever he likes really. We want him to be able to do whatever he wants and not be limited by his condition.

We'd like to say a huge thank you to everyone involved with Team Ewan. You can find out more about fundraising for the Trust at **cysticfibrosis.org.uk/fundraising**

10 years of bright ideas

This year, we celebrate 10 years of the Helen Barrett Bright Ideas Awards, providing financial support for adults with CF who want to run their own business. The Awards were established in memory of Helen Barrett, an entrepreneur with cystic fibrosis who, together with her partner, launched a successful gym that's still thriving today. We spoke to Helen's family about how it feels to see the awards create opportunities for people with CF.

Cystic Fibrosis Trust

Helen Barrett Bright Ideas Awards

"I love when I hear people talking about the Helen Barrett Awards – it keeps her name alive," says Helen's dad, Tony. "Helen would be delighted that the Awards have continued for 10 years, giving other people with CF the chance to start their own business. It's in line with her passions and the things she believed in and wanted to do. Helen had a business mindset even from a young age, and she worked so hard with her partner, Andy, to start the gym."

Doreen, Helen's mum, agrees. "I think Helen would have absolutely loved this project and she would be proud to hear her name being used by so many young business leaders. She always had big ideas, from selling clay models at car boot sales as a child, to her gym with her partner Andrew that's still going strong today. I see a lot of Helen in the award winners. The CF community is a special one and I'm happy Helen is able to support them in this way."

The family get involved with the Awards each year, as part of the panel which reads and reviews the nominees – an activity they all find inspiring. Mark, Helen's brother, says: "It's wonderful to see how Helen's entrepreneurial spirit is still helping others. I'm inspired every time I read the nominees each year and constantly amazed that these young entrepreneurs can run such successful businesses despite their health challenges."

"Having the opportunity to read the amazing things people are doing while managing CF, and the honour of calling up the winners, means so much to me," agrees Tony. "It provides an opportunity which is totally positive for people and without exception, the winners are special people. I'm so proud that the Awards have kept on supporting people with CF for so long."

Andy, Helen's business and life partner, sums it up: "The thought of giving someone in life who has constant daily struggles and stress beyond we can imagine the opportunity to pursue an idea, a dream that they have been thinking about for a long time, is incredible."

Read all about Helen Barrett Bright Idea Award winner Aiden on page 38 and keep an eye out this spring for the announcement of our latest Helen Barrett Bright Ideas Award winners and their businesses.

Friends, family and CF

Talking to friends and family about your child's CF can be challenging. It can be hard to explain the condition and how it's impacting your family while fielding questions from well-meaning loved ones.

But talking openly about CF can be really helpful. Sharing insights into the condition can help those around you understand why the treatments and medicines are so important, why your baby needs extra care, and how they can support you as you adjust to the diagnosis.

There's no right or wrong way to talk to people about your baby's CF. It's up to you how much you share, and when. We've put together some helpful tips to support you with getting conversations started.

Top tips for talking about CF

Be prepared

Before you start a conversation about CF, jot down what you'd like to say. You could even plan what you'd like to talk about in advance with your CF team. This can help you feel in control of the conversation.

Tell people how they can help

Loved ones often want to help, so let them know what you need – whether that's practical support or a distraction from CF.

Be ready for different reactions

Some people might ask lots of questions, while others might not. And some questions might come across as annoying, or hurtful. It's ok to decline to answer a question or redirect the conversation.

Be prepared for questions about genetics

A CF diagnosis can surprise families who didn't know they were gene carriers. Your relatives might have questions about what this means for them. Anyone with a family member who has CF or carries the gene can access testing on the NHS via their GP or your CF team. Find out more at **cysticfibrosis.org.uk/carriertesting**

Other places to get support

CF teams often include psychologists or social workers, who can help you plan conversations or even speak to your loved ones on your behalf. You can also direct friends and family to our website, where we have lots of information resources and videos, or to the Trust's Helpline.

Our online community forum is a great place for you to chat with other parents and people with CF, and our parent peer support service, CF Connect, will put you in touch with a trained parent volunteer who you can talk to in confidence about having a child with CF.

> "Don't shy away from the diagnosis now. Encourage people to ask questions and not to Google. Family and friends have been amazing in asking and learning about it from us – as we learn too."
>
> Sonja*, whose daughter Lily* has CF
>
> *names have been changed

Where to find support

cysticfibrosis.org.uk/helpline
cysticfibrosis.org.uk/cfconnect
cysticfibrosis.org.uk/newdiagnosis
forum.cysticfibrosis.org.uk

The future of CF care

As we come to the end of our 60th anniversary year, we take a moment to reflect on the remarkable changes in cystic fibrosis treatment and care over the past six decades. And as the needs of people with CF continue to evolve, we also look to the future and how we can continue to support and foster progress.

From the bleak outlook of 1964, when virtually all children with CF faced a devastating fate, to the more hopeful landscape of 2025, where the latest UK CF Registry data shows the majority of people living with CF are adults, the progress that has been made in CF care over the past 60 years has been remarkable.

Today, our care landscape is guided by standards and practices that Cystic Fibrosis Trust has played a pivotal role in shaping. From the publication of clinical guidelines to the UK CF Registry, together we've fought to ensure that every person with CF should receive the best support and treatment.

So where do we go from here?

As we navigate this changing landscape for CF, there's questions that need addressing:

- How do we ensure equal access to care for all members of the CF community, according to their individual needs?
- How do we harness the power of individual choice to shape a more personalised care experience?
- How do we address the growing demands on CF teams amidst workforce challenges within the NHS?

The story so far

In 1964, when The Cystic Fibrosis Research Trust (as it was known then) was established, 90% of children with CF didn't reach the age of 10. Fast forward to today, and the latest data from the UK Cystic Fibrosis Registry reveals the predicted survival age for someone born with CF in 2023 is just over 64 years.

Today's landscape of CF care is the result of many decades of progress and initiatives that the Trust is proud to have worked with others to deliver.

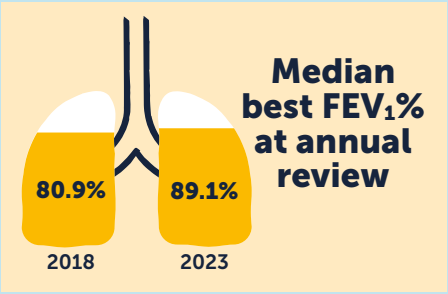
Highlights include:

- In 1983, the Trust began funding specialist CF centres and the first specialist doctors and CF nurses. Today, there are 59 specialist adult and paediatric CF centres in the UK.
- In 1996, the Trust published its first consensus document, **Clinical Guidelines for Cystic Fibrosis Care**, in partnership with the British Paediatric Association and the British Thoracic Society. This landmark publication aimed to standardise care nationwide, equipping clinicians with guidelines for best practice. Subsequent iterations, including the recent publication of **Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK (2024)**, have followed.
- In 2007, responsibility for hosting the UK CF Database was taken over by the Trust to form the UK CF Registry – a secure national database collecting data from consenting people across all cystic fibrosis centres in the UK. With coverage spanning over 99% of the UK's CF population, it has been an invaluable resource to CF teams, researchers, and people with CF.
- Following a relentless community campaign spearheaded by the Trust throughout the 1990s and 2000s, in 2007 the rest of the UK followed in the footsteps of Wales by adopting cystic fibrosis as part of the UK newborn screening programme.
- In 2024, landmark long-term deals were confirmed to make life-changing CF modulator drugs – Kaftrio, Symkevi and Orkambi – available across the four UK nations. This follows many years of campaigning by the Trust and CF community.

Where are we now?

There has been incredible progress; however, CF remains a lifelong, life-limiting condition without a cure.

Widespread access to CFTR modulator therapies, such as Kaftrio, has had a positive impact on the health and quality of life for many people with CF. These therapies have led to reduced pulmonary exacerbations and improved lung function, with over 79% of the UK's CF population now being treated with them. This shift in treatment is not only reshaping the overall health of the CF community but also redefining the experience of care for many people with CF.



Between 2018 and 2023 alone, UK CF Registry data reveals notable changes: the proportion of people with CF receiving at least one course of IV antibiotics per year decreased from 44.7% to 22.0%; median best FEV_1 (a measure of lung function) at annual review improved from 80.9% to 89.1%; the number of CF-related lung transplants went from 49 to fewer than 5.

But despite proving to be life-changing for many, modulator therapies are not a cure for cystic fibrosis. A large number of people with CF continue to live with the irreparable damage that they sustained before starting modulators, as well as with a range of persisting co-morbidities, such as CF diabetes.

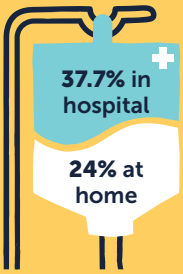
There is also a minority of people with CF who don't tolerate modulators, or are unable to benefit from them due to their genotype. This means a big difference in healthcare needs between those who can and can't benefit from modulators persists.

We are actively championing efforts to address this disparity. Genetic therapies offer promise in treating the root cause of CF for everyone, irrespective of mutation. Through the Trust's UK CF Clinical Trial Accelerator Platform (CTAP), early phase studies for genetic therapies are underway to assess their effectiveness.

Developing treatments for people who can't benefit from CFTR modulators was identified as a top research priority by the CF community during the James Lind Alliance (JLA) CF Research Priority Refresh and the Trust remains committed to making equitable access to CF care a reality.

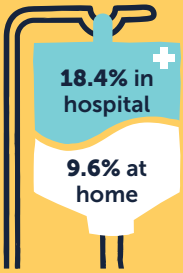
44.7%

of people had at least one course of IV antibiotics in **2018**



22.0%

of people had at least one course of IV antibiotics in **2023**



With the CF community evolving in size and age, new opportunities and challenges emerge, particularly for the NHS and CF teams dedicated to providing the best quality care to people with CF.

We also continue to fund and support crucial research aimed at improving the daily lives of individuals with CF. Trials such as CF STORM are looking to offer potential relief for people with CF on Kaftrio, by studying the extent to which stopping nebulised muco-active therapies results in lung function decline. This could help reduce the treatment burden that many with CF face.

Through the CF Antimicrobial Resistance (AMR) Syndicate and the Translational Innovation Hub Network for Lung Health and Infection in CF, we are also helping to tackle tricky infections and combat antibiotic resistance.

The future

The CF population is growing, with advancements in care meaning that people with CF are living longer.

Alongside general growth, the makeup of the CF population is also changing, with an increase in adults living with CF. Once a condition mainly affecting children, CF now prominently impacts adults, with 59.6% of individuals with CF recorded on the UK CF Registry in 2023 being aged 18 or above.

A 2023 survey conducted by the Trust of staff working within CF teams revealed a perceived shift, rather than a reduction, in workload, away from inpatient and acute care to more virtual and homecare. The survey found this was felt greatest in adult services.

The changing workload is, in part, driven by the evolving care needs of the CF community, as well as the growing number of adults with CF. While modulators have reduced the need for inpatient care for some, they have also contributed to new challenges in CF.

Some people with CF have found that modulators have had a negative impact on their emotional wellbeing. The Trust's changing workload survey found that across both adult and paediatric care, wellbeing support was an area of work that had perceptively increased for many staff in CF, illustrating the direct impact that evolving community needs are having on care delivery.

As demands on CF teams change, they will need to adapt to ensure the needs of all people with CF continue to be met. This will likely be complicated by wider workforce challenges impacting the NHS, which have been particularly acute for cystic fibrosis teams who have consistently reported higher vacancy rates compared to the NHS England average over the previous three years.

However, CF services continue to innovate. They already demonstrated adaptability, particularly during the COVID-19 pandemic with the rapid introduction of remote care. The adoption of remote monitoring and virtual clinics also highlighted the importance of individual choice in CF care, with many people continuing to prefer remote care even after the pandemic, as discovered in our recent patient experience surveys (PREMs).

Individual choice is set to play a pivotal role in shaping the future of CF care. Services will need to have capacity to meet the needs of individuals with the greatest clinical need and complexity, while also implementing person-centred models of care that offer choice and flexibility.

The voice of the CF community will be central in shaping how services navigate this, and the Trust will continue to support CF teams to meet these diverse needs.

As people with CF get older, it's expected that they will experience a range of co-morbidities and age-related conditions, which will require care from a range of medical professionals. As highlighted in our most recent survey of patient experiences in adult CF care, greater collaboration within and beyond CF teams will be vital.

We won't stop

Over the last year, the Trust has been working with the CF clinical teams and the CF community to develop updated standards of care for cystic fibrosis. Together with data from the UK CF Registry and our PREMs survey, we are striving to make sure teams are well equipped to embrace change.

None of this can be done without the involvement and participation of people with cystic fibrosis and the wider community, who play a vital role in everything we do.

As the care needs of people with CF continue to evolve, we remain committed to fostering and supporting continued progress in the care of people with CF until everyone can live without the limits of CF.

Find out more about all our work and the different ways we can support you at **cysticfibrosis.org.uk/support**

What's on your mind?

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

Hi, I'm going abroad this summer and I'm struggling to get travel insurance that will cover me. It's the first time I'm going abroad so wondered if you had any guidance on this? It's also going to be very hot, do you have any advice on keeping well?

Matthew's answer:
Thank you for your question and I hope you're looking forward to your holiday!

Although we cannot recommend any individual companies, we have a list of travel insurance companies that people with CF have told us they've been able to get affordable cover with in the past. Quotes can vary a lot, so it is worth shopping around, to make sure that you get quotes and cover which meets your needs and circumstances. Our Helpline can send this list to you.

You could also look at Medical Travel Compared (**medicaltravelcompared.co.uk**) which compares travel insurance quotes for people who have existing medical conditions.

The Money and Pensions Service (**moneyhelper.org.uk**) also have lots of useful information about travel insurance for people with pre-existing medical conditions.

As it's your first time abroad it might be helpful to let you know our website has lots of helpful information about going on holiday and things to think about and do to make sure your health is well taken care of while you're away. **Search holiday on our website.**

We also have information and guidance on staying safe in hot weather which I hope will help. You can find this at **cysticfibrosis.org.uk/hotweather**

If you'd like to talk to other people with CF about going on holiday and ask questions, our **online community forum** is a safe and friendly space where you can chat to others and ask questions.

If you're going away this summer and need information on travel insurance please contact our Helpline on **0300 373 1000**, **helpline@cysticfibrosis.org.uk** or message us on WhatsApp on **07361 582053**.

Question Time with YAG

We're Rosie, Tilly, Tehya and Chawan and we're all part of Cystic Fibrosis Trust's Youth Advisory Group, or YAG for short. We're a group of young people aged 14–25 who are living with CF, or who have a close family member living with the condition. We're here to make sure that the voices of young people with CF are heard loud and clear. We meet online twice a month, to chat, laugh and work hard to make a difference... and get to know amazing people along the way. Here we answer some pressing questions so you can get to know us a bit more!

What would be your advice on coping with the transition from paediatrics to adult care?

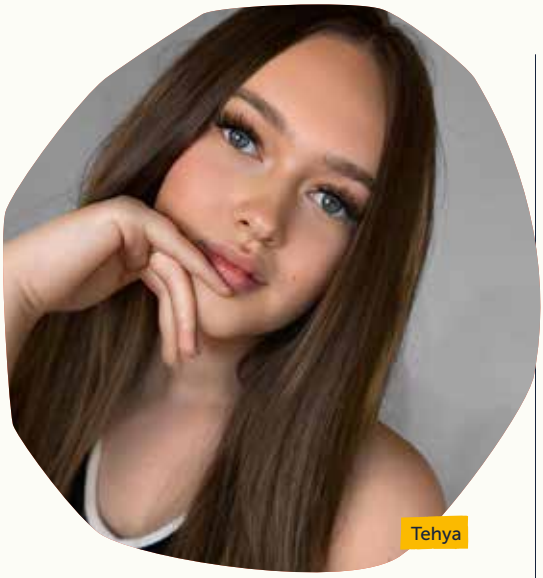
Rosie: The idea of moving up to adult care can be very daunting and worrying, but you aren't alone with these feelings; nearly every young person your age with CF will be feeling the same. I am currently preparing to move up to adult care myself and my paediatric team have been very helpful with supporting me. Your team can support you in many ways. For example, they can set up meetings with your future adult team and talk you through the process of transitioning to make it less scary.

What would you say to a young person thinking about joining YAG?

Tilly: YAG is something I will treasure and hold close to my heart for my entire life. The friends that I have made through the group are all very special to me, I'm really close to them and I feel so lucky that YAG led me to them, as we would never have been able to meet otherwise. The projects that we do are so impactful and important for not only the Trust but the wider CF community as well.

Rosie

> **"Having CF doesn't stop you from doing the things you're passionate about, no matter what that may be."**
>
> Rosie


Tehya

If you could step into somebody else's shoes for the day, who would it be and why?

Tehya: I would choose my dance teacher Holly because she is my biggest inspiration. I love how she can make a team into a family. She is an incredible dancer and dance teacher and I hope one day I can be as good as her. I would love to experience what it's like to dance like her and run a business like she does.

What's one thing you wish more people knew about CF?

Rosie: It doesn't define us. Having CF doesn't stop you from doing the things you're passionate about, no matter what that may be. There are so many ways to do the things you're passionate about while being mindful of your CF; for example, working with animals and hay can be risky, but I wear a mask and wash my hands frequently to help reduce the risk of infection.

If you were stranded on a dessert island, what three items would you take and why?

Chawan: In terms of survival, I would pack some matches. That way I'll have a fire to cook food, purify water with and stay warm. Also, I'd take a tent; that way I wouldn't have a to worry about shelter as I doubt I would be able to make a sufficient one myself! To keep my spirits up I would pack as many books as I'm allowed – the bigger they are the better. That way I would be able to keep myself entertained with interesting stories and feel less alone on the island. This question is a bit of a brain teaser, what would you bring?


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**

A place to remember

Our tribute or remembrance pages, created in partnership with MuchLoved, offer a lasting space to honour and cherish loved ones.

Many find comfort in online memorials, visiting them whenever they need, and sharing them easily with family and friends worldwide. The tribute pages are permanent, allowing people to add photos, messages, music, virtual gifts or light a virtual candle.

They also serve as a meaningful way to raise funds in a loved one's memory, keeping all your donations in one place.

There's no set timeline for creating a tribute; while some choose to start them to share funeral details, they can be set up whenever it feels right.

Our In Memory Officer, Susan, says: **"We understand the importance of keeping a loved one's legacy alive, not only for friends and family now but also for future generations who didn't have the chance to know them."**

Amy's son, Josh, was born in April 1995 and was diagnosed with cystic fibrosis at 18 months. He faced his treatments and hospital stays with resilience, never letting them hold him back. He loved music, cherished his family, and was a supportive friend to everyone around him.

Josh was closely involved in the lives of his three siblings, and even as his health declined, he found joy hearing about their experiences. Amy's promise to Josh is heartfelt: **"As life goes on, I'll carry you with me always. I'll keep sharing your story for as long as I have my voice, and in moments of joy, I'll think of you and smile."**

Josh's tribute page helps Amy and her family share his story, capturing loving messages and donations made in his honour. Friends and family have posted their memories, and recently, Josh's friend Liam held a gaming fundraiser linked to Josh's page.

Though Josh is deeply missed, Amy finds comfort in this tribute. She says: **"The tribute page, the fundraising, and staying connected to CF news all help keep his memory alive."**

Josh

> **"The tribute page, the fundraising, and staying connected to CF news all help keep his memory alive."**
>
> Amy, Josh's mum

We know how difficult it can be to begin a tribute, and our In Memory Officer, Susan, is here to support anyone who wants guidance on creating a remembrance page. You can reach her at **susan.jackson@cysticfibrosis.org.uk**, or find more information on our website.

Day in the life

Aiden is a recent winner of a Helen Barrett Bright Idea Award and has used the grant to set up an inclusive surf club in Cornwall for those with learning disabilities. He lives with a learning disability himself, is neurodivergent, and has cystic fibrosis.

1 Checking out the waves at my secret viewing spot in Cornwall.

2 Through my business Aloha Kakou, I want to offer experiences and opportunities to people who may not easily get them.

3 Here I am at the gym working on conditioning, which is really important for surfing and my general health.

4 Getting ready for a winter surf with my buddies – we're out on the water come rain or shine.

5 I work as a life experience facilitator, delivering Oliver McGowan training on learning disability and autism to NHS staff.

6 Some beautiful beach art!

Find out more about Aiden on Instagram: **@aloha_kakou_shaka**

Find out more about the Helen Barrett Bright Idea Awards at **cysticfibrosis.org.uk/hbbi**

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

Cystic Fibrosis Trust

Save the date for CF Week 2025!

9–15 June

Every year our amazing community comes together to wear yellow and help raise vital awareness and funds so everyone with CF can look forwards to a brighter future.

There are loads of ways to get involved. Just remember, whatever you do, **do it in yellow!**

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

Uniting for a life unlimited