Cystic Fibrosis Trust

CF Life

Issue 19
cysticfibrosis.org.uk

Your stories
Sophie's epic adventure

In focus
Fighting CF lung infections

Neurodiversity and CF
What it is and how it can affect you

Uniting for a life *unlimited*

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Issue 19 – September 2025

On the cover: Sophie, who features on p14
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Bottom; Morgan, who features on p21

Social

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Useful contacts

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

All magazine correspondence should be sent to our new address:

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Welcome to CF Life

In this issue of CF Life magazine, we delve into the work of the Translational Innovation Hub Network, the key questions we hope it will answer, and how it will make a difference to the lives of people with CF over the next five years.

Elsewhere in the magazine, we speak to our Trustee Sophie Pierce, the first person with CF to row an ocean. Sophie shares more about the highlights and challenges from this amazing adventure, and how she managed her CF in the middle of the Atlantic Ocean!

So much of our work would not be possible without all our volunteers, so we're delighted to give them a shout-out in this issue. Turn to page 22 to read about how Chris has volunteered with the Trust over the years and what it means to him.

We also share our latest information and resources on neurodiversity and CF; look at how GI (gastrointestinal) symptoms can impact daily life – and how we we're working to support people with these symptoms; and chat to CF nurse Caroline Whitton to hear about a typical day in her role.

We hope you enjoy reading this issue!

The CF Life team

We're always looking for new people to feature in CF Life. If you'd like to share your experiences, please get in touch with us at **magazine@cysticfibrosis.org.uk**

Uniting for a life *unlimited*

CF News

Support

We responded to the Government's plans to reform the benefits system for disabled people, highlighting the experiences of people with CF and their families. We worked with frontline experts, social workers and our Welfare and Rights Adviser to gather evidence and ensure MPs heard loud and clear the impact these changes could have to people with CF.

We asked people with CF and their families to contact their MP highlighting the impact of the reforms, and the Trust was able to meet with Sir Stephen Timms, Minister for Social Security and Disability, alongside other senior members of the Department of Work and Pensions.

Keep an eye on our social media channels for the latest updates on this bill and how we are responding.

Research

In June, we were delighted to announce £1.3 million of new research funding focusing on your research priorities, including innovative ways to treat NTM lung infections and early studies on better ways to treat CF diabetes.

The funding is for three research awards: a Strategic Research Centre to develop new treatments for the devastating lung infections caused by Mycobacterium abscessus (an NTM bacteria); a Development Award to investigate a new way of treating CF diabetes; and a Development Award to explore a newly found activator of the CF protein in the lung in more detail.

A big thank you to all our generous partners and donors who are helping us to fund these research awards to help improve the lives of people with CF. You can find out more at **cysticfibrosis.org.uk/research**

Fundraising

Thank you to everyone who showed their support for Wear Yellow Day and #Circuits4CF back in June. Together, you helped raise £132,000 for life-changing research and vital support… and counting!

From a **Dancing in Yellow** week held by Babyballet Southport, Formby and Crosby, to an epic walk along the Thames by two supporters in London, it's been amazing to see the wonderful ways you've raised vital funds and awareness.

Save the date for next year's Wear Yellow Day on Friday 12 June 2026 – and register your interest at **cysticfibrosis.org.uk/yellow**

Campaigning

The National Institute for Health and Care Excellence (NICE) has approved the once-a-day triple therapy, Alyftrek (vanza triple). Alyftrek is a treatment option for some people who are not eligible or able to take Kaftrio and an alternative for people who are already taking Kaftrio.

At the same time, NHS England confirmed an extension to eligibility for Kaftrio and Alyftrek – giving access to more people with CF.

At time of writing, announcements are expected to follow in Scotland, Northern Ireland and Wales.

Catherine, whose daughter Kate, 11, has CF, said: **"Although Kate has had a great response to Kafrio, we would expect her to have a better response to Alyftrek because Kate's second, rare mutation is listed as responding to Alyftrek, whereas it does not respond to Kaftrio."**

Whatever you do, do it in yellow

Information

We've been working with CF clinical experts to update our information on a variety of subjects, including cystic fibrosis-related liver disease, cystic fibrosis and bone health, and melioidosis and worldwide travel. We also spoke with people in the CF community who advised us on what we needed to include, how to make the language easy to understand, and which format the information would be best presented in.

If you're interested in getting involved in shaping our information, please message us **infoteam@cysticfibrosis.org.uk**

You can find all our information at **cysticfibrosis.org.uk/information**

It takes guts...

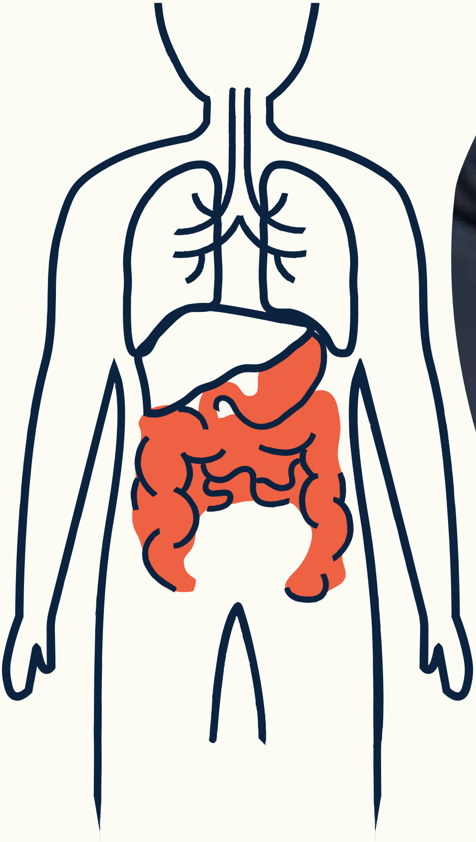
We know that gastrointestinal (GI) symptoms can be a daily challenge for people with cystic fibrosis – and can often be difficult to talk about. In fact, relief of GI symptoms was the third most important research priority identified through the Trust's James Lind Alliance priority setting partnership. We delve into what they are, the research that's looking for answers, and how we're working to increase understanding of these symptoms.

Cystic fibrosis can have wide reaching gastrointestinal (GI) symptoms. These are any symptoms in your digestive system or gut, and range from tummy pain and bloating to not absorbing nutrients well and even an increased risk of bowel cancer. GI troubles are common across all age groups and can affect nutritional status, energy levels, and mental wellbeing. Due to new treatments, many people have had improvements in other symptoms. This means GI issues may now have the biggest impact on the quality of life of some people.

For many people with CF, symptoms such as nausea, reflux, or unpredictable bowel habits can be a daily challenge. These issues often begin at a young age and can continue and evolve as someone gets older.

Even though they are very common, many people find GI symptoms difficult to talk about. This can mean these issues remain untreated, making things worse in the longer term and impacting physical and emotional health.

While pancreatic enzyme replacement therapy (PERT) and nutritional support have transformed GI management in CF, they do not fully address the underlying causes of gut discomfort and dysfunction. As more people with CF live longer thanks to advancements like modulator therapies, attention is increasingly turning toward the gut – and how it fits into the bigger picture of health.



What is the Trust doing to improve understanding of GI symptoms?

In response to this growing need for better understanding and resources, Cystic Fibrosis Trust is working with a group of CF and GI specialists to develop guidelines about the best ways to work with the CF gut.

"People with CF have told us that gut symptoms like acid reflux, nausea and bloating affect their lives significantly, so finding solutions to help is really vital. CF-related gut symptoms can sometimes affect daily life even more than breathing problems, particularly in adults, so it is great that the Trust is focusing on this important issue and I look forward to working with them," said Professor Bu'Hussain Hayee, a member of the CF GI working group and Clinical Director for Liver, Endoscopy and Gastroenterology at King's College Hospital NHS Foundation Trust.

To ensure people with CF can get the support they need, we also want to work with CF teams to develop understanding. A survey of several CF centres undertaken on behalf of the working group in 2024 highlighted variation in CF teams' access to GI services and to bowel screening. This supports the need for clearer guidance on how this should be managed so that everyone with CF can access the GI care they need.

During a workshop at our 2025 Multidisciplinary Team (MDT) Conference, delivered by members of the working group, a collaborative, personalised and holistic approach to GI care for people with CF was recommended. This included closer working with GI specialists and upskilling of CF teams, but also new resources for the community. The CF GI working group is now looking to generate more evidence and develop consensus guidance on best practices in managing GI issues in CF.

We have also recently updated our GI leaflet to provide the community with reliable information about CF gut issues. This, along with updates of all of our nutrition leaflets, is available on our website at **cysticfibrosis.org.uk/information**

> **"People with CF have told us that gut symptoms like acid reflux, nausea and bloating affect their lives significantly, so finding solutions to help is really vital."**
>
> Professor Bu'Hussain Hayee

> **"This is something that's intrusive to everyday life – and that was a strong motivation for me to do more in this area"**
>
> Professor Alan Smyth

Finding answers

Relief of GI symptoms was voted the third most important research priority when we asked the CF community about the research that matters most to them. Trust-funded researchers within our GRAMPUS-CF SRC aim to link the specific gut symptoms people with CF experience to what changes are taking place within their intestines. The results of their research could lead to more tailored medicines to treat people with CF in the future.

Not every person with CF experiences the same combination of GI symptoms, so it's likely there are different mechanisms that cause different symptoms. If scientists can identify these different 'clusters' of symptoms and the mechanisms behind each one, they can develop better, more personalised treatments in the future.

People with CF with gut symptoms at the Nottingham, Leeds and Belfast CF Centres have already been helping the researchers with their studies. Now, researchers have launched a new part of the study, meaning that people with CF can help their research, wherever they are, by telling them about their CF.

"We're asking people with CF to complete regular online questionnaires about any gut symptoms you experience. Your participation will be helpful whether or not you have trouble with gut symptoms and whether or not you are taking a CF modulator" said Professor Alan Smyth, who is the Principal Investigator of GRAMPUS-CF SRC. You can find out more and get involved by visiting the study website at **grampus-cf.org**

There is also ongoing research into the gut-brain axis. This is how your gut and brain talk to each other. Signals go both ways, so your gut can affect how you feel, and your feelings can affect your gut. The more we learn about this, the better we can help people manage their gut symptoms.

"I think we need to move away from the rhetoric that CF is a lung condition – it is so much more"

Emily's experience of managing GI symptoms

The unpredictability of my GI symptoms is my biggest battle day to day. You have to consistently assess your diet, intolerances, pancreatic insufficiency, and seasonal changes. It can knock you sideways and you need to adapt really quickly and plan for all eventualities, particularly for trips away, days in the office, and days out.

The main symptoms I suffer with are chronic bloating and pain. It's challenging as it hugely impacts my self-esteem. Body image is so hard in a world dominated by social media and pressure from others, and when you're already dealing with physical pain and discomfort, the mental side of it can be really tough.

I hope research can further explore what triggers GI issues in CF, particularly bloating and agonising pain. Adapting your diet is already hard enough when you have to eat more fat and calories, and track your consumption to take Creon. I would be much happier if I knew what triggered my body and what to avoid.

I think we need to continue to move away from the rhetoric that CF is a lung condition – unfortunately, it is so much more. Before I got really sick with my lungs, I was regularly hospitalised with GI symptoms and when I look back on that time, I found that harder to deal with than my time spent in hospital having IV antibiotics. We need to keep working to diversify the definition of CF in public consciousness, and I think being more open about GI issues is a crucial step in the right direction.

Here for you

If you have questions about GI symptoms, please get in touch with our Helpline team. Call them on 0300 373 1000, Monday–Friday 10am–4pm, email **helpline@cysticfibrosis.org.uk**, or message on WhatsApp at 07361 582053.

We continue to monitor issues with PERT supplies across the UK. Please visit our website for the latest information and updates.

> "We need to keep working to diversify the definition of CF in public consciousness, and I think being more open about GI issues is a crucial step in the right direction."

Emily

Crossing continents

Earlier this year, Dr Mike Gray, from Newcastle, and Dr Carlos Flores, from Valdivia, Chile, were awarded a Development Award (DA) grant by the Trust. One of the aims of these funding awards is to support researchers to conduct preliminary studies in new areas of CF research. We chatted to them to find out more about the research they're doing together.

From Newcastle to Valdivia is over 7,000 miles. How did the collaboration begin?

Mike: Carlos had connections to the UK from his PhD supervisor who worked in Cambridge before returning home to Chile. We first met at a research conference in Newcastle in 2009 and have been working together ever since!

Our labs are both interested in how chemicals are transported in lung cells. We use different methods to study this, so if one of our labs finds out something new, then researchers in the other lab can check the results – and hopefully confirm that the results are real. Trust-funded early career researchers in Newcastle have played an important part in this collaboration over the years.

Carlos: Recently, I found a link between a chemical called succinate and the CFTR protein in the lungs of mice. I contacted Mike in Newcastle, and they got the same result in lab studies of human lung cells. Linking succinate to CF was a new discovery, and we're delighted to be awarded this research funding to find out more about it!

Can you tell us more about what succinate does and why it's important in CF?

Mike and Carlos: We have discovered that when succinate is added to airway cells in the lab it switches on CFTR. In turn, this leads to an increase in hydration and mucus clearance in the lungs, defending them from infection.

This doesn't happen in lung cells from people with CF, but the response is restored with CFTR modulators. Succinate has different functions in lung cells. As well as preventing infections, it can also trigger lung damage called fibrosis in other lung conditions. There seems to be a tipping point where the actions of succinate shift from being protective to harmful.

In this Trust-funded research project we'll be investigating succinate in more detail.

How could this research make a difference for people with CF?

Mike and Carlos: We hope that our studies will give us a better understanding of what causes long term infections, inflammation and lung damage in people with CF.

Our results will tell us whether existing medicines that alter the function of succinate could be beneficial for people with CF in the future.

> "We hope that our studies will give us a better understanding of what causes long term infections, inflammation and lung damage in people with CF."

Dr Mike Gray and Dr Carlos Flores

Read more about our research goals at **cysticfibrosis.org.uk/research**

“It was amazing to recognise how advancements in CF care made this possible”

Earlier this year, our Trustee Sophie Pierce became the first person with cystic fibrosis to ever row across an ocean. We caught up with Sophie to hear more about this incredible feat.

Back in February, Cruising Free, a team of rowers from Neyland Rowing Club, Pembrokeshire, began their 3,200 mile unsupported row across the Atlantic Ocean. Part of the Atlantic Dash 2025, one of the toughest endurance events in the world, the team's epic challenge took 53 days, setting off from Lanzarote in the Canary Islands and finishing in Antigua in the Caribbean.

The team was made up of our trustee Sophie Pierce and her crewmates Polly, Miyah, and Janine. In completing the challenge, history was made: Sophie became the first person with cystic fibrosis to row an ocean, and Janine at 70 the oldest woman. The team also raised an incredible **£26,259** for three charities, including Cystic Fibrosis Trust.

"It was the most unbelievable feeling to complete it," Sophie says. **"It was satisfying to finish what we set out to achieve, especially given the challenges and my CF. But also, it was amazing to recognise how advancements in CF care made this possible. It's opened conversations about possibilities for others living with CF."**

Sophie grew up believing her life expectancy would be no longer than 30 years, but with Kaftrio her life has changed dramatically. **"Living with cystic fibrosis has given me times when I've not been well enough to live the life I've wanted to, and so I absolutely wanted to make the most of my newfound health. For me, this row wasn't just a crazy personal adventure, it's also a chance to reimagine the future of cystic fibrosis and bring hope that one day, everyone with CF will be able to cruise free through life."**

The challenge, as you'd expect, was far from plain sailing, with everything from four-metre-high waves to the exhaustion that comes with rowing for over 10 hours a day. **"The first week was hell – welcome to the world of ocean rowing," laughs Sophie. "Everything felt so hard, adjusting to such a harsh environment."**

Sophie adds: **"It was exhausting, and at times we thought, 'Oh my God, we're stuck out here.' But gradually everything started to get better, which was amazing."**

Another challenge was keeping on top of her cystic fibrosis while in the middle of the ocean. **"During the row, I took my normal medication plus 3 to 4 nebulizers daily. Taking tablets and doing nebulizers in a small, wet, moving boat was difficult. I had to wedge myself in and lie flat to do treatments,"** explains Sophie.

There was also lots of preparation in the lead-up to the challenge, and Sophie worked with her CF team for over two years to ensure her health wouldn't be compromised. **"My CF team was incredible. They supported my training, physiotherapy, and medication planning,"** says Sophie.

"As the event approached, we worked with pharmacists to ensure medications could be stored properly despite heat and limited power. For example, I needed a fridge on the boat – unusual for ocean rowing – so we added extra solar panels.

"We also developed a health maintenance and emergency plan in case I became unwell. This included priority medications and step-up plans. The medical teams for the event and my CF centre had copies."

And despite the tough moments, the highlights were incredible and far outweighed the difficulties, Sophie says.

"When the navigation lights were off, we rowed under a sky full of stars, saw comets, shooting stars, and even an eclipse. Life was simple out there: row, eat, sleep, repeat. That simplicity was beautiful compared to modern life."

The bond with her teammates is also something she'll never forget. **"We supported each other fully, connecting deeply with no pretense. We played silly games, shared stories, and had deep conversations,"** says Sophie.

And her advice for anyone else with CF looking to take on their own challenge? **"Go for it! You'll have to work hard, but don't let CF be a barrier. Talk to your CF care team, learn how CF affects you, plan for eventualities, and surround yourself with supportive people who push and believe in you."**

A big well done and thank you to Sophie, Polly, Janine and Miyah!

If you've been inspired by Sophie's challenge, find out how you can take on one of your own in aid of Cystic Fibrosis Trust. Visit **cysticfibrosis.org.uk/teamCF**

Knowing me, knowing you

Caroline Whitton is a Developmental CF Nurse Consultant at University Hospital Plymouth and Chair of the CF Nursing Association. We chatted to her about what a typical day looks like in her role, her hopes for the future of cystic fibrosis care, and how people with CF inspire her every day.

Can you tell us about your role and what a typical day looks like for you?
I've been working in cystic fibrosis care for 18 years now, progressing from clinical nurse specialist to developmental nurse consultant.

Every day in my role is different – it's one of the things I love about it. We're clinic-based, so we primarily see people with CF as outpatients. We do see inpatients too, but nowadays we don't have as many. We also do home visits based on patient needs. I love meeting young adults moving from paediatric to adult care and supporting them through this journey.

Can you tell us a bit about the CF Nursing Association (CFNA)?
The aim of CFNA is to bring together nurses across the UK to provide education, offer opportunities to learn from each other, share research, and support each other to provide the best care for people with CF. I'm passionate about CF nursing and the amazing work CF nurses do, which is often quite hidden. The role of CFNA chair has given me amazing opportunities to work with other organisations including NHS England, NICE, but particularly Cystic Fibrosis Trust.

Tell us what you love most about what you do.
There are lots of things, but it's the people with CF – I feel privileged and inspired to work with them.

Everyone working in CF is passionate and committed to improving services and patient care. That environment drives you.

My friends sometimes envy how much I talk about loving my job!

What do you hope for the future of CF?
I hope advancements in treatments continue so people with CF can live their lives needing less input from specialists like me, even if that means doing myself out of a job. For now, as health professionals and organisations, I hope we can continue to work collaboratively to strive for the best possible care for the CF community.

Find out more about the updated standards for the nursing management of cystic fibrosis and work of the CFNA at **cysticfibrosis.org.uk/nursingstandards**

A lasting tribute

Our tribute pages, in partnership with Much Loved, are special places where families can come together to share memories, messages, and photos of their loved ones. They offer comfort, connection, and somewhere to visit – whenever you need to.

For some, these pages have become more than just a memorial. They've become a way to do something positive in their loved one's name. Last year, thanks to funeral donations and fundraising challenges, over £45,000 was raised in memory for the Trust.

One inspiring story is from Jon and his brother Nick, who recently took on the challenge of walking the North Downs Way, Canterbury Loop to Dover in memory of their friends Ash, who died in 2010, and Steve, who died in 2024.

Determined to celebrate their lives and create a lasting legacy, they have raised an impressive £1,924 so far for Cystic Fibrosis Trust through the challenge. **"It was meant to be tough and was the best way to pay tribute to both of them,"** Jon said.

This generous fundraising has been added to a special tribute page dedicated to Ash and Steve, and the donations made in their name will help support important work for years to come.

We are deeply grateful to Jon, Nick, and everyone who supported them as these gifts make a real difference in the lives of those affected by cystic fibrosis.

If you would like to celebrate the life of a loved one and create your own lasting tribute, we encourage you to consider setting up a tribute fund. It is a powerful way to remember someone special while making a positive impact. For more information, please contact our In Memory Officer, Susan, at **susan.jackson@cysticfibrosis.org.uk** or visit our website **cysticfibrosis.org.uk/tributefunds**

Cystic Fibrosis Trust

Scan the code to download the catalogue

Information you can trust

We offer free, balanced information on all aspects of life with CF, including new diagnosis, treatments, family planning, and everything in between.

To find out about all our information, you can download a copy of our catalogue, which lists all our resources, including web content, videos, factsheets and booklets, so you can easily browse what's available and see what will be most useful to you. Download a copy at **cysticfibrosis.org.uk/information** or scan the QR code.

Trusted Information Creator

Patient Information Forum

Uniting for a life unlimited

Neurodiversity and cystic fibrosis

Neurodiversity may shape the way people experience living or caring for someone with cystic fibrosis. Find out more about what it is, how it might affect CF, and how you can access support.

What is neurodiversity?

Neurodiversity is a word used to explain that some people process things and see the world differently. Being neurodivergent is not a diagnosis or a medical condition itself, but does cover some specific conditions like autism and attention deficit hyperactivity disorder (ADHD). People who are not neurodivergent can be called neurotypical.

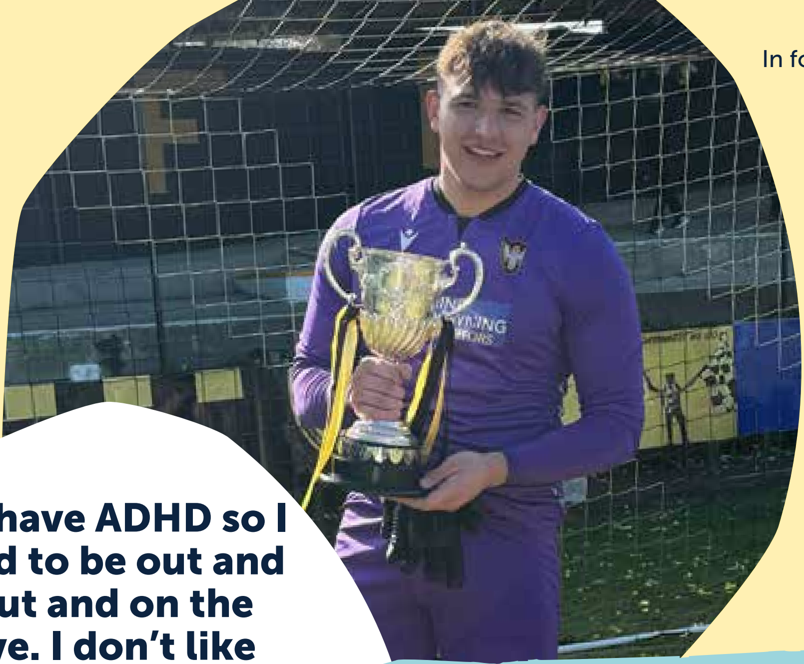
How might neurodiversity affect CF?

For people affected by CF, neurodiversity means processing and experiencing CF differently. That could be someone with CF, or a parent or carer of someone with CF.

People with CF who are also neurodivergent may have additional care needs that may require support to help them manage their condition.

Some studies suggest that across the world there are higher rates of ADHD in people with CF than in the general population. Other studies have highlighted the need for extra support for autistic adults and children with CF.

A 2023 study showed that children who are autistic and have CF can face extraordinary challenges, and healthcare providers need to be sensitive to their unique needs in order to deliver effective clinical care.



> **"I have ADHD so I need to be out and about and on the move. I don't like sitting down for too long. This has benefitted my CF because I love moving my body."**
>
> Morgan, who is aiming to become the first professional footballer with CF

As most people in the UK are neurotypical, health care, support and treatments aren't always set up with neurodiversity in mind. This means there can be a lot of barriers for people with CF who are neurodivergent to stay as well as possible.

People who are neurodivergent are all different and have their own strengths and challenges.

But if you're a neurodivergent person who has CF or cares for someone with CF, we're here to help.

Our Helpline is available to anyone looking for information or support, a listening ear, or just to talk things through. Call the team on 0300 373 1000 or 020 3795 2184, email **helpline@cysticfibrosis.org.uk**, or contact us on WhatsApp on 07361 582053.

Our online community forum is a safe space to chat with others in the CF community. We have a dedicated space for people affected by CF and neurodivergence to support each other and share experiences.

Get in touch with the National Autistic Society (NAS). NAS provides support through their advice and guidance page, their general enquiries Supporter Relations team and their Parent to Parent Emotional Support Helpline.

You can find more information and read other people's experiences of neurodiversity and CF at **cysticfibrosis.org.uk/neurodiversity**

Our volunteering heroes

We are incredibly privileged to be supported by volunteers and fundraisers here at Cystic Fibrosis Trust; people who give their time, passion and energy not for recognition, but because our cause means so much to them. For Chris Lilliman, volunteering for Cystic Fibrosis Trust has been more than a commitment – it's been a tribute and a journey of remembrance and hope.

Chris' connection to Cystic Fibrosis Trust is a personal one. His daughter Sarah, a fundraiser herself, had cystic fibrosis (CF) and died at the age of 37, twelve years ago. Following her diagnosis in 1979, Chris and his family attended many local fundraising events as well as organising some of their own.

"She was incredibly active – skiing, travelling – and very committed to raising awareness and funds for the Trust," Chris shares.

Her enduring legacy laid the foundation for his own involvement. While looking for volunteer opportunities following his retirement, Chris was introduced to the Nottingham Branch – which was formed in 1965 by Dr Derek Bates and his wife, Jenny – and through this, he was able to find a community of like-minded individuals who were driven to make a real impact.

> **"Volunteering isn't just giving your time – it's building hope, step by step."**
>
> Chris

The Nottingham Branch have hosted a number of fundraising and awareness raising events over their 60 years including an annual sponsored swim, jumble sales, sponsored walks, Viking challenge bike rides, Santa Fun Runs and, of course, the iconic Grantham Canal Walk.

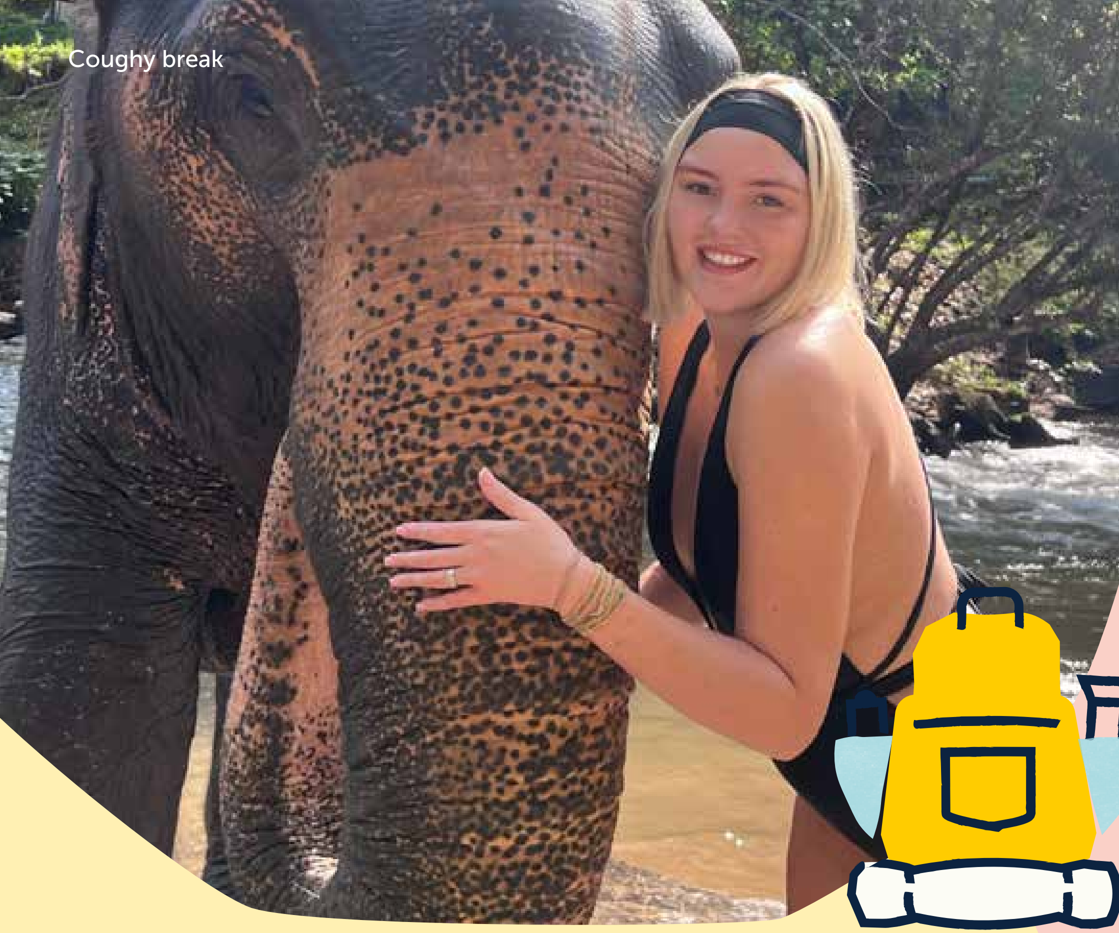
As well as his involvement with the Nottingham Branch, Chris also volunteers on our Helpline, supporting the CF community with applying for grants and accessing other support. He's also continued to fundraise during this time and told us his most memorable fundraising moment was during the COVID-19 pandemic, where he decided to take matters – and a map – into his own hands. **"I was supposed to do a fairly easy sponsored circular walking route around the Peak District, but what I didn't account for was the altitude! Eleven hours later, I'd climbed 13,000ft!"**

During his time volunteering and fundraising, Chris has witnessed firsthand how CF care has evolved. **"My daughter wasn't diagnosed until she was four. Today, heel prick tests mean we identify it early. Back then, Creon was a powder – now it's a tablet. This and much more shows that we've come a long way."**

However, Chris, and so many volunteers and fundraisers, recognise the importance of the journey still ahead of us all. **"We need better ways to prevent lung damage and infections. Better antibiotics. More control. The fight isn't over. I volunteer because I've seen the impact of this condition. We've made huge strides, but there's more to do. Volunteering isn't just giving your time – it's building hope, step by step."**

You can join your local volunteer branch, or find out about our other volunteering opportunities, on our website at **cysticfibrosis.org.uk/volunteering**

We'd like to thank Chris for his contribution to this article and his unwavering support. We'd also like to thank the members, past and present, of the Nottingham Branch for their dedication to Cystic Fibrosis Trust. Special thanks goes to Michael and Carole Headland, John and Sue Bowker, David and Kate Jackson, Ron and Wendy Clements, and Gail Doherty.



Travelling changed my life

Regan, 22, shares her experience of travelling with CF, her top tips, and how it's changed her outlook on life.

My CF journey

I was diagnosed with CF at birth. In 2017, at 15, I had an episode of DIOS which was routine for me. However, this time it didn't resolve like it usually does and I ended up in excruciating pain and had to have surgery. The surgery was supposed to be two hours but it took 12. My surgeon admitted that he had no idea what else to do and eventually after 12 hours sewed me up and told my family to say their goodbyes.

I was placed in a coma and then everyone came to be by my side. I eventually woke from my coma none the wiser of how distraught everyone was or what had happened. My life changed after this; I ended up being fitted with a feeding tube. It's now been eight years, and I take daily intense laxatives just to make my bowels work. I will be on a 6+ hour laxative pump overnight, every night for the rest of my life, but at least I'm alive!

A lifelong love for travelling

I love the freedom of travelling and the fact I get to be more than just the girl who's always in hospital.

"Where is my next trip going to be?" is always on my mind! Recently I decided to bite the bullet and do a big trip – South East Asia. I travelled around Thailand for just over four weeks. I knew this was going to be the beginning of a lifelong dream to see the world.

One memorable moment was in middle of the jungle in Chaing Mai, staying in an open bamboo hut, completely off-grid with my medicine pump hanging from the top of our hut on a clothes hanger, watching a group of elephants have a bath in the river below. It was true magic.

Always be prepared

Travelling can take a lot of preparation. I work closely with my CF team, particularly around my medication, and make sure I have a fit-to-fly letter explaining my condition and medication. I have a dosette box for my tablets for the week ahead and always check I have enough water to mix my powder medications as soon as I arrive somewhere. Staying hydrated is tough, especially in hot countries, so electrolytes are my go-to. I carry carabiner clips so I can hang my medicine pump securely wherever I stay.

> **"I have never let CF stop me but travelling has only made me want to prove that goal 10 times more."**

Travelling has changed how I see life

My advice to others with CF is just do it! Plan your trip carefully, research the nearest hospitals at each destination, stay safe, be smart, hydrate, and fall in love with being unapologetically yourself.

Travelling has changed how I see life. I should be dead but instead here I am witnessing some of the most beautiful things I've ever seen and at such a young age. I have never let CF stop me but travelling has only made me want to prove that goal 10 times more. I want to show others with any form of disability, not just CF, that anything is possible if you really want it.

If you are thinking of going travelling, please speak to your CF team for advice. You can find more information on travelling with CF on our website at **cysticfibrosis.org.uk/travel**

Game-changing research for CF lung health

CF lung infections can have a huge impact on the daily lives of people with CF. Our new Translational Innovation Hub Network for CF Lung Health and Infection aims to change that, fast-tracking improvements in how lung health and chronic lung infections are detected, treated and managed. But how did it come about, and what difference could it make? Here's everything you need to know!

Back in 2017, we announced the funding for the first Innovation Hub based in Cambridge and led by Professor Andres Floto. We committed £5 million worth of support to this 5-year research programme, which the University of Cambridge matched pound for pound.

The Innovation Hub significantly advanced efforts to improve the management of lung infections for people living with CF – from generating new knowledge about how to prevent certain lung infections being passed on, to developing computer algorithms which can predict when a flare-up of infection (an exacerbation) will occur and identifying several new opportunities for antibiotic discovery.

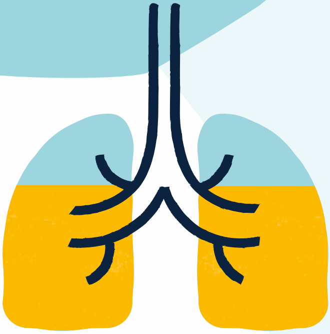
Translational
Innovation
Hub Network
for lung health & infection

This collaborative programme also brought world-class scientists into the field of CF research for the first time, and spring-boarded the careers of over 20 young researchers. To find out more about the impact of the first Innovation Hub, you can read the Innovation Hub impact report at **cysticfibrosis.org/innovation-hubs**

The success of this Innovation Hub played a huge part in inspiring the creation of the Translational Innovation Hub Network, funded in partnership with LifeArc.

LifeArc is a not-for-profit medical research organisation which supports researchers across academia and industry to help turn their ideas into real solutions for patients. The Trust started talking to LifeArc in the summer of 2021, one of the first projects was to organise an online workshop with the CF community.

> **"The workshop with people living with cystic fibrosis was instrumental in shaping our priorities and highlighting where we could make the greatest impact."**
>
> Heather McKinnon, Head of the Chronic Respiratory Infection Translational Challenge, LifeArc



Addressing the challenge

We need to find better ways to diagnose and treat lung infections, tackle antimicrobial resistance, and stop the disruption that lung infections can cause to the lives of people with CF and their loved ones.

However, it can take about 15–20 years for exciting research findings to lead to a new test or a new treatment becoming available for people to use. This time is spent gaining a better understanding of the results, testing ideas in the lab and clinical trials, and then scaling up the production of the product and meeting regulatory requirements. All these activities are collectively called translational research.

Translational research can be expensive and time-consuming, and many exciting results don't result in new treatments or tests. LifeArc has lots of experience turning research ideas into new medicines, and they use their expertise to help speed up progress. They support researchers by giving advice, working together, providing funding, and offering access to lab facilities. Together LifeArc and the Trust agreed to fund a translational research network in cystic fibrosis.

> "The dream, for me, is to have less of a treatment burden and more time feeling like a valuable member of society."
>
> Sarah, who has CF

The network

The aim of the CF Innovation Hub Network is to continue the successful model of the original Innovation Hub, but in a way that increases the impact for people with CF. The idea is to fund Innovation Hubs across the UK, each of which will have a translational research programme centred around:

- developing new or repurposed treatments for CF lung infections and inflammation
- preventing and treating exacerbations
- diagnosing infections and inflammation.

The four Innovation Hubs were announced in October 2024, based at the Universities of Cambridge, Liverpool, Manchester and Imperial College London.

Working together

Collaboration is at the heart of the CF Innovation Hub Network, and includes programmes to engage and involve the CF community and industry, and to train and develop the next generation of CF researchers and scientists.

The network will be governed by both external scientific experts and members of the CF community, to make sure that the programme can deliver a positive impact for people with CF.

Let's explore what each of the four Innovation Hubs will be researching:

Can we predict when a flare-up (exacerbation) will occur and what the best treatments are for each person?

The **Flare-CF** Innovation Hub, led by Professor Andres Floto at the University of Cambridge, aims to develop predictive tools which can identify early indicators of exacerbations (flare-ups) and help choose the best combination of antibiotics for each CF individual, to better personalise treatments and improve their effectiveness.

Ultimately, the **Flare-CF** Innovation Hub could help to reduce treatment burden for people with cystic fibrosis and help to limit side-effects, including antibiotic resistance.

If you're growing more than one bug, how does this affect the best way to treat them?

The **Precision-CF** Innovation Hub, led by Professors Jane Davies and Darius Armstrong-James at Imperial College London, aims to improve the detection, diagnosis and treatment plans of lung infections in people with CF. They will do this by learning more about how different bugs living together in the lung affect each other and the person with CF, as well as exploring the development of new, acceptable tests for CF lung infections using a range of sample types.

Precision-CF hopes to improve health outcomes, reduce the negative impacts of lung infections for people with CF, and help bring us closer to having new and more effective clinical tests for CF lung infections – especially for people who don't cough up sputum.

What factors influence when you get a flare-up of infection and how well you respond to treatment?

The **Pulse-CF** Innovation Hub, led by Professor Alex Horsley at the University of Manchester, aims to better understand the causes and triggers of exacerbations, and why people respond differently to treatment. The hope is that this will improve how these flare-ups are prevented and managed for each person with CF.

Could bacteriophage therapy be used to treat CF lung infections?

The **Trailfinder-CF** Innovation Hub, led by Professor Jo Fothergill at the University of Liverpool, aims to develop new and more tailored treatment approaches for CF lung infections, by developing phage therapy.

Trailfinder-CF hopes to identify and develop new ways to help doctors select the best treatments that can then be tested in future trials. By developing phage therapy for CF in the UK, this could offer an alternative treatment option for those with highly resistant infections, help to prevent antimicrobial resistance, and improve treatment effectiveness.

The legacy

Our hope is that this exciting network can make a real difference for people like Laura and Sarah, and everyone in the CF community.

To find out more about the network and opportunities to get involved in trials, visit **cysticfibrosis.org.uk/innovation-hub-network**

> "CF has a huge impact on my daily life, it's 24/7. The symptoms change from one day to the next. I think these Innovation Hubs are a fantastic opportunity to be able to change the way CF is managed."
>
> Laura, person with CF and Patient Lead for Pulse CF

What’s on your mind?

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

I’m a new paediatric CF social worker. We have lots of families asking questions about starting school, as well as older children in secondary school wanting help to navigate and speak up about CF. What resources do you have to support these families?

Matthew’s answer:
We have a range of resources and online content that can support the families in your service as they navigate both primary school and secondary school to make sure the children’s experiences are as joyful and rewarding as possible.

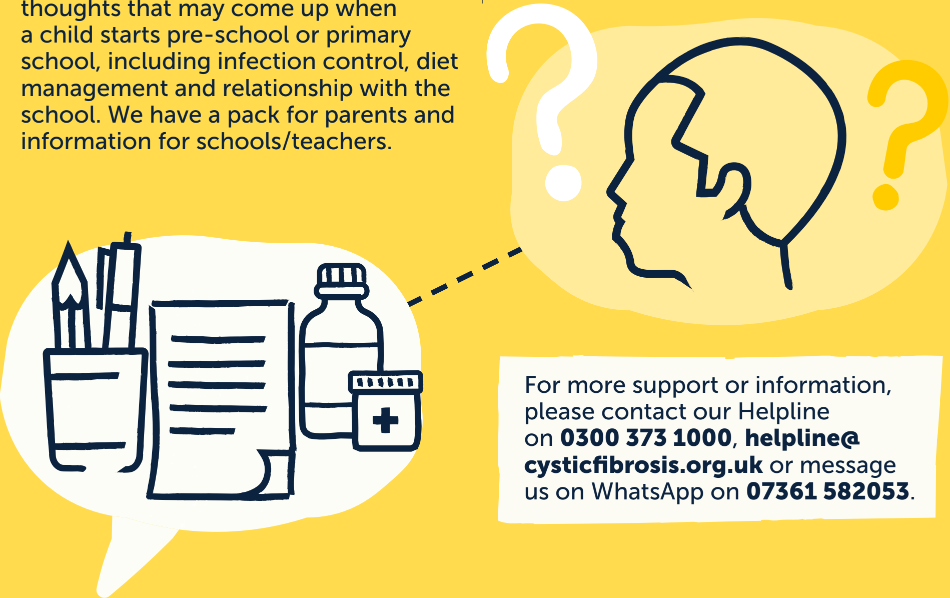
First is our pre-school and primary school pack **(search school on our website)**. The booklet is designed to outline some of the feelings and thoughts that may come up when a child starts pre-school or primary school, including infection control, diet management and relationship with the school. We have a pack for parents and information for schools/teachers.

For your older children in secondary school, we have our Class Passes **(search secondary school on our website)**, which can be ordered as a physical card, or downloaded digitally to their phone. These have a few different things on them including asking for toilet breaks, leaving the classroom to cough, or move to a different seat. We also have a secondary school pack for parents and information for school/teachers.

For both primary and secondary age children, we have an Individual Healthcare Plan template to help families in their conversations with the school about their child’s CF.

We also have information for teachers, which you can share too. Find it at **cysticfibrosis.org.uk/teachers**

Parents can also ask for help from other parents by joining our online community (**forum.cysticfibrosis.org.uk**). This is a safe, moderated space where people affected by CF can ask questions and seek support from one another.



For more support or information, please contact our Helpline on **0300 373 1000**, **helpline@cysticfibrosis.org.uk** or message us on WhatsApp on **07361 582053**.

"It's the coolest thing I own"

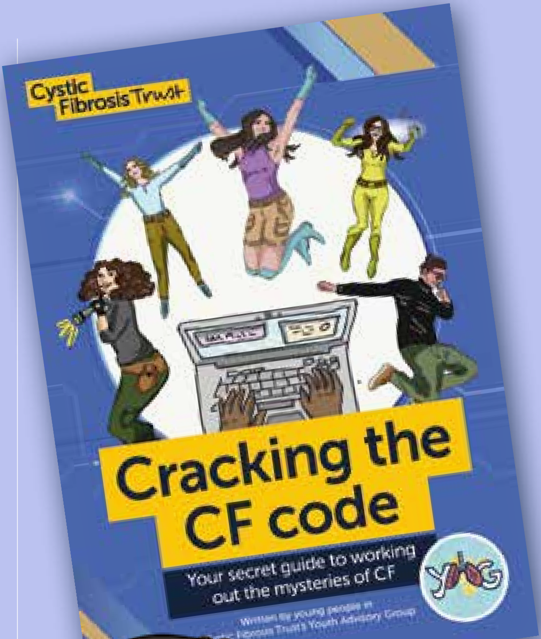
Cracking the CF Code is our new resource for children with CF. It was completely written by young people in our Youth Advisory Group (YAG), who used their knowledge and experiences to explain tricky medical words and concepts to children. Tilly, Rosie and Tehya, who are all members of YAG, explain more about the inspiration behind it.

Tell us about **Cracking the CF Code**!

Rosie: **Cracking the CF Code** is a secret spy-themed dictionary aimed at kids to help them understand terms they may hear in the hospital or around their CF. The book follows five secret agents who guide the reader through different areas and help them understand with definitions and personal stories. But it isn't only for kids – it's also a great resource for anybody who wants to learn!

How did YAG go about creating it?

Tehya: YAG spent more than two years making this dictionary – defining words, writing personal stories, and so on. In our meetings we'd normally be separated into breakout rooms with around 3 to 4 of us, where we discussed definitions for words we were going to use in the dictionary. Bahar, who works in the youth team at the Trust, made illustrations to go with some of the words to help those reading further understand the definitions. Once the dictionary was written, it went through professionals and now it's finally available to order.



Cystic Fibrosis Trust

Cracking the CF code

Your secret guide to working out the mysteries of CF

Written by young people in Cystic Fibrosis Trust's Youth Advisory Group

YAG

Tehya

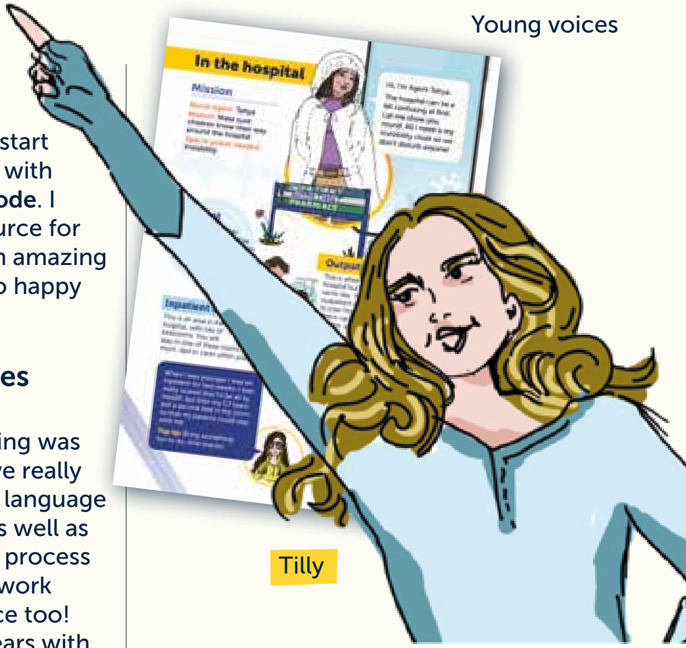
Why did you want to be involved?

Rosie: I first joined YAG at the start of the project and I fell in love with the idea of **Cracking the CF Code**. I believe it is an incredible resource for children and families. It was an amazing introduction to YAG and I'm so happy to have worked on it.

Were there any challenges in writing it?

Tilly: I wouldn't say that anything was particularly challenging, but we really pushed ourselves to make the language accessible for young people as well as informative and accurate. The process also helped develop our teamwork skills and probably our patience too! Writing a dictionary for two years with lots of people was a weighty job but it never felt stressful or difficult.


Rosie



Tilly

What is your favourite thing about **Cracking the CF Code**?

Tehya: The fact that it came from the voices of the younger generation affected by CF. I also love that we can say we wrote it ourselves and that all of the definitions are written not by professionals, but by people who live with CF and who have experienced things in this dictionary.

How does it feel now that it's published?

Tilly: It's the coolest thing I own! To hold it in my hands and be able to flick through and see my name and words (and cartoon face!) makes me feel so proud of all of us! I've shown everyone I know. The feedback on it has been mind-blowing and it's an amazing souvenir from my time at YAG – I can't wait to see what we create next!

You can download or order a copy of **Cracking the CF Code** on our website at **cysticfibrosis.org.uk/crackingtheCFcode**

Day in the life

Verity is an opera singer living with CF. She took some time out of her day to share her typical routine – featuring vocal warm-ups, meds and royalty!

1

Getting ready for the show by drinking plenty of water, performing vocal warm-ups, and most importantly, doing my nebs!

2

I've gone from 16 pills a day to only having to take three in the morning and at night – it makes me so grateful for the advancements in cystic fibrosis treatments.

3

With a good book and a stunning view, I have my pistachio spread toast and tea before taking my CF 'sweeties' – this is what I called all my pills as a child.

4

Later that evening after all my meds, nebs and puffer, I was ready to step out as Musetta in Puccini's La Bohème.

5

After a fantastic run of La Bohéme in Seattle, it was time to head home and get my music ready for the next job in Germany.

6

Bright smiles and ringing ears after a fantastic concert for the people of Poxau, including the Prince and Princess of Merode, pictured in the centre of this photo. A true "pinch me" moment.

You can follow Verity on Instagram **@verityhallsoprano**

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

#TeamCF needs you!

Runners, bakers, skydivers, knitters, swimmers... whoever you are and however you choose to support us, you're helping to change lives.

Every pound you raise helps ensure that more people with CF and their families can truly live a life unlimited. It helps us to improve care, offer invaluable support to everyone who needs it, campaign for change, and fund life-changing CF research.

Find out more about all our events at **cysticfibrosis.org.uk/teamCF** or scan the QR code.

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Uniting for a life unlimited