Cystic Fibrosis Trust

Annual Report and Financial Statements for the year ended 31 March 2025

Unstoppable together

Uniting for a life unlimited

Contents

We won't stop until CF does.

> "Whenever I accomplish something, I think of my donor and hope they would be proud."

Zanib, who has CF and had a lung transplant in 2020

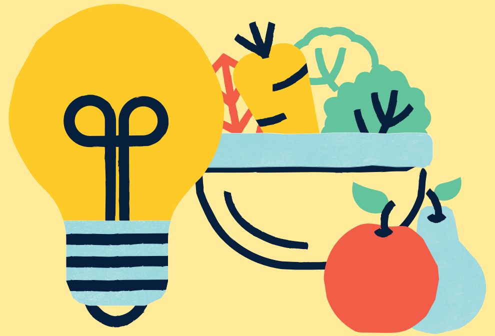
Thanks to you, in 2024/25…

We launched two new regional trial networks within our CTAP programme, meaning that even more people with CF will have the opportunity to take part in clinical trials.

We awarded £1,379,000 across Strategic Research Centres (SRCs) and Development Awards (DAs) to support groundbreaking projects.

We helped people with CF access over £2.1million in benefits through our Welfare and Rights Advice Service.

We've handled over 4,500 enquiries to our busy Helpline across phone, email, WhatsApp, and social media.



We provided 550 Winter Support Fund grants, supporting low-income households with the basics needed to stay well over the difficult winter months.

We had an incredible combined reach of 4.7m across our social media channels and over 1,000 pieces of media coverage with a huge potential editorial reach of over 2 billion.

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2025. The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Charities Act 2011 and the Statement of Recommended Practice: Accounting and Reporting by Charities second edition effective 1 January 2019.

The requirements of 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013' are included within this Trustees' report. Pages 54 to 97 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 2024/25 Annual Report, which documents another year of impact, challenge and change.

I hope you will find it a comprehensive and impressive document and I would like to start by thanking everyone in the CF community for all they have done over the last 12 months to make the successes we report possible.

I am proud to be Chairman of the Trust and from that vantage point I can see how important all of our partners are as we strive together for a life unlimited.

The year saw us continue to mark the 60th anniversary of the Trust. Through supporter events and an awards ceremony, we were able to celebrate what has been achieved but also be very clear about all that remains to be done.

The anniversary gave us the opportunity to tell more stories, with podcasts, a special edition of CF Life and a digital timeline showing decades of progress, alongside the many challenges that still come with CF.

To address these we've funded more research, adding to our portfolio of Strategic Research Centres and funding a number of Development Awards.

In October, we announced our largest ever partnership, a £15 million Translational Innovation Hub Network co-funded with medical research charity LifeArc. The focus of this work over the next five years will be improving the diagnosis and treatment of CF lung infections and maintaining lung health.

Richard Hunt CBE

> **"The anniversary gave us the opportunity to tell more stories, with podcasts, a special edition of CF Life and a digital timeline showing decades of progress, alongside the many challenges that still come with CF."**

We continue to work with new partners, funding a research study with Bowel Cancer Research UK to examine one potential aspect of growing older with CF.

Alongside our research activity, we have supported and developed our Clinical Trials Accelerator Platform, which has now enrolled over 6,000 people since its inception eight years ago.

We have ensured that the UK CF Registry provides comprehensive and timely information and analysis, supporting the best possible care and treatment for people with CF.

In fact, Registry analysis was at the heart of one of the most significant moments of the year, when, after a period of uncertainty, NICE gave formal approval for the long-term use of a portfolio of modulators on the NHS. Even as we marked that moment, our thoughts were already turning to the next drug in the pipeline, with Alyftrek being licensed for use by the MHRA in March.

This progress has been accompanied by concern about the supply of some medicines, most notably Creon, and we have been working throughout the year to do what we can to inform the CF community and minimise any long-term impact.

Promoting the highest quality care has remained a central priority and this year saw the publication of new **Standards of Care** for the treatment of CF. We also expanded our portfolio of events to include a conference focused on the future of CF care.

As we look to the future, we are also ensuring that we are able to support people's needs today.

Our Helpline has handled thousands of queries and over the winter months, we provided vital funds to 550 households. This is the highest ever.

Our Work Forwards programme has now held over a hundred advice sessions to help people in to employment and the Helen Barrett Bright Ideas Awards celebrated 10 years of backing so many aspiring entrepreneurs.

All of this is only possible due to the incredible support and involvement of the CF community. You fuel us with your fundraising and inspire us with your voice.

I would like to thank all colleagues whose work in the Trust has made this year so successful and to my colleagues on the Board, my personal thanks for your commitment and support.

We will not stop until CF does.

Thank you.

Richard Hunt CBE
Chairman of Trustees

Uniting for a life *unlimited*

> "Cystic fibrosis is a 365 day a year, 24 hour treatment regime… it doesn't stop. You never get a day off."
>
> Jonathan, who has CF and featured in our **No day off** campaign

Objectives and activities

Our vision is to deliver a life unlimited for people with cystic fibrosis, and our objectives, as stated in our Articles of Association, are to promote:

- research into the causes of, and a cure for, cystic fibrosis and the dissemination of the useful results thereof for the public benefit
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from cystic fibrosis in any form
- the education of the general public about the causes and effects of cystic fibrosis.

About CF

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. You are born with CF and cannot catch it later in life. One in 25 of us carries the faulty gene that causes it, usually without knowing. More than 11,000 people in the UK live with the condition, enduring a brutal daily routine of physiotherapy and taking over 30 tablets a day just to stay healthy. Despite these treatments, some people with CF will go on to require a double lung transplant. The median age of death for someone with CF in 2023 was 46.

About us

Our mission

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all. We won't stop until we can all lead the lives we want. Until cystic fibrosis stops damaging and shortening lives.

Our vision

Our community is uniting towards the ultimate goal of effective treatment for all. We're at the forefront of innovation and progress. Boundaries will be broken by groundbreaking research and incredible discoveries that change lives for the better. To get there, we will inspire our community. We will campaign with passion. Use facts and information to empower us. And support each other – improving care and building better mental resilience and physical health.

It's thanks to our incredible supporters, clinicians, researchers, professionals, partners, and, most importantly, people with CF that over the last 60 years we've been able to make vital breakthroughs and discoveries in CF understanding and treatment.

We're uniting for a life *unlimited*

Our goals

Physically well

Together, we can live without the physical challenges of cystic fibrosis.

Mentally well

Together, we can manage the mental pressures of cystic fibrosis.

Fulfilment

Together, we can lead the life we want as part of a connected community.

Measuring success

We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact to the CF community. We hold impact workshops to assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track progress via internal monthly and quarterly monitoring mechanisms, including both data-driven and narrative analysis, backed up by SMART Key Performance Indicators.

Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.

To achieve these ambitious goals, we will work with our community and partners across the UK and internationally to support innovative, high-quality research, achieve access to the best treatments, drive up the quality of care, and provide and advocate for the support needs of people with cystic fibrosis.

We also know that to deliver on this vision we need to adapt and change as an organisation, including a greater focus on:

- **putting people with cystic fibrosis at the heart of everything we do**
- **building international and domestic partnerships**
- **optimising our working culture**
- **being great and innovative fundraisers**
- **making effective use of data and analytics, including implementing our new data strategy and a new quantitative impact framework**
- **working in ways that bring together our diverse community and staff, including our new equity, diversity and inclusion strategy.**

Uniting in research

We are continuing to drive and support innovative, world-leading research such as the Translational Innovation Hub Network on lung health and infection in CF in partnership with LifeArc. We are expanding clinical trial opportunities through establishing new regional networks within our Clinical Trials Accelerator Platform (CTAP), and strengthening partnerships across the life sciences sector, enabling faster access to new treatments and better outcomes for people with CF.

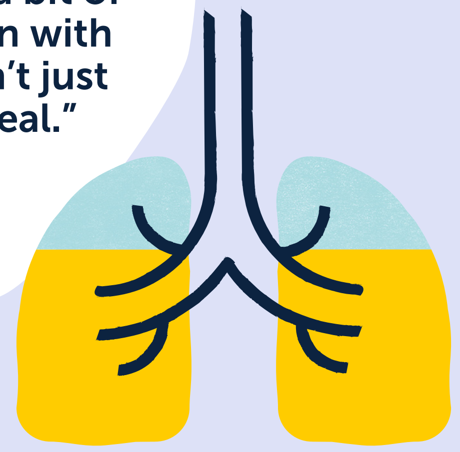
Developing effective treatments for all

CTAP remains one of the leading global CF clinical trials networks, screening over **9,000** participants and enrolling more than **6,000** since its launch eight years ago. This year, people with CF who are unable to benefit from modulators had the opportunity to take part in three new genetic therapy studies that could address the underlying cause of CF.

Two new regional trial networks have been launched within our CTAP programme, meaning that even more people with CF will have the opportunity to take part in clinical trials. One network covers the whole of Scotland and North East England, and a second spans across the South West of England.

> **"Not all CF centres are able to run clinical trials. Thanks to our regional network we're talking to each other and improving how we work together. It means that it's easier for people to take part in research going on at a CF trial centre within the network."**
>
> Dr Don Urquart, chair of the Scotland and Northeast Regional network

> **"Living with CF diabetes is like constantly being on a rollercoaster. It's juggling what I eat with how much insulin I'm giving myself. Mentally, it can cause a bit of an unhealthy obsession with what I'm eating – I can't just sit down and have a meal."**
>
> Annabelle, who has CF



Treating symptoms and complications of CF throughout the body

CF diabetes (CFD) is a difficult illness to manage alongside other CF symptoms.

The insights we gathered from those with lived experience of CFD through our involvement activities have informed many activities across the Trust, from a workshop at our MDT conference in March to a review of our information resources. They've also shaped the direction of a research project focused on creating an educational tool for those with CFD. Participation in involvement activities benefits members by empowering them to engage further.

To improve how CFD is treated and managed, we awarded **£300,000** over three years to Drs Ildem Ackerman and Vicky Salem to explore whether a Type 1 diabetes therapy could work for CF diabetes, potentially eliminating the need for insulin.

Improving the diagnosis and treatment of CF lung infections and maintaining lung health

In October, we announced a new £15 million Translational Innovation Hub Network, co-funded with medical research charity LifeArc.

Guided by insights and experiences of people with CF, the new CF Innovation Hubs will address new ways to detect, diagnose, treat, and manage lung infections and lung health, and help to overcome some of the barriers that can prevent scientists from turning their discoveries into real outcomes for patients.

"This condition affects everything about my life, every single day. I have to adjust my life around my symptoms, in everything from work to friendships.

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

The new network aims to accelerate groundbreaking research, building on the success of the original CF Innovation Hub at the University of Cambridge, which made world-class advances in our knowledge of CF lung infections.

> **"This funding, along with the wraparound support provided by the CF AMR Syndicate, will help advance promising solutions to the urgent need for more effective treatments for CF lung infections. The aim is to accelerate the discovery of novel therapies that could significantly improve the lives of people with cystic fibrosis."**
>
> Dr Heather McKinnon, Head of Chronic Respiratory Infection at LifeArc

Uniting researchers to achieve a life unlimited for people with CF

This year we have held several events to build and strengthen the network of innovators, researchers and clinicians working in CF research.

In June over **60 delegates** attended our Industry Symposium immediately prior to European CF Society meeting in Glasgow. A third of the delegates were from organisations across the life sciences sector. We **presented a new animation** and invited speakers to highlight the **Trust's research support offer** to industry innovators. The event was kindly supported by **LifeArc**.

In October over **35** early career researchers attended our first Early Career Researchers conference in person or online to network, learn more about Cystic Fibrosis Trust, and empower them to continue to work in CF research in the future.

LifeArc

CF AMR Syndicate

The CF AMR Syndicate brings together academia, industry, patient organisations, R&D experts, clinical teams and, most importantly, people with CF. Your voice is key in helping innovators understand the unmet needs of people with cystic fibrosis.

In the last year, six biotech companies won support from the Syndicate's **Collaborative Discovery Programme** (CDP) to develop new anti-infective treatments guided by the Syndicate's patient-focused wishlists, known as Target Product Profiles. The companies are receiving hands-on expert support to develop their products.

Dr Lucy Allen

> "We are delighted with the success of the CF Innovation Hub on lung health, which exemplifies what can be achieved with this level of investment and multidisciplinary collaboration."
>
> Dr Lucy Allen, Director of Research and Healthcare Data

Enabling people to live longer, healthier lives

Improving the understanding of the physical and mental health challenges people with CF face as they grow older is an important area of CF research, and it starts with people with CF sharing their lived experience. Through our involvement activities, Laura Eccles shared her thoughts on growing older with CF with over **2,000 researchers** and clinicians at the opening session of the European CF Society.

As people with CF grow older, they face diseases, such as cancer, cardiovascular disease, and dementia, that may require earlier or adapted screening due to CF symptoms and complications. As guidelines are developed, it is vital that they are informed by the CF community.

One way we're supporting this is by funding a research study with Bowel Cancer Research UK, led by Professor Laura Ashley at the University of Leeds, to gather the views and experiences of people with CF and their CF teams on bowel cancer screening.

Accelerating research

Our CF Accelerating Research package supports life science industry partners to align their work with CF community needs. Through support from the UK CF Registry, our involvement work, and the support of our Clinical Trials Accelerator Platform, CTAP, the Trust has enabled companies to refine study designs, improve trial feasibility, and increase the speed at which clinical trials are set up and delivered.

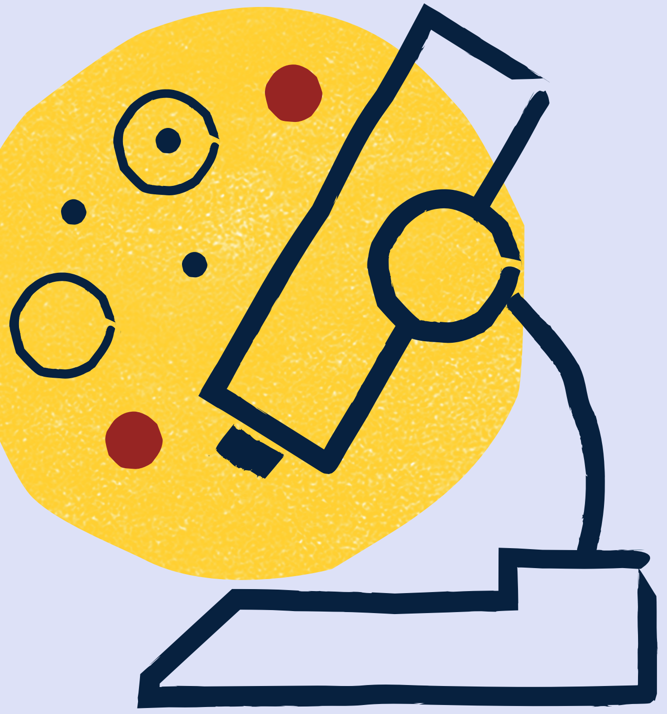
Over the past year, we engaged **12** new commercial sponsors and maintained relationships with many more across a range of therapeutic areas, from pre-clinical studies to phase 3 trials testing the effectiveness of medicines.

This ongoing commitment to industry collaboration continues to drive progress in drug development, trial accessibility, and ultimately, improved treatment options for the CF community.

Funding world class research

We awarded **£1,379,000** across Strategic Research Centres (SRCs) and Development Awards (DAs) to support groundbreaking projects, exploring treatments for *Mycobacterium abscessus* lung infections and CF diabetes, and new ways to improve lung health.

Additional funding was allocated to early career researchers and novel CF studies through Venture Innovation Awards (VIAs), Fellowships, and Summer Studentships.



Putting people with CF *first*

Collaborating with and supporting the clinical community to promote the highest quality of care

Our Clinical Advisory Group (CAG), made up of specialists in CF care, advises the Trust's information resources and clinical programmes. Its Chair oversees the longstanding Clinical Fellowship scheme, which helps launch careers in CF and has produced many leading clinicians.

The Trust sponsors and provides secretariat duties for the UK Cystic Fibrosis Medical Association, supporting doctors delivering CF clinical care nationwide. The Trust's clinical guidelines continue to promote best practice in CF care provision. In 2024/25 we published guidelines on:

- standards of care
- clinical psychology services
- nursing management of cystic fibrosis.

We also produced lay summaries of each guideline for people with CF and their families.

Updates are underway on several other key guidelines, including:

- antimicrobial treatment
- infection prevention and control
- physiotherapy management of cystic fibrosis.

Improving quality of care in CF

In October 2024, our patient experience survey of over 1,250 adults with CF showed that CF care is generally rated highly by those who receive it. However, some respondents struggle to access psychologists, social workers or pharmacy staff when needed. The survey also highlights a growing desire and need for person-centred care in the context of an ageing and diversifying CF population.

We continued to monitor staffing levels in CF services using our staffing tool, with a record **51 CF centres** contributing in October 2024. Participating CF centres received bespoke feedback in March 2025, and we published an updated report on UK CF service resourcing in early April.

We also worked with local CF teams on improvement projects and collaborated with CF professional interest groups to explore and address UK-wide challenges in CF care, such as gaps in psychology staffing.

Future of CF care conference

In March 2025, the Trust hosted its second dedicated conference for CF professionals, which featured presentations, panels, and workshops on ageing, CF diabetes, and gastrointestinal care. Over **150 CF professionals** attended, with many reflecting on how the event supported their professional development in CF. 100% of those who completed our evaluation survey said that the event met their expectations, describing it as excellent, informative and inspiring.

> **"I found the whole MDT event very helpful for me as I am new in post. I was very interested in how other teams in the country work. The workshops and panel discussions were highly informative."**
>
> Neil, who attended the MDT conference

Supporting the CF community through issues that affect them

Creon shortages

Creon shortages over the past year have caused stress and disruption for many people with CF. In response, we provided timely information and guidance to help people access medication. We engaged directly with the Department of Health and Social Care and the media to highlight the significant health impacts on people with CF, ensure that the voices of our community are heard, and push for solutions.

Households under financial pressure

Rising living costs coupled with the extra costs of living with CF continue to exert significant financial pressure on those in the CF community. Financial concerns are a key reason people contact our Helpline. We continue to hear regularly from people whose health is being directly impacted by poverty, as they struggle to afford the costs of food, travel, and keeping their home warm and dry, diverting time and energy from managing their CF.

This winter, over **550 households accessed our Winter Support Fund** – the highest levels ever – with 1 in 5 of grant recipients reporting missed CF clinic appointments in the past year, and 1 in 4 reporting weight loss due to food insecurity.

100% of Winter Support Fund recipients felt that the support had helped to maintain their or their loved one's CF health, and 70% of CF professionals surveyed felt it reduced winter hospital admissions.

This dramatic impact highlights both the troubling effect of living on a low income with CF, and the value of our welfare grants programme in supporting physical and mental health in vulnerable households.

Making sure our community is heard

Throughout 2024/25, we remained committed to amplifying the voices of the CF community and addressing the critical issues that affect them. The 2024 **Your Life and CF** survey captured invaluable insights from over 10% of the CF community into daily challenges like financial burdens, mental health concerns, and access to care.

These insights have directly informed our advocacy efforts, ensuring that our policy recommendations are rooted in the lived experiences of those with CF. For instance, the survey highlighted the continuing need for improved access to CF social workers and psychologists, leading us to advocate for appropriate support for these roles in the Darzi Review and subsequent consultation on the NHS 10-year plan.

Additional focus groups and engagement sessions with people with CF, their families, and healthcare professionals have provided a platform for the community to share their experiences and contribute to shaping our campaigns and policy positions.

In 2025, responding to community concerns about air quality and its impact on respiratory health, we began initiatives aimed at advocating for cleaner air policies and regulations.

Our campaign for free prescriptions in England has continued, targeting the outdated exemption list that excludes many with CF. Working with the Prescription Charges Coalition, we successfully lobbied for a freeze on prescription charges this year and continue to campaign for a comprehensive review of the exemption criteria.

Post-election, we're engaging newly elected MPs to ensure the voices of people with CF are heard, championing equitable access to treatments, financial support, and environmental health.

By centring the voices of those affected by CF in our work, we ensure that our advocacy is not only informed but also empowered by the community we serve as we race towards effective treatments for all. We won't stop until everyone can live without the limits of cystic fibrosis.

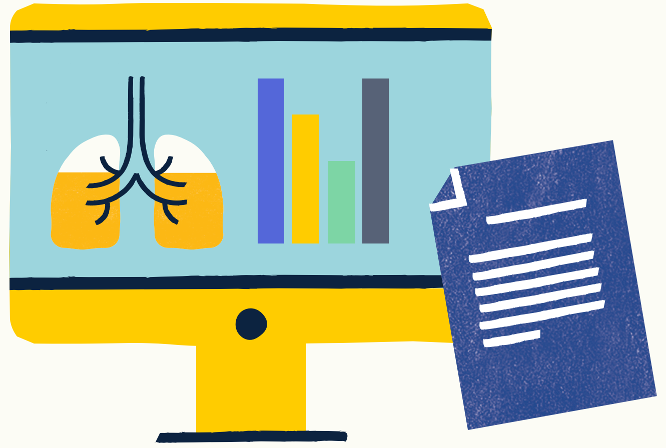
> **"Paying for my own prescription makes me feel unseen and invalidated as a student living with a life-changing illness. It's another cost on top of so many extra costs that CF brings to my life."**
>
> James, a Trust campaigner who has CF


James (left), James's dad, James's twin brother (who also has CF), and their mum

The UK CF Registry

The UK CF Registry is a world-class database that holds anonymised data on approximately 99% of people with CF in the UK who have consented to their data being submitted by their CF team.

Registry data is vital in helping people with CF and their families understand CF and make informed decisions, supporting research, improving services, monitoring the safety and efficacy of new treatments for CF, and helping commissioners provide funding to NHS CF centres.



In 2024/25 we have:

- supported three pharma research studies worth over £1.3million by providing analysis and reporting, and presented interim results at international conferences
- received up to £155,000 from NHS contracts for generating public reports and supporting the commissioning of CF services in England
- submitted anonymised 2023 data to the European CF Society Patient Registry (ECFSPR)
- received 60 data requests:
  - 43 requests were reviewed and approved by the Registry Research Committee.
  - 2 were declined and 2 are under review pending more information.
  - 8 requests from ECFS Patient Registry requesting UK data were approved.
  - 5 requests were withdrawn prior to review by Committee.

Data Validation Programme

23 centres had a Data Validation Visit (DVV) in 2024 which showed high data entry quality, with no variables below 97% for adults and paediatrics – an improvement since 2022. These visits confirm the Registry's suitability for use in research, pharmacovigilance studies, and NHS commissioning. Furthermore, undertaking these visits virtually have proven to be cost and time efficient. The UK CF Registry Data Validation Programme (DVP) has been adopted as a model of best practice by other CF Registries in Europe. For the 2023 data, a report has been sent to the ECFSPR to be added to their European Data Validation.

Registry development

The Registry platform was updated to enhance inclusivity and useability. We added new fields for gender identity; a new race-neutral lung function calculation; the new CFTR modulator therapy vanzacaftor (Alyftrek™); and reasons for pausing modulators. We also expanded the CF variant list in line with the CFTR2 database. A new dashboard enables users to monitor the annual review and encounter records across their patient cohort, and a new consent feature allows users to log and upload multiple consent forms. These changes reflect changes in CF care and the evolving needs of the CF community.

Annual Registry report

The 2023 UK CF Registry data report, published in November 2024, reported that there were **11,318 people with CF** registered within the UK CF Registry, of whom 93% had an annual review in 2023. It presented new data on modulator use, including demographic data on those not taking modulator therapies. **8,212 people with CF** were reported as being on a CFTR modulator by December 2023.

With colleagues across the Trust's Research and Healthcare Data Directorate, we launched an Accelerating Research support package for industry, showcasing how Cystic Fibrosis Trust can provide support across the clinical research pathway. The UK CF Registry has supported three pharma companies with pre-feasibility data identify suitable CF centres for trials.

> **"The UK CF Registry 2023 Annual Registry report shows that the median predicted survival for someone born with CF today has increased to 64 years in the UK but also shows that the survival gap between men and women with CF is closing. Differences in outcomes between genders is a hugely under-researched area in clinical medicine but we have the valuable resource of UK CF Registry data to begin to help identify and understand these differences as we strive to deliver personalised care to people living with CF."** – Dr Jamie Duckers

Uniting for the CF community

Day-to-day support

Over the past year the CF community has faced significant challenges. We've been here to provide trusted information and emotional support to the CF community when it matters most.

We started this year in a place of uncertainty about the future of modulator treatments due to the NICE appraisal. We supported the community through this with key information updates and a safe space to share worries. We were delighted to then provide information on the positive conclusion to the appraisal as well as further updates on drug development and approvals as they happened.

More recently, we have been on hand to support the community with concerns about the impact of planned welfare reform, and we will continue to work with people affected by CF to advocate for their rights as this develops.

Alongside reactive support, we've continued to provide a range of services and resources to help people with CF manage daily challenges and the unpredictable impacts of the wider economic and political times we live in. Throughout all of this, we continue to provide individualised, holistic and flexible support that empowers people with CF to overcome barriers and live the lives they want.

> “In the most challenging times, we received lots of advice and support from the online forums on Cystic Fibrosis Trust’s website, especially when we were having treatment to conceive our daughter and wanted someone to speak to about our concerns. It was great to have a support network, information and all of the resources we needed.”

Claire, whose husband Bob has CF

Claire, Bob and their daughter Katy

> “When I heard of the Helen Barrett Bright Ideas Awards, I felt excited at the possibility of getting help to make my dreams into a reality.”

Aiden, who has CF

Aiden

Grants

This year, we provided **1,465** welfare grants totalling over **£380,000**, our largest volume of grants ever. This included **550** Winter Support Fund grants, supporting low-income households with the basics needed to stay well over the difficult winter months. Alongside the grant, those supported by the Winter Support Fund received regular emails signposting to extra support, and were offered help from our welfare team to explore further financial aid.

Through the Joseph Levy Education Fund, we awarded **53** grants to support people with CF pursuing higher or further education. We also granted a total of **£20,000** to **10 people** with CF through our Helen Barrett Bright Ideas Awards to help them advance their own businesses. And thanks to support from the Joseph Levy Foundation, we supported over **60** adults and children facing a tough time with their CF to have a holiday or short break.

Over 90% of those who responded to our surveys told us the grant they received had positively impacted their physical and mental health.

“I was sleeping on the floor with handed-down sheets and pillows; it was uncomfortable, and I don’t know how long I would’ve been in that position without the grant.” – James, who has CF

Benefits advice

Our welfare benefits and income maximisation services continued to ensure people affected by CF were able to access the financial support they need – undertaking complex casework and providing support around benefit appeals and tribunals.

Government welfare reform proposals have caused deep concern in the CF community. Our specialist frontline knowledge in how CF interacts with the benefits system has put us in a strong position to support and advocate for people affected by CF.

This year, we helped over **300** people to secure benefits income of over **£2.1 million** – vital income to help them meet the extra costs of living with CF. We also helped **58** people access income maximisation services, identifying additional income for them of over **£4,000** per household.

Many of those affected by CF tell us that navigating the benefits system causes immense stress and worry, which affects their physical and mental health. Our specialist, dedicated service eases some of this worry, helping the CF community access the financial support they need to look after their health.

"CF and all the health and financial issues it comes with can be sometimes overwhelming. I feel there are people at the Trust who understand and genuinely want to help." – Cora*, who has CF (*name has been changed)

> **"All I could think about was the life expectancy of 41; I was 32 and I had an 8-year-old to think about. But the Trust were full of empathy and compassion and just listened to me, which is exactly what I needed."**
>
> Cheryl, who received a late diagnosis at 32

Helpline

Our Helpline service has provided practical support and information and a listening ear across phone, email, WhatsApp, and social media, handling over **4,550** enquiries this year. We improved our case recording to ensure a high-quality, consistent service and built capacity through volunteering. As the gateway to all our support services, the Helpline often deals with our most complex enquiries, ensuring people contacting us get the right support at the right time.

100% of those who responded to our feedback surveys said they would recommend our service to others.

Empowering the CF community through high-quality, accessible information

Last year we updated our extensive information offer with several new and updated resources, including:

- marathon training tips for people with CF
- testing for CF carriers in families
- clinical trials
- staying well over winter.

We updated our newborn diagnosis resource, providing families with sensitive, helpful information at the point of diagnosis, including a new series of e-newsletters to support families through their baby's first year.

We published two key clinical guidelines: our flagship Standards of Care guidelines, and, for the first time, new guidelines for clinical psychology services. Both guidelines were complemented by accessible lay summaries.

We also responded to ongoing and emerging issues with timely updates on topics such as the Creon shortages, collaborating with clinicians to publish accurate and timely information.

We retained our accreditation with the PIF TICK, a quality kitemark demonstrating our adherence to best practice in the production of health information.

Trusted
Information
Creator
Patient Information Forum

> **"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

Dedicated support for children and young people

Our youth programme had a busy and fun-packed year. Building Brighter Futures, our programme for 6–14-year-olds with CF and their siblings, saw **116 children** attending **5 courses** and **28 one-off events**, including foam-clay classes, resilience workshops and science experiments explaining CF symptoms!

Our Youth Advisory Group (YAG) of 14–25-year-olds held **24 meetings**, creating a dictionary of CF terms for children and helping steer the Trust's work for young people.

Strong Beginnings supported parents of children with CF aged 0–6, with events such as peer support groups, Q&A sessions with CF physios, and baby massage classes. **59 parents** attended and shared positive testimonies of how the events helped them cope at the start of their CF journey.

> "We had a conversation the other day about there being a cure for CF one day. He said he doesn't think he would get rid of it even if he could, because he only gets to do the Zoom workshops because he has CF!"
>
> Nikolas*, whose son Hugo* is a member of Building Brighter Futures

> "YAG is always looking for projects and campaigns that help to make our CF community better."
>
> Tilly, YAG member


Tilly

> "The connections we made have become an essential part of our lives. We now chat almost daily with the parents we met, and having this support system as our little girl grows up has been truly life changing. Thinking about it makes me quite emotional – we are no longer alone on this journey".
>
> Yakov*, whose daughter Gabi* has CF

> "It meant a lot to have someone acknowledge the challenges I've been facing and provide clear, practical guidance to help me move forward. The conversation felt like a safe space where I could be open about my frustrations, stress, and anxiety, which was incredibly valuable during such a difficult time."
>
> Sanjana*, who has CF

(*names have been changed)

Work Forwards

Work Forwards employment programme

Thanks to funding from the National Lottery Community Fund, the Work Forwards programme continued to deliver employment, work, and careers support to people affected by cystic fibrosis. We supported **89** people through **107** advice sessions. We delivered **7** online sessions attended by **87** people, including a webinar on pensions – a first for the CF community, reflecting the changes in CF in recent years.

Many of our online sessions have been led by people with CF, including drama therapy sessions to build confidence in discussing CF with employers. We continue to share a broad range of stories of people with CF in a wide range of jobs and careers, reaching thousands of people.

We also delivered this year's Helen Barrett Bright Ideas Awards, which provide grants and support around self-employment, and have strengthened our support and guidance to applicants this year. This year marks 10 years of the Awards, and we're particularly delighted that previous Award winners have been actively involved in delivering sessions for our youth programme using their professional experience.

Diverse and together

This year, we've continued to find new ways to reach and engage people affected by CF – in the right way, at the right time. We have built new relationships with a diverse range of storytellers who generously share their time and stories with us to support our work, raise awareness and support our community.

We make sure the voice of the CF community is always heard and profiled through the stories we place in the media, on our website and through our fundraising materials. High-profile campaigns like our 60th anniversary and CF Week have been shaped and influenced by people with CF and their families via our active involvement groups.

> **"My wish is that the CF community continues to spread awareness by sharing stories. We can work together to continue fundraising and enlightening the world to the struggles that people with CF go through on a daily basis and show the impact donations make."**
>
> Sophie, who lost her dad to cystic fibrosis

CF in the media

We've had another incredible year for media, with over **1,000 pieces of media coverage**. We would like to thank all the journalists we've worked with, and all our spokespeople and storytellers for helping us to raise awareness of cystic fibrosis.

We raised awareness of the Creon shortages with the Sunday Times and the Express, and achieved national coverage with our awareness campaign. The Trust was also mentioned in hundreds of pieces of coverage when NICE approved permanent access to modulators.

Many regional and trade outlets picked up the launch of the CF Innovation Hubs and we also worked with First News on a child-led storyteller piece.

Our Trustee Sophie Pierce embarked on a row across the Atlantic, which gained great regional coverage, and news that the MHRA approved Alyftrek dominated national and regional health news.

We had 1,012 pieces of coverage over the last year with a huge potential editorial reach of over 2 billion.

60th anniversary

We continued to mark our 60th anniversary year, recognising that while there have been significant achievements over the last 60 years, there is still a lot more to do to ensure everyone with CF can live a life unlimited.

We held supporter events, a special awards ceremony, and shared content on the theme of **we won't stop**, including a podcast episode with our chief executive David Ramsden and a special edition of CF Life magazine.

I had to drive hours for the cystic fibrosis pills that keep me alive

The number of drugs in short supply — including those for life-threatening conditions — has risen dramatically, leaving pharmacies unable to help patients

Amber Gibb requires daily medication for cystic fi

JONNY WEEKS FOR SUNDAY TIMES

MAJOR STEP Miracle daily pill to help condition suffered by 10,000 people could soon be available on the NHS

The new drug could be rolled out on the NHS by August

sabel Shaw, Health reporter

ublished: 11:05, 17 Mar 2025 | Updated: 14:23, 17 Mar 2025

New research hubs in Liverpool and Manchester use AI to help detect Cystic Fibrosis

GRANADA | LIVERPOOL | GREATER MANCHESTER | CYSTIC FIBROSIS | Tuesday 1 October 2024 at 1:11pm

> "I attended Cystic Fibrosis Trust's 30th anniversary at St James's Palace in London all those years ago and as Harvey and I live and breathe, today and in the future, it is testament to the hard work and dedication of everyone at Cystic Fibrosis Trust."
>
> Hazel, who has CF

Since 1964

Cystic Fibrosis Trust
14 June 2024

Ahead of Trooping the Colour, we're delighted to announce His Majesty has confirmed he will be continuing as our Patron.
We're thrilled to have his ongoing support for everyone affected by #cysticfibrosis.

Jake Sugden Photography

Actress Elizabeth Green, who played the Character of Jade in Eastenders

Social media

Across Facebook, Instagram and TikTok we had an incredible combined **reach of 4.7m** and over **734,000** impressions across LinkedIn and X.

We've continued our social media initiatives, including Research Wednesday, Fundraiser Friday and a monthly CF media round-up, which aim to give space on a regular basis to share CF research news, celebrate the amazing achievements of our supporters, and keep the community updated on everything that is happening in the world of cystic fibrosis.

Our social channels allow us to respond to the CF community in a timely fashion on key themes such as the ongoing issues with Creon, the NICE appraisal of Kaftrio, and the Government's planned changes to disability benefits. Our ability to turn around video content, quickly enabled us to reassure our community during some challenging moments.

These are some of our top performing posts in 24/25:

- Our top-liked post on Facebook was our post confirming the King will continue as our Patron, with 665 likes and over 21,000 impressions.
- On Instagram, our highest-liked post was our video from CEO David Ramsden on the NICE Kaftrio approval, with 1,605 likes. This fell during CF Week and was a fantastic boost for the community amid ongoing worries around Creon supply.
- On TikTok, we were lucky enough to have Elizabeth Green, who played Jade (a character with CF) on Eastenders, in the office with us to film some Wear Yellow Day content. She answered questions about her experience and what she learned about CF preparing for the role, which accrued 458 likes.

Volunteering

Over the last year, we've been really grateful for the contribution of our volunteers, supporters and branches and groups, who provide invaluable support. All our volunteers come from a wide range of backgrounds and their individual experience and contribution enriches our work for people affected by CF. We've opened more volunteering activities from home, which has allowed more volunteers to support us and who otherwise would not have been able to volunteer. To recognise and acknowledge our volunteers, we celebrated National Volunteers Week in June 2024 and Trustee Week in November 2024.

Being an effective organisation

Our ability to achieve our vision depends on optimising our organisational effectiveness and working culture so that we can be a great workplace where our employees, volunteers, and other supporters are supported to do their best.

For our employees, we nurture this by building a rewarding working environment, and from our staff survey we know that our staff value many aspects of working for Cystic Fibrosis Trust, such as flexible working, a generous holiday entitlement, learning and development opportunities, and engaging communications, including regular briefings led by our CEO. During the last year we relocated to a smaller office with updated technologies and facilitating more effective use of office space, resulting in cost savings and an improved working environment.

As we move into 2025/26, we are in the process of developing our policies and practices to further improve our working culture, and help our people develop new skills and knowledge to continue to support the changing cystic fibrosis community.

Sharon receiving another fantastic donation to Cystic Fibrosis Trust

> "I never thought I'd be able to make a difference to people who've got the condition right now; I thought it would just be the next generation. So it's an amazing feeling to know I've helped my cousin Donna and how grateful she is for the work I do with the Fakenham branch."
>
> Sharon, from our Fakenham branch

Professor Jo Fothergill presenting at our ECR conference

> "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."
>
> Ali*, who attended our Early Career Researcher conference

Events

This year we held a one-day symposium in London for early career researchers (ECRs). The event gave them the opportunity to come together in an informal session, meeting their peers and learning from more experienced CF researchers.

We held a hybrid CF Live community event in Glasgow, to coincide with the European Cystic Fibrosis Society conference which took place in the city in June 2024. We also held an online CF Live later in the year focusing on adult CF care.

The end of 2024 also saw two events to mark our 60th anniversary: a supporter event at the Royal College of Physicians, and an awards ceremony, hosted by Richard Madeley, to showcase and thank members of the CF community.

Our second conference for multidisciplinary teams (MDT) took place in Birmingham in March 2025. The one-day event saw over **150 individuals from MDTs across the UK** attend for a series of talks, workshops, and panel discussions.

We also held a hybrid CF Live event for the local CF community in Birmingham the night before the MDT conference, with presentations from Trust staff and local CF centre representatives.

And in early 2025, we launched the Coffee and Careers webinar series. We are joined by an experienced researcher at each webinar who has a conversation with our host about their career to date, focusing on how they got started, how they ended up where they are now, learning opportunities over the years, and advice for early career researchers.

Celebrities

Our celebrity supporters and ambassadors have continued to provide vital support, awareness and fundraising for the Trust.

A special thank you to our ambassadors:

- James Dunmore, who ran the London Marathon for us in less than three hours, raising vital funds
- Jenny Agutter, who authored our Gift in Wills campaign and officially welcomed guests at our 60th anniversary supporter event
- Richard Madeley, who hosted our 60th anniversary awards ceremony.

We're also incredibly grateful for support in 2024/25 from Ben Shephard, Vincent Franklin, Jack Kinsey, Annette Badland, Eleanor Matsuura, Roger Black, David Haig and Anna Maxwell Martin.

A huge thank you to all our celebrity ambassadors and influencers who continue to support our vital work!

Sharing stories from our community

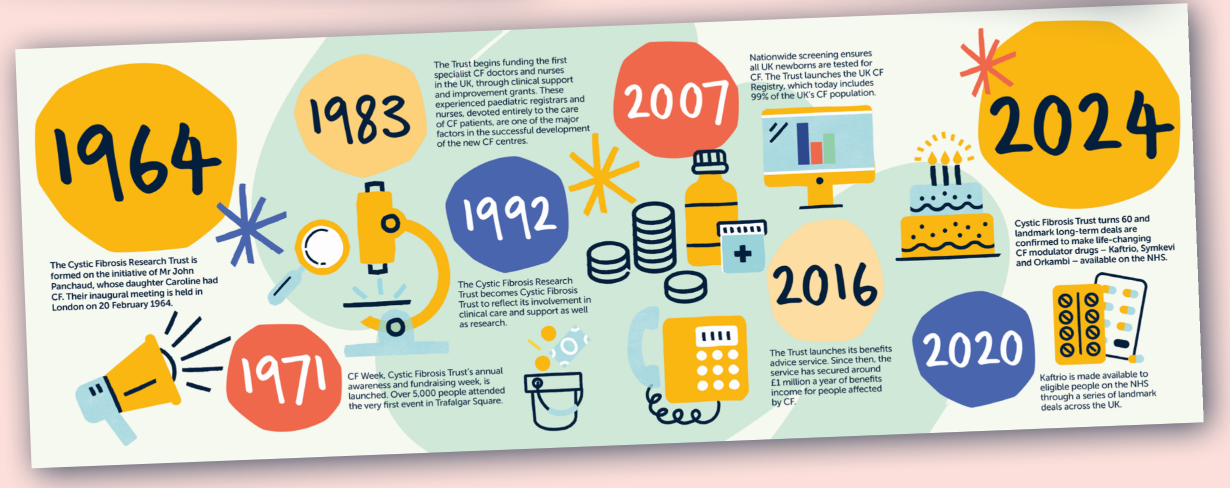
We strive to share diverse stories from our community through our blogs and video content. This year we've developed multiform content which covers a range of topics, such as CF research, living with CF as a young person, mental health, taking part in clinical trials, neurodiversity, starting a business, bereavement, and more.

We listen to our community to share what's important and relevant to them, keeping them involved every step of the way to ensure we're telling their stories in their own authentic voices.

> "I feel privileged to be an ambassador for Cystic Fibrosis Trust. It's very important to me to feel that I am, in however small a way, helping people with CF lead the longest and best possible lives."
>
> Richard Madeley

Richard Madeley hosting our 60th awards ceremony


Cystic Fibrosis Trust
Since 1964 We won't stop until CF does
CF Life
Then and now
Rob reflects on how CF has changed in his lifetime
Fly on the wall
Celebrating clinical trials
Dealing with diagnosis
How we can support you
Uniting for a life unlimited


1964
The Cystic Fibrosis Research Trust is formed on the initiative of Mr John Panchaud, whose daughter Caroline had CF. Their inaugural meeting is held in London on 20 February 1964.

1971
CF Week, Cystic Fibrosis Trust's annual awareness and fundraising week, is launched. Over 5,000 people attended the very first event in Trafalgar Square.

1983
The Trust begins funding the first specialist CF doctors and nurses in the UK, through clinical support and improvement grants. These experienced paediatric registrars and nurses, devoted entirely to the care of CF patients, are one of the major factors in the successful development of the new CF centres.

1992
The Cystic Fibrosis Research Trust becomes Cystic Fibrosis Trust to reflect its involvement in clinical care and support as well as research.

2007
Nationwide screening ensures all UK newborns are tested for CF. The Trust launches the UK CF Registry, which today includes 99% of the UK's CF population.

2016
The Trust launches its benefits advice service. Since then, the service has secured around £1 million a year of benefits income for people affected by CF.

2020
Kaftrio is made available to eligible people on the NHS through a series of landmark deals across the UK.

2024
Cystic Fibrosis Trust turns 60 and landmark long-term deals are confirmed to make life-changing CF modulator drugs – Kaftrio, Symkevi and Orkambi – available on the NHS.

Our magazine

CF Life is our twice-yearly magazine, packed with the latest news, features, and real life stories from the CF community. It is mailed to over 20,000 of our supporters across the UK and can also be read online.

To mark our 60th anniversary, this year we published a special edition of CF Life magazine, featuring a fold-out timeline of key milestones from our history.

Our cover story was an interview with supporter and involvement group member Rob. Rob has CF and first featured on the cover of CF Life predecessor, CF News, as a 6-year-old boy to mark the Trust's 30th anniversary. 30 years later and he shared his story once again.

In 24/25, we also covered topics including:

- transplant and CF
- dealing with a new diagnosis
- research into CF lung infections.

A big thank you to everyone who has contributed to CF Life magazine this year!

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

CForYourself podcast

Our podcast launched in June 2022 with host Lucy having a cup of tea and a chat with others in the CF community, talking openly and honestly about a whole range of topics. For this year's series, we asked the community what they wanted us to talk about, and we've covered everything from pregnancy to exercise.

CForYourself is all about sharing honest insights into life with cystic fibrosis – the good, the bad and everything in between and has been a huge success with our community and beyond. While most of our listeners are in the UK, we've also reached the CF community across the world, from Australia to Argentina.

Series 3 highlights

- 8 episodes
- 1,126 downloads
- Most popular episode: Pregnancy and CF

> "What an exciting episode! The discussion around CF and pregnancy is so important... this podcast is a fantastic resource for anyone navigating pregnancy with CF."
>
> Emma, podcast listener

Lucy Baxter, host of the CForYourself podcast

> "I wanted to be a guest editor for CF News because I am grateful to the Trust for so many things and I wanted to give back to this organisation. I am also an aspiring writer, so this is a great opportunity for me, and I'm happy to be given the chance to write something as personal as my CF."
>
> Sarah, CF News guest editor

Whatever you do, do it in yellow

CF Week

CF Week is our annual awareness and fundraising week, ending with the brightest fundraising day of the year – Wear Yellow Day! CF Week 2024 focused on 60 years of Cystic Fibrosis Trust, the amazing progress we've made during that time, and the work that still needs to be done to ensure everyone with CF can live a life unlimited.

Highlights included:

- We shared a diverse range of stories from across the CF community, including Shanique and Thiago's, which had over **7,000** views across all platforms.
- Our e-newsletter CF News was guest edited by Sarah from the CF community, who shared her CF journey and being part of the LGBTQIA+ community.
- We aired a special podcast episode which went behind the scenes at Cystic Fibrosis Trust.
- We empowered the CF community to tell their story and share their #CFTruths through our social media platforms.
- Wear Yellow Day raised a fantastic **£125,000**.
- Celebrities including Ben Shephard, Vincent Franklin, Jenny Agutter and Elizabeth Green all got involved.
- June was a record month for website donations, with over 224 one-off donations.

Uniting in fundraising

We'd like to take this opportunity to thank all of our incredible supporters, donors, organisations, charitable trusts and foundations, and corporate partners who have supported our work this last year. It is because of you that we can be there for people with CF every step of the way.

In 2024/25, we raised an amazing £6.9m gross and £4.7m net. This was £1m less than last year, mainly due to a decrease in legacy income. We saw growth in several income streams – namely events, in-memory, and trusts. Overall, our income has not returned to pre-pandemic levels and remains impacted by the cost of living crisis and increasing competition for funds.

That said, we continue to innovate and develop our fundraising campaigns and appeals, building on learning from the year before. Our flagship Wear Yellow Day attracted one of the largest number of supporters to date.

It was a pleasure to have the opportunity to mark our 60th anniversary with our supporters and funders, and to reflect on the milestones the Trust and the CF community have experienced together. We also had the opportunity to honour some of the incredible fundraising achievements of our supporters at our 60th anniversary awards.

This year also saw the launch of our new Translational Innovation Hub Network, which builds on the successful model of the original Innovation Hub at the University of Cambridge. The new Network aims to drive a transformative shift in research to develop innovative diagnostic and treatment approaches that support the clinical management of lung health and infections, ultimately improving the quality of life for people living with CF. In partnership with LifeArc, over £3.5m has been committed across the four hubs in its launch year and we are delighted that the Robert Luff Foundation have continued their support for the new Hub Network.

Community and event fundraising

Thanks to all our incredible fundraisers, we have raised an incredible **£2,267,000** this year.

Our supporters took part in an array of challenge events, including London Marathon, Edinburgh Marathon, London Landmarks, Great North Run, London to Brighton Bike Ride, and skydives up and down the country. They also headed off around the world to take on overseas treks, marathons and other gruelling challenges. Together, these amazing individuals raised over **£1,171,000** for the Trust.

The CF community continue to get behind our Wear Yellow, Festive and FeBrewary campaigns, coming together at key points in the year to show their support. Alongside this, lots of people contributed their own way, just like our very own trustee, Sophie Pierce, who raised funds and awareness and even broke a world record by rowing the Atlantic in her crew of four, in 53 days.

Wear Yellow Day goes from strength to strength, raising **£125,000** last year. Over 212 individuals, 145 schools, and 250 parents of children with CF (who form the CF Mamas and Papas) came together to make it one of the biggest and brightest Wear Yellow Days to date.

We are also grateful to have the continued support and dedication from our branches and groups who resolutely raise awareness and funds to support the Trust's work. The year's total is **£98,000**, with activities ranging from carol concerts, fairs and garden parties, to running challenges and celebratory balls.

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

> **"For me, this row isn'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."**
>
> Sophie, our Trustee, who has CF

Pamela and her son Max, who has CF

> **"I started the CF Mamas fundraising group a few years ago after speaking to some special CF mummies. We wanted to do something as a big group and not only raise very important funding but also awareness."**
>
> Pamela, on setting up CF Mamas and Papas

Regular gifts

We're deeply grateful for our regular donors, whose ongoing support raised an incredible **£780,000** in 2024/25, including Gift Aid. Thanks to a telemarketing campaign, we gained an additional **£8,300** through upgraded and reactivated gifts. Giving this way is one of the most sustainable ways to support the Trust, allowing us to plan ahead and make a real difference in the lives of those affected by cystic fibrosis, funding life-changing research and vital care.

Gifts in Wills

Supporters leaving a gift in their Will to Cystic Fibrosis Trust continue to make an extraordinary and lasting difference, funding groundbreaking research and crucial support services for people with cystic fibrosis.

Thank you to everyone who has chosen to support us in this very special way, **with particular appreciation in 2024/25 for the 117 gifts received and 72 gifts pledged**. These considered acts of kindness bring us closer to a future where everyone can live a life unlimited by cystic fibrosis.

Giving through gifts in Wills remains a vital contribution to the current and future work of the Trust. This year our legacy appeal had a fantastic response rate of 14%, with more supporters making the choice to have a positive impact on our futures.

We continued to highlight the importance of having an up-to-date Will and promoted our free Will offers, helping supporters to be in control of their wishes and make a difference to causes that are close to their heart.

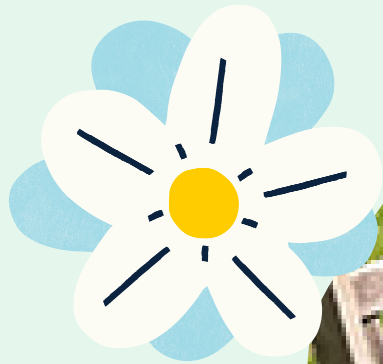
In memory

We are profoundly grateful to everyone who has donated in memory of someone special. In 2024/25, **over £250,000** was given in expression of love, remembrance, and a shared commitment to a future where everyone with CF can live free from the limits of the condition.

These gifts create real and lasting impact, and play a vital role in supporting our work.

Many families and friends chose to commemorate their loved ones through our Book of Remembrance, dedication wall, or personal tribute funds. These meaningful spaces provide comfort and connection, allowing memories to be celebrated and shared.

To those who have chosen to honour a life in this way – thank you. Your generosity keeps memories alive and offers support and hope to others affected by cystic fibrosis.



Sophie and family

> **"As a family tradition, we choose not to send Christmas cards and instead donate this money to the Trust so it can be put to good use and help families similar to us. Cystic Fibrosis Trust has meant so much to me and my family since Dad passed because of their aim to spread awareness, find treatments and support people with CF alongside their families."**
>
> Sophie, who lost her dad Paul to CF

Corporate partnerships

Building partnerships with existing and new corporate partners helps us raise both funds and awareness for the Trust. Crane CPE funded us for the sixth year running from their Crane Widows and Children Fund, and the skills and expertise of the Bip Group assisted us in ensuring that our Helen Barrett Bright Ideas Awards continue to support entrepreneurs with CF to launch or grow their businesses.

We were delighted to be named as charity of the year by Project Leaders, Atlantic Pumps, and Pyvital. Events such as the UK CF Clinical Trials Conference, UKCFC, and the Annual Registry Meeting are essential in showing the work we do. This would not be possible without the support of our sponsors, some of whom come back year after year. Our MDT conference, held in Birmingham in March 2025 with sponsorship from Recode Therapeutics, Enterprise Therapeutics, Essential Pharma and Nordice Pharma, was a standout event for us this year.

We would also like to thank our partners who have shared their expertise and resources with us this year, including Bird and Bird, and Cushman and Wakefield. We would like to thank Bauer Media Outdoor (formerly Clear Channel) for their gift-in-kind outdoor advertising to help support our vital awareness campaigns.

Philanthropy

We would like to thank the generous and committed support of trusts, foundations, and the National Lottery Community Fund, whose grants have been critical to our provision of services and new programmes for the CF community, alongside world-leading research.

We are especially thankful for our long-term partners, the Robert Luff Foundation, the Joseph Levy Foundation, and Garfield Weston Foundation.

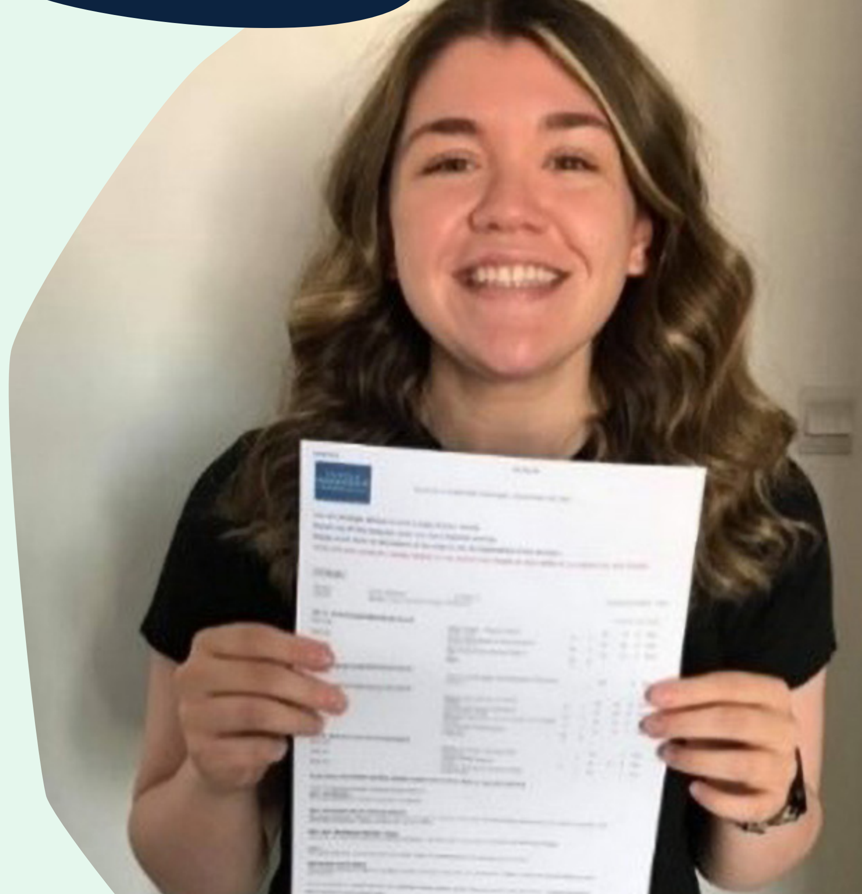
Thanks to the generosity of these supporters, over the last year we have continued to ensure that people with CF can live a life unlimited. This has included progressing vital research, helping young people to build their futures and offering grants through our Winter Support Fund.

We are also deeply grateful for the committed support of our Sixty Five Roses Club members who are able to support us with a minimum donation of **£1,000** each year. The Club is thriving, with over **70 members** now helping to fund projects that support people with CF when they need us most.

Supporter experience

The Trust received 19 complaints in 2024/25. This is broadly in line with the 29 received in 2023/24, and 19 in 2022/23, with the main areas of improvement being more effective use of data (fewer mailing-related errors) and in dealing with sensitive subjects (like bereavement). Complaints are closely monitored and reviewed by senior management on an ongoing basis. In addition, we regularly review our complaints policy and processes to make it easier for people to give us feedback and to ensure that we listen and learn from what our supporters and community are telling us.

> **"Without the help of the Joseph Levy Education Fund grant, my university experience would have been completely different. The support that was there allowed me to pursue my degree knowing that I would be able to handle both university life and keep myself well."**
>
> Emily, who has CF



Looking to the future

> "I want to be able to inspire people. I'm 40 now, and I have friends with kids with CF. It's important for me to be able to say I'm 40, I have a full time job, and I can do all these amazing things as well."
>
> Rich, who has CF

Uniting in research for a life unlimited

We continue to work towards our research goals, guided by the priorities of the CF community. By funding innovative, world-class research and maximising our research partnerships, we're committed to improving the lives of a diverse CF community. We're excited about the potential of our partnership research programmes, such as CF AMR Syndicate and the Translational Innovation Hub Network, to improve the lung health for everyone with CF.

We're constantly seeking new partnerships and attracting companies to develop their products with the CF community in the UK. We offer combined research support to deliver trials that are easy to set up, efficient and meaningful, and could make a difference to people with CF and their families.

Early phase trials being supported by our CTAP programme will continue to assess medicines for people who can't benefit from modulators. Studies using UK CF Registry data will continue to monitor the long-term effects of modulators and help us better understand the changing nature of CF.

> **"It's a very exciting time in CF care. For 34 years of my life, there didn't seem to be any huge advancements, and now they are coming thick and fast. In all honesty, it's the most hopeful I've ever felt, and that's comforting as someone approaching 40 that didn't even think I'd be here, let alone experiencing these huge leaps forward in treatment."**
>
> Sarah, who has CF

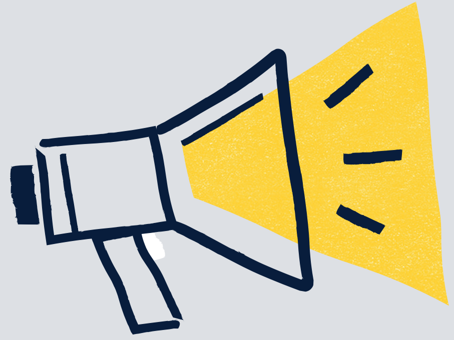
> **"Cystic Fibrosis Trust have been amazing and the research and developments that have come about as a result of the charity's efforts has been incredible to see. Kaftrio has made a huge difference for me and my brother, but I know it's not a cure and some people can't benefit from it, so I'm determined to run for everyone in the CF community."**
>
> Nell, who has CF

Being great fundraisers

Growing our income remains a key priority at the Trust so that we can build on the progress we have made, and make sure that in 2025 and beyond people with CF can live their lives without limits.

Next year we are embarking on a new fundraising strategy, with a renewed focus on building our supporter numbers and ensuring they have an excellent experience of supporting the Trust. Innovation will continue to run through our plans across all income areas, so we can offer a diverse portfolio of engaging and exciting ways for people to get involved – be that in their own time; participating in challenge events; or by taking part in one of our mass participation campaigns. We plan to develop more multi-year relationships with trusts and launch a new giving circle to help accelerate funding for our research programmes. Alongside this we will continue to fundraise to meet our £1.5million contribution towards the Translational Innovation Hub Network.

We want to get closer to our supporters, branches, CF centres, and corporate partners to work together to raise funds as one community with a shared purpose to improve the lives of people with CF and their loved ones.



Campaigning hard

Looking ahead, our advocacy will continue to focus on critical issues impacting the CF community. The impact of toxic air quality remains a significant concern, and later this year we will leverage findings from our commissioned research with the York Health Economics Consortium to advocate for stronger environmental policies.

The Government's emphasis on science and innovation presents opportunities to advance CF research and treatment. We will advocate for policies that support research funding, innovation, and improved mobility for scientists, accelerating progress in CF care.

With a new legislative agenda unfolding, we remain vigilant, ready to respond to policy reviews and budget announcements as we have on the Government's Pathways to Work social security reforms. Our commitment is unwavering: to seize every opportunity to advocate for improved care, support, and a future free from the limitations of cystic fibrosis.

Day-to-day support

We continue to develop our services and resources to meet changing needs, while maintaining our core provision.

This year, we've strengthened our peer support provision, recognising the importance of providing safe spaces for the CF community to come together and support each other. We have piloted new online events, continued to develop our online community, and provided updated training to our CF Connect volunteers, who provide parent-to-parent support over the phone. We have now shaped a clear forward strategy for peer support, highlighting the key role it plays in supporting emotional wellbeing and physical health. Over the year ahead, we will be developing this further with a view to seeking funding to expand our peer support provision.

We have been working with another national charity to explore ways to provide enhanced grief support to those bereaved by CF, and we will be taking this partnership forward in the year ahead.

Over the coming year, we will be developing information to support people with CF to manage their mental health and wellbeing, and starting work on updating our information around family planning, as well as continuing with updates to our guideline documents, including antimicrobial treatment, infection prevention and control, physiotherapy, and nutrition.

We will also be developing our work to support those in the CF community who are neurodivergent.

Jacob

> "When Jacob was first diagnosed, the CF nurse at the hospital handed us a pamphlet from the Trust explaining what CF is. It helped us to have that information in one place and meant I didn't go searching on Google, which would have been the worst thing for me to do."
>
> Morag, whose son Jacob has CF

> "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."
>
> CEO David Ramsden

Quality improvement and clinical engagement

In 2025/26, we will report on findings from our first ever survey for CF professionals, which looks at how CF care and workload are evolving from the perspective of those working in the specialty. Data collection started in March 2025 and findings are anticipated in the early summer.

In October, new data will be collected on staffing levels in CF services as part of our annual CF staffing tool. And in November, we will open the third cycle of our patient experience survey in children's services.

We are continuing to roll out and expand our quality improvement support offer for CF centres, to support them to explore their data insights and plan targeted quality improvement activities.

The UK CF Registry

The UK CF Registry remains at the forefront of collaborative innovation, continuously expanding its portfolio to better serve people with CF. We are developing a new purpose-built CFSPID Registry. In parallel, we are partnering on new research initiatives, including projects focusing on pregnancy and cystic fibrosis.

The Registry continues to support collaborative studies monitoring the long-term health outcomes of Kaftrio, with publication of results expected in 25/26 alongside plans to present results at international conferences.

As the structure of the NHS evolves with the dissolution of NHS England, we are committed to maintaining strong partnerships with NHS organisations to ensure alignment with national priorities that will benefit people with CF.

Financial review

Results for the year

Over the last 12 months, like many charities, the Trust has faced challenges in maintaining income due to the wider economic climate. Therefore, the Trustees approved a business plan with a deficit budget for the financial year which assumed reduced income and reduced grant awards whilst maintaining services and support at a level similar to previous years.

The result for the year, excluding movements on investments, was a deficit of £1.8m (2024: deficit of £0.4 million) which is £0.4m better than budget, largely due to efficiencies and cost reductions made during the year.

Total income of £12.0m is £2.6m lower than in 2024, whilst total expenditure has decreased by 8% (£1.3m), which is principally due to a reduction in grant awards (and unclaimed grant commitments recredited to our accounts).

This deficit has been funded from unrestricted reserves. As explained below (see Reserves, page 58), despite the deficit in the year, the Trust continues to hold strong reserves. The Trustees have agreed a four-year financial plan to increase income whilst broadly maintaining activity at current levels. The aim is to deliver a balanced position by March 2029, while ensuring that the Trust maintains reserves within its reserves policy.

Income

The Trust’s income from normal activities for the year to March 2025 was £12.0m (2024: £14.7m).

Voluntary income of £6.5m (2024: £8.0m) includes amounts from regular giving programmes and appeals, from branches, groups and communities, corporate partnerships and trusts. In common with many charities, the on-going cost of living crisis means that generating voluntary income remains challenging. Whist individual giving income is broadly similar to last year, income from trusts has reduced by £0.9m, primarily due to receiving a £1.2m donation in the prior year for a specific research project.

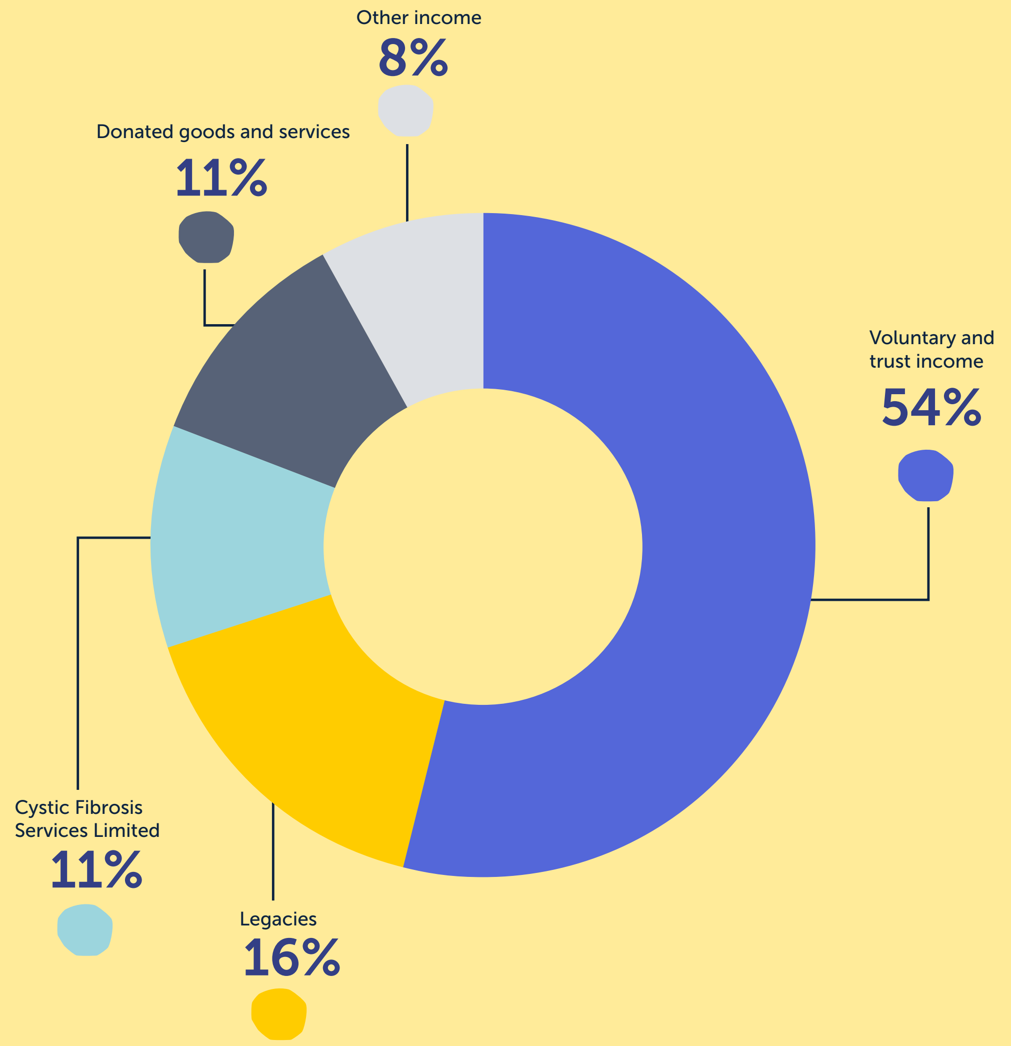
Legacy income of £2.0m is £0.6m less than in 2024, a year in which the Trust benefitted from several exceptional large gifts.

Income generated by Cystic Fibrosis Services Ltd (“CFSL”), the Trust’s trading subsidiary, was £1.3m (2024: £1.3m). This income is mainly generated from contracts with pharmaceutical companies for our UK CF Registry to produce study reports for the regulators of medicinal products. The company expects to confirm contacts to support further studies within the next few months which will secure further income over the next three years.

We benefit from generous corporate donations in kind including outdoor advertising and advice supporting our campaigns. The value of these services was £1.3m (2024: £1.5m). The corresponding cost value of this donation is included in charitable expenditure as part of the information, advice and support costs.

Other income of £0.9m in the year (2024: £1.2m) includes investment income, contracts for services and recoverable VAT.

Income 2024/25



Expenditure

The Trust’s total expenditure for the year was £13.8m, a £1.3m decrease compared to the previous year.

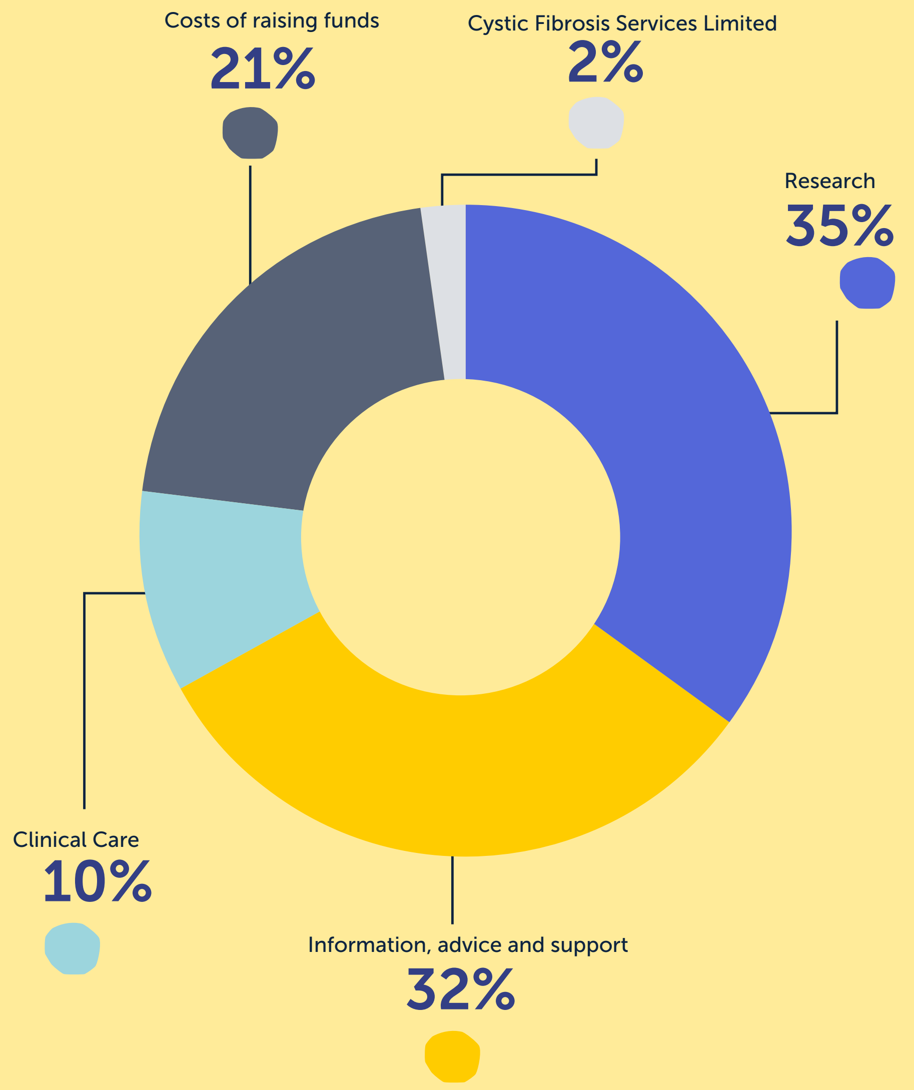
Expenditure on charitable activities in the year was £11.0m (2024: £12.3m). This includes funding research, providing information and advice and support and promoting the best clinical care. The reduction in costs is due to careful cost control during the year, which included a reduction in staff headcount and reduced research grant expenditure. Grants to support charitable activities included:

- £2.7m (2024: £3.9m) grants to a range of medical, academic and charitable institutions to support research. The Trust continues to seek funding and co-funding to enable it to increase funding for this vital research. The Trust also reviewed grants made in previous years where there has been no recent activity, and this resulted in £0.5m (2024: £0.3m) of grants made in previous years being recredited to our accounts
- £0.3m (2024: £0.4m) to fund the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme
- £0.3m (2024: £0.3m) grants to CF Centres to fund data collection for the Registry
- £0.3m (2023: £0.3m) to individuals through our Welfare Grant programme

(The total grants awarded are detailed in Note 5 to the financial statements.)

The cost of raising funds was £2.8m (2024: £2.7m).

Expenditure 2024/25



Investment policy

The Trust holds significant investments in cash and cash equivalents, and in a managed investment portfolio.

	2025 £'000	2024 £'000
Cash and cash equivalents	**11,558**	12,024
Managed investment portfolio	**5,835**	5,796
Total	**17,393**	17,820

The Finance and Audit Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to adopt a balance between generating sufficient income to support the on-going activities of the Trust, whilst maintaining the real capital value of the investments over the long-term.

The majority of the managed investment portfolio is kept in liquid funds although there is some exposure to less liquid assets such as property. Approximately 84% of the portfolio is now invested in the Responsible Multi-Asset Fund which aims to have a positive impact on people and the planet by avoiding harm through environmental, social, and governance integration and exclusions, benefiting stakeholders through responsible business activities and contributing to solutions through influence and investing for impact. The remaining funds are invested across various funds including the Charities Property Fund, Trojan Ethical Fund and the Columbia Threadneedle Responsible Equity Fund. The Trust does not permit direct investment in tobacco.

A number of small endowment funds are invested on a total return basis, enabling the Trust to utilise both income generated by the funds and increases in capital value, while protecting the original inflation-adjusted endowment values.

We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance and Audit Committee.

Review of investments in the year

The value of the investment portfolio (including endowment funds) was £5.8m as at 31 March 2025 (2024: £5.8m). Due to market conditions, there was no significant investment gain in the year. The Trusts targets a return of CPI plus 3%. Since the end of the financial year market conditions have been volatile, but despite losses in April, at the date of this report the value of the investment portfolio has increased to over £6.0m. No change was made to the allocation between amounts held as stocks and shares and that held as cash in the portfolio.

Income generated on investments totalled £0.7m (2024: £0.6m).

Reserves

The Trust has a reserves policy which is based on best practice as set out by the Charity Commission in CC19 **Charity reserves: building resilience**. The Trustees actively review the Trust's reserves to ensure that the Trust has sufficient funds to support future activities and meet all its commitments and obligations.

The Trust holds the following reserves:
Restricted funds which are to be used for specific uses specified by the donor. Expenditure which meets the donor's criteria is charged against the specific fund. At 31 March 2025 restricted funds totalled £0.5m (2024: £0.5m). Note 21 lists the individual restricted funds and their movement in the year.

Endowment funds where the donor requires the Trustees to hold the funds as capital investments. Income from the investment can be used by the Trust as specified in the terms of the endowment. The Trust is not entitled to spend the capital fund without permission from the donor. At 31 March 2025 the endowment funds totalled £1.0m (2024: £1.0m). See note 20 for information about the individual endowments.

Designated funds which are funds that the Trustees have set aside for specific projects or initiatives. There are three designated funds:

- Organisational reserve: £0.8m (2024: £1.0m) has been established for investment in process improvement and our digital/data strategy, including implementation of a new Customer Relationship Management (CRM) system.
- Fixed asset reserve of £0.06m (2024: £0.13m). The reserve is maintained as fixed assets cannot be readily realised as cash.
- Research fund reserve of £0.5m (2024: £nil). As explained in note 5 (page 80) various grants awarded in previous years totalling £465,000 were credited back to reserves in the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful. The Trustees consider that the funds have been committed to fund research and that this commitment remains. Therefore, they have created a designated fund for future research.

Retained Reserves which can be used to fulfil any part of the Trust's objectives.

The Trustees have adopted a reserves policy designed to ensure the Trust maintains sufficient funds to continue its activities, particularly in light of recent economic volatility.

The Trustees have set a minimum level of retained reserves and an upper target with the aim that unrestricted funds fall within this range. In setting this **core reserves range** the Trustees have considered:

- The level of reserves required to mitigate income risk. This includes the challenge of fundraising in the current economic environment and the risks associated with not securing further contract income for the UK CF Registry.
- The risk of not being able to contain costs in line with future saving targets.
- Risks of a significant fall in the value of the Trust's investment portfolio due to market volatility and the impact of falling interest rates.
- Maintaining sufficient working capital headroom.

Based on the 2025/26 budget and a review of the above risk factors, the target core reserves range is between £4.0m and £6.5m.

At 31 March 2025 the Trust's retained reserves were £6.7m (2024: £8.7m) which is slightly above this core reserves range. The Trustees approved a detailed business plan with a deficit budget for the next financial year which maintains services and grant awards at a level similar to last year and which will bring the Trust's retained reserves within this core range. (Retained reserves are forecast to be £5.3m at March 2026 and reduce further to £5.0m by March 2027.)

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

Principal risks and uncertainties

The Board of Trustees is responsible for ensuring effective risk management and internal controls to manage the major risks the Trust faces, including agreeing the Trust's 'risk appetite' (how much risk the Trust is willing to tolerate in key areas) and keeping oversight of the Trust's risk management framework. This framework, managed by the Senior Leadership Team, includes a Strategic Risk Register and provides a consistent approach to identifying, assessing and dealing with the risks facing the Trust. It is monitored at least quarterly to support informed decision-making and ensure appropriate mitigations and controls are in place to effectively manage any risks to our objectives.

The main strategic risks and uncertainties that management and Trustees have identified and the key actions to mitigate these risks are:

Strategic risk	Strategies/plans for managing risks
Relevance	
• Failure to be relevant and responsive to the needs and expectations of people with cystic fibrosis and our wider community could damage our reputation and ability to deliver our objectives. • Failure to get our message across in a way that conveys the impact of our work means we will not be seen as relevant and will not reach widest possible audience, and damage our reputation, losing support, credibility and income. • Failure to Influence key external stakeholders and decision makers will impede our ability to deliver on our strategy and erode our relevance in eyes of the community.	• Our strategies and work programmes reflect the views and priorities expressed by people with cystic fibrosis through consultation, involvement and co-design. • Our Equity Diversity and Inclusion Strategy reinforces our commitment to listening and representing the full range of stakeholders across our community. • We have detailed audience insight research analysis and are implementing the findings. • We continually develop strategies on emerging priorities, including Air Quality, Housing, Poverty, CF Care resourcing, and benefits and welfare reform. • Policies and processes in place to ensure quality control and the relevance of our messaging, including 'red flag' processes on potentially sensitive communications. • Our close links with the community, and ability to listen and closely monitor discussions and sentiment, gives us early warning on many emerging community priorities/issues.
Financial	
• Failure to operate a sustainable financial model could heavily compromise the Trust's operational viability and its ability to deliver for people with cystic fibrosis.	• The strategic financial framework for the next four years and budget for 2025/26 includes measures to closely track income and expenditure and is scrutinised by the Finance and Audit Committee. Our plans ensure that we will maintain unrestricted retained reserves within policy. • The new Fundraising strategy focusses on maximising sustainable net income, including exploring innovative new sources of income. • Our business planning has strong focus on prioritisation, and additional cost savings are actively explored.
Data	
• Failure to optimise our use of and adequately protect our data will limit our impact, reach, income and relevance, and harm our reputation if it falls into the wrong hands.	• We have a GDPR compliance framework, Data Protection Policies and Data Protection Officer. There is ongoing staff training. • We have implemented a data strategy with the focus on three strands: upgrading our CRM, ensuring data quality and ensuring we have a data-centric culture. • We continually review our data security including access controls (e.g. multifactor authentication) and utilise automated monitoring and reporting. • We have implemented a new AI policy and will continue to review this rapidly developing area.
People	
• Failure to deliver People Strategies that effectively support, protect, and develop our staff and volunteers will erode our ability to recruit and retain highly skilled and motivated staff and could have significant reputational impact.	• We have a comprehensive range of policies in place covering welfare, safeguarding, recruitment and retention, learning and development and employee benefits. These are reviewed and updated regularly with external professional support. Trustees have oversight of these through the People Committee. • There is a strong communications, feedback and learning processes in place (CEO briefings, staff survey, elected employee reps, exit interviews).
Autonomy	
• Failure to maintain autonomy in relationships with pharma, academic institutions and funding partners will compromise our relationships with the wider clinical community and may harm our reputation.	• Our governance processes include systematic declaration of interests, conflict of interest guidelines and robust research governance and awards processes. • Partnership working and ethical policies are in place defining criteria for establishing new partnerships to ensure risk is considered.

Processes in place regarding risk management and internal control include the following:

- A risk management framework that meets the Charity Commission's requirements. A top-down risk review by the Senior Leadership Team, and a bottom-up review by individual functions, is undertaken throughout the year and the risks identified through this process are documented in a risk register.
- The Finance and Audit Committee receives reports from the external auditors on the effectiveness of controls and, where appropriate, adopts the recommendations made in the external auditors' reports.
- The Board of Trustees receives a comprehensive risk management report each quarter to assist it in ensuring that an effective process is in place. This report provides an update on the risk reviews undertaken and provides the Board with the opportunity to engage in dialogue about, and to provide input into, the evaluation and management of key risks.
- Formal project delivery groups are established for major projects and programmes to ensure that these are carefully planned, managed and implemented.

Our work with the pharmaceutical industry

Our mission is to make sure everyone can live without the limits of cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

Partnerships between medical research charities and the life sciences industry can help us deliver that mission and bring huge benefits to patients including accelerating the development of new drugs and ensuring the safety and improvement of existing treatments.

We run the following flagship programmes involving pharmaceutical industry partners:

Clinical Trials Accelerator Platform

CTAP is a UK-wide initiative bringing together CF centres to increase participation and access to CF clinical trials. This initiative is building infrastructure and funding additional research capacity to support the life sciences industry with commercial clinical trial delivery.

As part of our collaboration with industry, CTAP offers a centralised feasibility service to support pharmaceutical companies with identification of suitable CF centres for clinical trial delivery.

Venture & Innovation Awards (VIAs)

VIAs support transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the life sciences industry.

The UK CF Registry

Long-term safety and efficacy studies of drugs available to people with CF across the UK are supported by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the regulators of medicinal products is covered by pharmaceutical companies holding the market authorisation for these medicines. You can read more about our work with industry to make medicines safer at **cysticfibrosis.org.uk/registry**.

In 2024/25 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £1.3m (2024: £1.3m) in fees for this service. This income was used to support and maintain the Registry, including staff costs, data collection through Centre grants and IT hosting and development.

Sponsorship and donations

The Trust seeks sponsorship and grants from pharmaceutical companies to ensure we have the funds to run the events that we know are so important for healthcare professionals and people affected by cystic fibrosis. These events enable us to keep these audiences informed on vital aspects of clinical care and research.

We would like to thank Vertex who provided Independent Medical Education Grants for the UK Clinical Trials Conference in March 2024, the Early Career Researchers conference in October 2024 and the Multi-disciplinary Team (MDT) Conference in March 2025. Recode Therapeutics were our headline sponsors at the MDT conference in March 2024 and sponsored our CTAP conference in March 2024 for which we were most grateful. Thanks also go to Enterprise Therapeutics, Essential Pharma and Nordic Pharma for their sponsorship support of the MDT conference.

Statement of Trustees' responsibilities

The Trustees, who are also directors of the Cystic Fibrosis Trust for the purposes of company law, are responsible for preparing the Trustees' report (including the Group Strategic Report) and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group, and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently,
- observe the methods and principles in the Charities SORP,
- make accounting estimates that are reasonable and prudent,
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustees investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware,
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustee's Report incorporating the Strategic Report was approved and authorised for issue by the Board of Trustees on 30 July 2025 and signed on its behalf by:

Richard Hunt, Chairman

Independent auditor's report to the members and trustees of Cystic Fibrosis Trust

Opinion

We have audited the financial statements of Cystic Fibrosis Trust (the 'charitable parent company') and its subsidiary (the 'group') for the year ended 31 March 2025 which comprise consolidated statement of financial activities (incorporating the income and expenditure account), the consolidated and charity balance sheets, the consolidated statement of cash flows, the principal accounting policies and the notes to the financial statements. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the charitable parent company's affairs as at 31 March 2025 and of the group's income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group and charitable parent company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report and financial statements, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report, which is also the directors' report for the purposes of company law and includes the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the trustees' report, which is also the directors' report for the purposes of company law and includes the strategic report, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the charitable parent company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- proper and adequate accounting records have not been kept by the charitable parent company, or returns adequate for our audit have not been received from branches not visited by us; or
- the charitable parent company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the charitable parent company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the charitable parent company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- The engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulation;
- We identified the laws and regulations applicable to the charitable parent company and group through discussions with key management;
- We focused on specific laws and regulations which we considered may have a direct material effect on the accounts or the activities of the charitable parent company and group; and
- We assessed the extent of compliance with the laws and regulations identified above through making enquiries of key management and review of minutes of trustees' meetings.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the trustees and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees as a body, in accordance with Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Buzzacott Audit LLP

Shachi Blackmore (Partner)
For and on behalf of Buzzacott Audit LLP, Statutory Auditor
130 Wood Street,
London
EC2V 6DL

Date – 30 July 2025

Buzzacott Audit LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Cystic Fibrosis Trust

Consolidated statement of financial activities

For the year ending 31 March 2025

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2025 £'000**	Total Funds 2024 £'000
Income and endowments from:						
Donations and legacies	2	7,468	2,564	-	**10,032**	12,402
Charitable activities						
Other trading activities		1,257	-	-	**1,257**	1,304
Investments	3	655	-	-	**655**	628
Other income		70	-	-	**70**	332
Total income		**9,450**	**2,564**	**-**	**12,014**	14,666
Expenditure on:						
Raising funds	4	2,841	4	-	**2,845**	2,748
Charitable activities						
Research	4	3,584	1,526	2	**5,112**	6,409
Clinical care	4	672	749	-	**1,421**	1,477
Information, advice and support	4	4,192	262	-	**4,454**	4,460
Total charitable activities		**8,448**	**2,537**	**2**	**10,987**	12,346
Total resources expended	4	**11,289**	**2,451**	**2**	**13,832**	15,094
Net (expenditure)/income before investment gains/(losses)		**(1,839)**	**23**	**(2)**	**(1,818)**	(428)
Realised investment losses		-	-	-	**-**	(2)
Unrealised investment gains/(losses)	19	70	-	(30)	**40**	413
Net investment (losses)/gains		**70**	**-**	**(30)**	**40**	411
Net (expenditure)/income		**(1,769)**	**23**	**(32)**	**(1,778)**	**(17)**
Transfers between funds	19	35	(35)	-	**-**	-
Net movement in funds		**(1,734)**	**(12)**	**(32)**	**(1,778)**	(17)
Reconciliation of funds:						
Total funds brought forward		9,840	468	1,032	**11,340**	11,357
Total funds carried forward	19	**8,106**	**456**	**1,000**	**9,562**	11,340

All of the operations are continuing.

There were no recognised gains or losses other than those stated above.

A prior year comparative consolidated statement of financial activities has been included in the notes to the accounts (note 22).

The notes on pages 72 to 95 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated and charity balance sheets

For the year ending 31 March 2025

		Consolidated		Charity	
	Notes	**Total 2025 £'000**	Total 2024 £'000	**Total 2025 £'000**	Total 2024 £'000
Fixed assets					
Tangible assets	7	**64**	132	**64**	132
Investments	8	**5,835**	5,796	**5,835**	5,796
		5,899	5,928	**5,899**	5,928
Current assets					
Debtors	9	**2,996**	5,076	**2,934**	5,041
Cash held as short term investment		**11,558**	12,024	**11,558**	12,024
Cash at bank and in hand		**2,584**	4,046	**2,576**	4,036
		17,138	21,146	**17,068**	21,101
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	10	**(5,444)**	(6,235)	**(5,444)**	(6,235)
Creditors and accrued charges	11	**(2,714)**	(2,772)	**(3,494)**	(3,625)
		(8,158)	(9,007)	**(8,938)**	(9,860)
Net current assets		**8,980**	12,139	**8,130**	11,241
Creditors: amounts falling due after one year					
Grants payable	10	**(5,317)**	(6,727)	**(5,317)**	(6,727)
Total net assets		**9,562**	11,340	**8,712**	10,442

Continued on the next page

Cystic Fibrosis Trust

Consolidated and charity balance sheets (continued)

For the year ending 31 March 2025

	Notes	Consolidated		Charity	
		Total 2025 £'000	Total 2024 £'000	**Total 2025 £'000**	Total 2024 £'000
The funds of the charity:					
Endowment funds	20	**1,000**	1,032	**1,000**	1,032
Restricted income funds	21	**456**	468	**456**	468
Unrestricted funds					
Designated reserves					
Organisational reserves	19	**868**	1,000	**868**	1,000
Fixed asset reserve	19	**64**	132	**64**	132
Research fund reserve	19	**465**	-	**465**	-
Total designated funds		**1,397**	1,132	**1,397**	1,132
Retained reserves		**6,709**	8,708	**5,859**	7,810
Total unrestricted funds		**8,106**	9,840	**7,256**	8,942
Total charity funds	19	**9,562**	11,340	**8,712**	10,442

The notes on pages 72 to 95 form part of these financial statements.

Approved and authorised for issue by the Trustees on 30 July 2025 and signed on their behalf by:

Richard Hunt, Chairman
Company number 3880213

Cystic Fibrosis Trust

Consolidated Statement of cash flows

For the year ending 31 March 2025

	2025 £'000	2024 £'000
Net cash provided by/(used) operating activities (Note A)	**(2,584)**	565
Cash flows from investing activities:		
Dividends and interest	**655**	628
Purchase of property, plant and equipment	**-**	(41)
Purchase of investments	**-**	(255)
Movement in cash awaiting investment	**1**	(21)
Proceeds of sales of investments	**-**	279
	656	590
(Decrease)/increase in cash held as short term investments	**466**	(539)
(Decrease)/increase in cash (Note B)	**(1,462)**	616

No separate reconciliation has been prepared between the movements in net debt of the charity as there is no difference between the movements in cash and cash equivalents and the net cash (debt) of the charity.

Notes to cash flow statement

Note A – Reconciliation of net income to net cash flow from operating activities

	2025 £'000	2024 £'000
Net income for the reporting period (as per the statement of financial activities)	**(1,778)**	(17)
Adjustment for:		
Depreciation charges	**68**	64
Dividends and interest from investments	**(655)**	(628)
(Gains)/losses on investments	**(40)**	(411)
Decrease/(increase) in debtors	**2,080**	1,513
Increase/(decrease) in creditors	**(2,259)**	44
Net cash (used in)/provided by operating activities	**(2,584)**	565

Note B – Reconciliation of cash and cash equivalents in the reporting period

	2025 £'000	2024 £'000
Cash and cash equivalents at the beginning of the reporting period	**16,070**	14,915
Change in cash and cash equivalents in the reporting period	**(1,462)**	616
Increase in short-term investments	**(466)**	539
Cash and cash equivalents at the end of the reporting period (being cash at bank and in hand and cash held as short-term investments)	**14,142**	16,070

	2025 £'000	2024 £'000
Analysis of cash and cash equivalents:		
Notice deposits (less than 3 months)	**11,558**	12,024
Cash at bank and in hand	**2,584**	4,046
Total cash and cash equivalents	**14,142**	16,070

Cystic Fibrosis Trust

Notes to the Financial Statements

For the year ending 31 March 2025

1. Accounting policies

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

Basis of preparation
The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) (Charities SORP FRS 102), and the Companies Act 2006.

Cystic Fibrosis Trust meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Charity status
The Trust (charity registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 96. In the event of the company being wound up, each member is liable for a sum not exceeding £1.

Consolidation
The financial statements include the results and assets and liabilities of the Trust and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own statement of financial activities under section 408 of Companies Act 2006. The deficit of the parent charity was £2,629,000 (2024: deficit of £916,000).

Cystic Fibrosis Services Limited's results for the year ended 31 March 2025 are summarised in note 13. The net surplus for the year of £852,000 (2024: £899,000) will be donated in full to the parent charity after the year end.

Income
All income is recognised once the Trust has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably.

Donations and income from legacies are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable. Donations in kind are non-monetary donations received by the Trust. Income, and the corresponding cost of the donation, is recognised when the service is provided. The value of the income and expenditure is the estimated fair market value of the service provided.

Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

Interest on funds held on deposit is recognised in the statement of financial activities when receivable and the amount can be measured by the Trust. This is normally upon notification of the interest paid or payable by the bank.

Investment income is recognised on a receivable basis and the amounts can be measured reliably. Dividends are recognised once the dividend has been declared and notification has been received the dividends are due.

1. Accounting policies (continued)

Expenditure
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the Trust to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably.

Expenditure is recognised on an accruals basis as a liability is incurred and includes irrecoverable VAT where applicable.
Expenditure is classified under the following activity headings:

- Expenditure on raising funds comprises those costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs.

- Expenditure on charitable activities comprises those costs relating to activities where the primary aim is congruent with the objects of the Trust, along with an apportionment of support costs. This includes grants made to research institutions and individuals, the provision of information and support services to people with cystic fibrosis and their families, peer reviews of cystic fibrosis centres and the development of the CF Registry.

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the direct costs in each activity category.

Grants payable are included in the statement of financial activities when approved and the intended recipient has either received the funds or has been notified of the award and has satisfied any initial conditions. Grants approved but not paid at the end of the financial year are accrued.

Foreign currency transactions
Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the statement of financial activities.

Employee benefits
Employee benefits are accounted for as follows:

- Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.
- Termination payments are accounted for on an accrual basis and in line with FRS 102.
- Pension contributions: the Trust operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Trust pays fixed contributions into a separate entity. Once the contributions have been paid the Trust has no further payment obligations. The contributions are recognised as an expense in the statement of financial activities when they fall due.

Taxation
No charge to taxation arises on the result for the year because the Trust can take advantage of the tax exemptions available to charities.

Leases
The Trust recognises expenses under "operating leases" relating to capital equipment which it does not own. The annual rentals are charged to the statement of financial activities on a straight line basis over the lease term. The primary lease accounted for in the financial year is rent of office space.

1. Accounting policies (continued)

Fund accounting
Endowment Funds are funds where the donor requires the Trust to hold the funds as capital investments. Income from the investment can be used by the Trust as specified in the terms of the endowment. The Trust is not entitled to spend the capital fund without permission form the donor.

Restricted funds are to be used for specific uses laid down by the donor. Expenditure which meets the donor's criteria is charged against the specific fund.

Unrestricted funds are those which the Trust are free to use for any purpose in furtherance of the charitable objects. The Trustees may set aside some of the unrestricted reserves for specific purposes, for example to fund a future project. These funds are classified as designated funds.

Fixed assets and depreciation
All assets costing £500 or more and with an expected useful life exceeding one year are capitalised.

Tangible assets are stated in the balance sheet at cost less accumulated depreciation. Depreciation is provided at rates designed to write off the cost of the cost of the assets, less any residual value, by equal annual instalments over their estimated useful lives at the following rates:

Furniture and fittings	33%
Computer hardware	33%
Computer software	33%
Website development	33%
Platform development	50%

Website and platform development costs are capitalised on the basis that they lead to an asset that will generate funds for the Trust or where the primary aim is part of the objects of the Trust. The assets are depreciated once the asset is ready for use.

Investments
Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values of investments are shown as unrealised gains and losses in the statement of financial activities. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value.

Gains and losses on the sale of investments are shown as realised gains and losses in the statement of financial activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired during the financial year.

1. Accounting policies (continued)

Financial Instruments
The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value:

- Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

- Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

- Creditors and provisions are recognised where the Trust has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Critical accounting judgements and estimates
Preparation of the financial statements requires the Trust and management to make significant judgements and estimates. These judgements and estimates are continually evaluated and are based on historical experience and other factors, including expectations of future events.

The items in the financial statements where judgements and estimates have been made include:

- estimating entitlement to legacy income particularly in relation to complex estates
- estimating the useful economic life of tangible assets for the purposes of determining depreciation rates
- providing for bad debts
- allocation of support costs
- estimating future income and expenditure for assessing cash flows to assess whether the Trust is a going concern (see below).
- valuation of donations in kind received during the year.

The value of the contribution of the many thousands of hours donated by its unpaid volunteers as not been reflected in these financial statements. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

Going concern
The Trustees have reviewed the financial statements and supplementary financial information, including the budget for the year to March 2026 and forecasts and projections for the following three year, and conclude that the Trust will continue to operate within or above its reserves policy throughout that period and that the Trust is a going concern.

2. Income from donations and legacies

	Unrestricted Funds 2025 £'000	**Restricted Funds 2025 £'000**	**Total 2025 £'000**	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	Total 2024 £'000
Branches, Groups and Community	2,249	18	**2,267**	2,224	45	2,269
Legacies	2,093	143	**2,236**	2,745	196	2,941
Individual donations	309	37	**346**	309	40	349
Corporate	104	14	**118**	267	5	272
Regular giving and appeals	1,155	1	**1,156**	1,204	2	1,206
Trusts	31	2,351	**2,382**	187	3,093	3,280
Appeal for Innovation Hub	-	-	**-**	-	306	306
Donations in kind	1,338	-	**1,338**	1,543	-	1,543
NHS National Services England and Scotland	189	-	**189**	236	-	236
Total income from donations and legacies	**7,468**	**2,564**	**10,032**	8,715	3,687	12,402

Total income from donations and legacies includes gift aid of £463,000 (2024: £455,000).

Donations in kind refer to non-monetary donations received from partner organisations. They are recognised at the best estimate of their value as derived from the donor. In 2025 £1,338,000 (2024: £1,543,000) was recognised as income in respect of donated digital and cinema advertising space and professional fees. This was used to raise awareness of cystic fibrosis and the work of the Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, advice and support costs in note 4.

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3. Investment Income

	Unrestricted Funds 2025 £'000	Restricted Funds 2025 £'000	**Total 2025 £'000**	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	Total 2024 £'000
Income from listed investments	615	-	**615**	607	-	607
Bank interest	40	-	**40**	21	-	21
Total investment income	**655**	**-**	**655**	628	-	628

4. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2025 £'000**	Total 2024 £'000
Raising funds	-	-	2,293	552	**2,845**	2,748
Charitable activities						
Research	1,413	1,111	1,655	933	**5,112**	6,409
Clinical care	286	75	784	276	**1,421**	1,477
Information, advice and support	118	283	3,186	867	**4,454**	4,460
Total charitable activities	**1,817**	**1,469**	**5,625**	**2,076**	**10,987**	12,346
Total resources expended	**1,817**	**1,469**	**7,918**	**2,628**	**13,832**	15,094

Support costs are apportioned based on the direct costs in each activity category.

4. Expenditure (continued)

Analysis of allocated Support Costs – current year	Governance £'000	Finance £'000	IT Support £'000	People and Organisational Development £'000	Office and Facilities £'000	**Total 2025 £'000**	Total 2024 £'000
Fundraising	122	78	162	66	124	**552**	438
Research	206	132	274	111	210	**933**	972
Clinical care	61	39	81	33	62	**276**	235
Information, advice and support	191	123	254	103	196	**867**	712
Total costs	**580**	**372**	**771**	**313**	**592**	**2,628**	**2,357**

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2024 £'000**
Raising funds	-	-	2,310	438	**2,748**
Charitable activities					
Research	1,976	1,962	1,499	972	**6,409**
Clinical care	454	77	711	235	**1,477**
Information, advice and support	149	167	3,432	712	**4,460**
Total charitable activities	**2,579**	**2,206**	**5,642**	**1,919**	**12,346**
Total resources expended	**2,579**	**2,206**	**7,952**	**2,357**	**15,094**

4. Expenditure (continued)

Analysis of allocated support costs – prior year

	Governance £'000	Finance £'000	IT Support £'000	People and Organisational Development £'000	HQ & Facilities £'000	**Total 2024 £'000**
Fundraising	108	42	128	59	101	**438**
Research	240	93	285	130	224	**972**
Clinical care	58	22	69	32	54	**235**
Information, advice and support	176	68	208	96	164	**712**
Total costs	**582**	**225**	**690**	**317**	**543**	**2,357**

Net income for the year is stated after charging

	2025 £'000	2024 £'000
Auditors remuneration excluding VAT	**28**	29
Depreciation	**67**	64
Operating leases – building	**282**	269
Operating leases – other	**3**	3
Trustees' travel expenses	**5**	1

5. Grants

Grants were awarded during the year as follows:

	2025 £'000	2024 £'000
Grants to institutions	**2,885**	4,453
Grants to individuals	**401**	332
	3,286	4,785

Grants made to, and for, individuals affected by Cystic Fibrosis are for expenses such as respite care, building adaptations and equipment rental. These grants benefited a large number of individuals throughout the Trust's network of regions and branches.

During the year, grants were awarded to the following institutions:

	2025 £'000	2024 £'000
University of Cambridge	**964**	1,210
Imperial College London / Royal Brompton Hospital	**320**	1,116
University of Liverpool	**311**	182
University of Birmingham	**300**	-
Newcastle University	**275**	850
University of Manchester	**222**	-
Action Medical Research	**100**	105
Utrecht University, Netherlands	**75**	75
Medicines Discovery Catapult Limited	**42**	81
University of Northumbria	**55**	-
Innovation Hub Cambridge	**-**	100
Medical Research Council	**-**	100
Other Institutions (less than £20k)	**44**	132
	2,666	3,870

Other grants (see notes below)	2025 £'000	2024 £'000
Clinical fellowship grants		
Royal Brompton Hospital	**78**	-
Liverpool Heart and Chest Hospital	**-**	78
Trial coordinator grants to CTAP centres	**282**	436
Registry support grants to CF Centres	**324**	326
Release of grants made in previous years	**(465)**	(257)
Total grants made to institutions	**2,885**	4,453

Grants for medical research
Included in the above grants to institutions for medical research are grants to fund the Translational Innovation Hub Network which was launched in 2024 in partnership with LifeArc. The total grant programme will be £15.0m across five years. Grants made in the year to 31 March 2025 were:

	2025 £'000	2024 £'000
University of Manchester	**222**	-
Imperial College London	**302**	-
University of Cambridge	**96**	-
University of Liverpool	**307**	-
	927	-

Other grants
Trial coordinator payments: the Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme.

Registry support grants: the Trust provides grants to NHS Hospitals to support the collection of clinical data used by the Trust's Registry.

Release of grants made in previous years: Various grants totalling £465,000 (2024: £257,000) were released during the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful.

6. Staff costs

	2025 £'000	2024 £'000
Salaries	**5,287**	5,107
Social security costs	**565**	547
Other pension costs	**328**	318
	6,299	5,995

The average number of staff employed by the Trust:	2025 No.	2024 No.
Raising funds	**38**	38
Research	**24**	22
Clinical care	**10**	8
Information, advice and support	**38**	43
Support costs	**23**	23
Total average monthly headcount	**133**	134

The number of employees whose gross salary exceeded £60,000 in the year was:	2025 No.	2024 No.
£60,001 – £70,000	**7**	4
£70,001 – £80,000	**3**	3
£80,001 – £90,000	**1**	1
£130,001 – £140,000	**1**	1

Pension contributions to defined contribution pension schemes for employees noted above totalled £56,571 (2024: £44,083).

The total remuneration paid to key management personnel, including social security and employer pension contributions, was £669,676 which relates to 8 individuals who served on the Senior Leadership Team during the year (2024: £657,196 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. £4,987 of expenses were settled on behalf of 6 Trustees during the period (2024: £1,201 was paid to 5 Trustees). Trustee indemnity insurance is in place for the protection of the Trustees.

7. Tangible and intangible assets

Group and charity	Furniture and fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 1 April 2024	630	970	286	462	183	2,531
Additions	-	-	-	-	-	-
Disposals	(630)	(837)	(242)	(403)	(183)	(2,295)
At 31 March 2025	-	133	44	59	-	236
Depreciation						
At 1 April 2024	630	904	254	428	183	2,399
Charge for the year	-	33	15	20	-	68
Disposals	(630)	(837)	(242)	(403)	(183)	(2,295)
At 31 March 2025	-	100	27	45	-	172
Net book value **At 31 March 2025**	-	33	17	14	-	64
At 31 March 2024	-	66	32	34	-	132

At 31 March 2025 the Trust vacated its property at One Aldgate and moved to a new office. The disposals in the year represent fully depreciated assets that are no longer in use and were disposed of as part of the office closure.

8. Investments

Group and Charity	**Total 2025 £'000**	Total 2024 £'000
Opening market value	5,796	5,388
Additions at cost	-	255
Disposals at opening book value	-	(230)
Net gains/(losses) on investments	40	362
	5,836	5,775
Change in cash	(1)	21
Closing market value	5,835	5,796

Represented by:	**Total 2025 £'000**	Total 2024 £'000
Equities	512	587
Fixed Interest and multi-asset funds	5,030	4,909
Property	184	184
Cash	109	116
	5,835	5,796

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment.

The only asset that presents more than 5% of total investments in either financial year is the Responsible Multi-Asset Fund. The Trust's holding at 31 March 2025 was £4,924,000 (2024: £4,809,000).

The historical cost of investments held within the Trust portfolio at 31 March 2025 was £4,853,000 (2024: £4,853,000) and accumulated unrealised gains at 31 March 2025 were £1,252,000 (2024: (£1,213,000).

9. Debtors

	Group 2025 £'000	Group 2024 £'000	**Charity 2025 £'000**	Charity 2024 £'000
Trade debtors	55	35	-	-
Prepayments and accrued income	2,903	4,981	2,896	4,981
Other debtors	38	60	38	60
	2,996	5,076	2,934	5,041

10. Grants Payable

Group and charity	**2025 £'000**	2024 £'000
Opening grant creditor	**12,792**	13,263
Grants awarded during the year	**3,286**	4,785
Grants paid during the year	**(5,487)**	(5,256)
Closing grant creditor	**10,591**	12,792
Represented by		
Grants due within one year	**5,274**	6,065
Grants due after one year	**5,317**	6,727
	10,591	12,792

The Trust has considered the discounting of grant commitments due in more than one year but has not made any adjustments to the figures disclosed above as the impact of discounting is negligible.

11. Creditors

	Group 2025 £'000	Group 2024 £'000	**Charity 2025 £'000**	Charity 2024 £'000
Trade creditors	**576**	857	**572**	857
Other creditors	**43**	41	**42**	41
Other taxation and social security	**135**	147	**135**	147
Amounts owed to subsidiary undertaking	**-**	-	**790**	932
Accruals and deferred income	**1,960**	1,727	**1,955**	1,648
	2,714	2,772	**3,494**	3,625

12. Financial Instruments

	Group 2025 £'000	Group 2024 £'000	**Charity 2025 £'000**	Charity 2024 £'000
Financial assets measured at amortised cost	**14,201**	16,109	**14,224**	14,224
Financial assets measured at fair value	**5,835**	5,796	**5,835**	5,796
Financial liabilities measured at amortised cost	**(12,414)**	(15,063)	**(12,418)**	(15,142)
Net financial assets measured at amortised cost	**7,622**	6,842	**7,641**	4,878

The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Financial assets held at fair value include assets held as investments.

Financial liabilities measured at amortised cost include trade creditors, other creditors, accruals, grants payable, deferred income and amounts due to group undertakings.

13. Interest in subsidiary undertaking

Cystic Fibrosis Services Limited is a company incorporated in England and Wales (company number 00900164) and is a wholly owned subsidiary of the Cystic Fibrosis Trust.

The subsidiary's activities include studies and report services to the pharmaceutical industry and sale of charity Christmas cards and other merchandise.

Summary profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March 2025:

	Total 2025 £'000	Total 2024 £'000
Sales and sundry income	**1,257**	1,304
Cost of sales and administration	**(338)**	(339)
Intercompany recharges	**(67)**	(66)
Net contribution to parent charity	**852**	899

13. Interest in subsidary undertaking (continued)

Summary balance sheet:	**Total 2025 £'000**	Total 2024 £'000
Current assets		
Debtors	**853**	968
Cash at bank	**8**	10
	861	978
Creditors: amounts falling due within one year	**(9)**	(79)
Net assets	**852**	899
Capital and reserves		
Called up share capital (£2)	**-**	-
Profit and loss account	**852**	899
Shareholder's funds	**852**	899

The Trust owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd which comprises 100 ordinary shares of £1 each. Two shares have been allotted, which are called up and fully paid.

The subsidiary's profit for the year will be donated in full to Cystic Fibrosis Trust after the year end.

14. Lease commitments

At 31 March, the Trust's future minimum operating leases payments relating to buildings were:

	Property		**Equipment**	
	2025 £'000	2024 £'000	**2025 £'000**	2024 £'000
Within one year	**205**	271	**2**	2
Between two and five years	**409**	-	**6**	6

Operating lease expenditure in the year is disclosed in note 4.

15. Contingent assets

As at 31 March 2025, the charity had been notified of a further 13 residual and pecuniary legacies which have not been recognised as income in the Statement of Financial Activities as they do not meet the criteria detailed in the accounting policies. These legacies have an estimated value of £275,000 which has not been accrued.

16. Related party transactions

The group has taken advantage of the exception which is conferred by FRS102 Section 33.1A **Related Party Disclosures** that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

Total donation income from the trustees in the period was £30,681 (2024: £16,701). In addition, six of the trustees (2024: seven trustees) were involved in fundraising activities carried out by regional fundraising branches.

Six trustees claimed expenses totalling £4,987 in the year (2024: four trustees totalling £1,201). These expenses related to travel and subsistence.

17. Post balance sheet events

There were no post balance sheet events or contingent liabilities when the accounts were signed and authorised for issue.

18. Analysis of net assets between funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2025 £'000**
Tangible fixed assets	64	-	-	**64**
Investments	4,835	1,000	-	**5,835**
Current assets	16,682	-	456	**17,138**
Current liabilities	(7,988)	-	-	**(7,988)**
Liabilities due in more than one year	(5,317)	-	-	**(5,317)**
Provisions due in more than one year	(170)	-	-	**(170)**
	8,106	**1,000**	**456**	**9,562**

Prior year funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2024 £'000**
Tangible fixed assets	132	-	-	**132**
Investments	4,764	1,032	-	**5,796**
Current assets	20,678	-	468	**21,146**
Internal obligations	(8,837)	-	-	**(8,837)**
Current liabilities	(6,727)	-	-	**(6,727)**
Liabilities due in more than one year	(170)	-	-	**(170)**
	9,840	**1,032**	**468**	**11,340**

19. Current year fund movements summary

	Balance 31 March 2024 £'000	Investment Gains/(Losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
The funds of the charity						
Endowment funds (Note 20)	1,032	(30)	-	(2)	-	**1,000**
Restricted funds (Note 21)	468	-	2,564	(2,541)	(35)	**456**
Unrestricted funds						
Designated reserves						
Organisational reserve	1,000	-	-	(132)	-	**868**
Fixed asset reserve	132	-	-	**(68)**	-	**64**
Research funds	-	-	-	-	465	**465**
Total designated funds	**1,132**	**-**	**-**	**(200)**	**465**	**1,397**
Retained reserves	8,708	70	9,450	(11,089)	(430)	**6,709**
Total unrestricted funds	**9,840**	**70**	**9,450**	**(11,289)**	**35**	**8,106**
Total charity funds	**11,340**	**40**	**12,014**	**(13,832)**	**-**	**9,562**

Movements in funds for prior periods are presented in note 23.

The designated funds are explained on page 58.

Retained reserves are funds which can be used to fulfil any part of the Trust's objectives. The Trustees have adopted a reserves policy designed to ensure the Trust maintains sufficient funds to continue its activities, particularly in light of recent economic volatility.

The Trustees have set a minimum level of retained reserves and an upper target with the aim that unrestricted funds fall within this range. Based on the 2025/26 budget and a review of the above risk factors, the target core reserves range is between £4.0m and £6.5m.

At 31 March 2025 the Trust's retained reserves were £6.7m (2024: £8.7m) which is slightly above this core reserves range. The Trustees approved a detailed business plan with a deficit budget for the next financial year which maintains services and grant awards at a level similar to last year and which will bring the Trust's retained reserves within this core range. (Retained reserves are forecast to be £5.3m at March 2026 and reduce further to £5.0m by March 2027.)

Transfers between funds

Transfers were made between retained reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been backfilled by restricted donations.

20. Endowment funds

	Balance 31 March 2024 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
Ena Bennie Endowment	523	(16)	-	(1)	-	**506**
EW Joseph Endowment	173	(5)	-	-	-	**168**
Joseph Levy Endowment	288	(9)	-	(1)	-	**278**
Sally Wrigley Memorial Fund	20	-	-	-	-	**20**
Other Endowment funds	28	-	-	-	-	**28**
Total endowment funds	**1,032**	**(30)**	**-**	**(2)**	**-**	**1,000**

Movements in funds for prior periods are presented in note 23.

The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.

- The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.
- The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home.
- The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education.

21. Restricted funds

	Balance 31 March 2024 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
Restricted funds related to research						
Gene Therapy Research	-	-	2	(2)	-	-
General medical research	-	-	174	(174)	-	-
Sport England – Helping the active stay active	32	-	-	(32)	-	-
University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis	-	-	37	(37)	-	-
UCL Great Ormond Street Institute of children	-	-	5	(5)	-	-
The CFTR Folding and Function SRC	-	-	23	(23)	-	-
UK CF Infection Biorepository	106	-	-	(64)	-	**42**
Project Breathe	42	-	-	(42)	-	-
Maternal, Infant, Reproductive and Child Health in CF	-	-	75	(53)	-	**22**
Gut symptoms	66	-	10	(76)	-	-
Translational Innovation Hub Network	24	-	1,121	(986)	-	**159**
Quality Improvement Project	35	-	-	-	(35)	-
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	309	-	1,447	(1,494)	(35)	227

21. Restricted funds (continued)

	Balance 31 March 2024 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
Restricted funds related to Information and Support						
Joseph Levy/Education grants	3	-	140	(66)	-	**77**
Building Brighter Futures	-	-	35	(19)	-	**16**
Support services (inc. welfare grants)	57	-	77	(98)	-	**36**
Work Forwards (England)	39	-	83	(72)	-	**50**
Work Forwards (Scotland)	4	-	-	(4)	-	-
Helpline	-	-	5	(5)	-	-
Total funds related to Information and Support	103	-	340	(264)	-	179
Other funds						
Clinical Trials Accelerator Platform (CTAP)	-	-	751	(751)	-	-
CTAP Clinical Trials Conference	5	-	-	(3)	-	**2**
Carols by Candlelight	5	-	-	(3)	-	-
Improving Transparency of Processes	10	-	-	-	-	**10**
Workforce survey (Vertex Circle of Care)	-	-	14	(14)	-	-
Vertex IME study	-	-	12	(12)	-	-
Other older funds	36	-	-	-	-	**36**
Total other funds	56	-	777	(783)	-	50
Total restricted funds	468	-	2,564	(2,541)	(35)	456

Movements in funds for prior periods are presented in note 23.

Restricted funds related to research are donations relating to grant commitments made by the Trust to research institutions.

Restricted funds related to information and support are donations to fund activities supporting people with cystic fibrosis and their families. These include:

- **Joseph Levy Education grants** – funding people with cystic fibrosis in their education and studies.
- **Building Brighter Futures** – funding a youth programme supporting young people with cystic fibrosis. This fund is supported by National Lottery Community Fund.
- **Support Services** – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
- **Work Forwards (England)** – funding to support people with cystic fibrosis so that they can take advantage of opportunities, build new futures and strengthen their long-term financial resilience. This is supported by the National Lottery Community Fund.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ending 31 March 2025

22. Prior year consolidated statement of financial activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2024 £'000**
Income and endowments from:					
Donations and legacies	2	8,715	3,687	-	**12,402**
Charitable activities					
Other trading activities		1,304	-	-	**1,304**
Investments	3	628	-	-	**628**
Other income		332	-	-	**332**
Total income		**10,979**	**3,687**	**-**	**14,666**
Expenditure on:					
Raising funds	4	2,742	6	-	**2,748**
Charitable activities					
Research	4	4,401	2,008	-	**6,409**
Clinical care	4	655	822	-	**1,477**
Information, advice and support	4	4,082	378	-	**4,460**
Total charitable activities		**9,138**	**3,208**	**-**	**12,346**
Total resources expended	4	**11,880**	**3,214**	**-**	**15,094**
Net income/(expenditure) before investment gains/(losses)		**(901)**	**473**	**-**	**(428)**
Realised investment gains/(losses)		(2)	-	-	**(2)**
Unrealised investment gains/(losses)		353	-	60	**413**
Net investment gains/(losses)		**351**	**-**	**60**	**411**
Net (expenditure)/income		**(55)**	**473**	**60**	**(17)**
Transfers between funds	23	679	(679)	-	**-**
Net movement in funds		**129**	**(206)**	**60**	**(17)**
Reconciliation of funds:					
Total funds brought forward		9,711	674	972	**11,357**
Total funds carried forward	23	**9,840**	**468**	**1,032**	**11,340**

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ending 31 March 2025

23. Prior year movements in funds

Summary	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
The funds of the charity:						
Endowment funds (see below)	972	60	-	-	-	**1,032**
Restricted funds (see below)	674	-	3,687	(3,214)	(679)	**468**
Unrestricted funds:						
Designated reserves						
Organisational reserve	1,000	-	-	-	-	**1,000**
Fixed asset reserve	155	-	-	-	(23)	**132**
Appeal deficit	(1,285)	-	-	-	1,285	**-**
Total designated funds	**1,155**	**-**	**-**	**-**	**23**	**1,132**
Retained reserves	8,556	351	10,979	(11,880)	702	**8,708**
Total unrestricted funds	**9,711**	**351**	**10,979**	**(11,880)**	**679**	**9,840**
Total charity funds	**11,357**	**411**	**14,666**	**(15,094)**	**-**	**11,340**

The following transfers were made between funds in the year to 31 March 2024

- A transfer was made to the Fixed asset reserve to match the current balance on Fixed Assets
- Other transfers were made between Retained reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been backfilled by restricted donations.

Endowment funds	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Ena Bennie Endowment	491	32	-	-	-	**523**
EW Joseph Endowment	162	11	-	-	-	**173**
Joseph Levy Endowment	271	17	-	-	-	**288**
Sally Wrigley Memorial fund	20	-	-	-	-	**20**
Other endowment funds	28	-	-	-	-	**28**
Total endowment funds	**972**	**60**	**-**	**-**	**-**	**1,032**

24. Prior year movements in funds (continued)

Restricted funds

	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Restricted income funds						
Appeal: Innovation Hub at Cambridge	-	-	306	-	(306)	**-**
Restricted funds related to research:						
Genetic therapies	-	-	3	(3)	-	**-**
General medical research	-	-	260	(260)	-	**-**
Sport England – Helping the active stay active	32	-	-	-	-	**32**
University of Sheffield: Preventing Gastointestinal Cancer in CF	-	-	34	(34)	-	**-**
UCL/Great Ormond Street Institute of child health: Therapeutic gene editing	-	-	20	(20)	-	**-**
SRC Costed Extensions	-	-	379	(379)	-	**-**
University of Sheffield: Pulmonary magnetic resonance imaging for CF	366	-	7	-	(373)	**-**
UK CF Infection Biorepository	-	-	213	(107)	-	**106**
Project Breathe	-	-	1,188	(1,146)	-	**42**
Queen's university Belfast: Developing a novel gene therapy platform	-	-	15	(15)	-	**-**
Translational Innovation Hub Network	15	-	62	(38)	-	**64**
Quality Improvement Project	35	-	-	-	-	**35**
Gut Symptoms	39	-	27	-	-	**66**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**476**	**-**	**2,514**	**(2,002)**	**(679)**	**309**

24. Prior year movements in funds (continued)

	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Restricted funds related to Information and Support						
Joseph Levy/Education Grants	11	-	41	(49)	-	**3**
Building Brighter Futures	16	-	-	(16)	-	**-**
Support services (inc. welfare grants)	93	-	212	(248)	-	**57**
Work Forwards (England)	13	-	83	(57)	-	**39**
Work Forwards (Scotland)	9	-	-	(5)	-	**4**
Helpline	-	-	5	(5)	-	**-**
Helen Barrett Bright Ideas Awards	-	-	3	(3)	-	**-**
Total funds related to Information and Support	**142**	**-**	**344**	**(383)**	**-**	**103**
Other funds						
CTAP (Clinical Trials Accelerator Platform)	-	-	804	(804)	-	**-**
CTAP Clinical Trials Conference	14	-	7	(16)	-	**5**
Carols by Candlelight	6	-	3	(4)	-	**5**
Improving Transparency of Processes	-	-	15	(5)	-	**10**
Other older funds	36	-	-	-	-	**36**
Total other funds	**56**	**-**	**829**	**(829)**	**-**	**56**
Total Restricted Reserves	**674**	**-**	**3,687**	**(3,214)**	**(679)**	**468**

Structure, governance and management

Royal Patron
- HRH King Charles III, KG, KT, GCB, OM

Honorary President
- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees
- Richard Hunt CBE **(Chair)**
- Sean Collins
- Anne Byrne
- Richard Hoey
- Michelle Shore
- Joanna Barrett
- Sophie Pierce
- Sonya Trivedy
- Professor Martin Walsh
- Jane Wainwright
- Neil Priscott
- Dr Maya Desai (appointed 23 May 2024)

Engagement Committee
- Richard Hoey **(Chair)**
- Sean Collins
- Joanna Barrett
- Sophie Pierce
- Neil Priscott

Finance and Audit Committee
- Sean Collins **(Chair)**
- Anne Byrne
- David Sawer (Independent member – resigned 29 April 2025)
- Michelle Shore
- Ed Rushton (Independent member, Investment Sub-Committee)
- Nick Wood (Independent member, Investment Sub-Committee)

People Committee
- Michelle Shore **(Chair)**
- Sonya Trivedy
- Joanna Barrett
- Dr Maya Desai (appointed to the People Committee 16 September 2024)

Senior Leadership Team
- David Ramsden – Chief Executive
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising (resigned October 2024)
- Vanessa Newton – Director of Fundraising (appointed October 2024)
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research and Healthcare Data
- Alex Fowles - Director of Finance and Resources
- Dr Sarah Clarke - Associate Director, Data and Quality Improvement

Company Secretary
- Alex Fowles

Principal and Registered Office
33 Creechurch Lane
London
EC3A 5EB

020 3795 1555
enquiries@cysticfibrosis.org.uk
cysticfibrosis.org.uk

Company limited by guarantee
Company registration number:
3880213
Charity registration number:
England & Wales — 1079049
Scotland — SC040196

Auditors
Buzzacott Audit LLP
130 Wood St
London
EC2V 6DL

Bankers
National Westminster Bank plc
15 Bishopsgate
London
EC2N 3NW

Investment Managers
Cazenove Capital Management
12 Moorgate
London
EC2R 6DA

Legal structure

Cystic Fibrosis Trust ('the Trust') is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1999 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

> **The Board of Trustees ('the Board') has full legal responsibility for corporate governance and all operations of the Trust, including determining its strategic direction.**

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 12 Trustees with a range of skills. Several committees such as the Finance and Audit Committee, People Committee, Engagement Committee, Research Grant Review Committee and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Recruitment, induction and training of Trustees

Trustees consider the relevant skill set required to enable effective oversight and proper governance of the Trust. New Trustees are appointed after a rigorous recruitment process, which includes national advertising and can include recommendations.

Upon appointment to the Board, to help facilitate their understanding of the current issues concerning the Trust, each new Trustee is provided with information tailored to reflect any specific areas of responsibility. The new Trustee will meet with the Chair, Chief Executive Officer and staff working within their own specialist area.

Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Trust to the Chief Executive Officer, David Ramsden, and his Senior Leadership Team (SLT).

The Chief Executive Officer and the SLT report to the Board both formally at the Board meetings and informally (as appropriate) throughout the year, thereby ensuring a regular flow of information to aid decision making.

The remuneration of key management personnel is determined by a recognised job evaluation framework which takes into account the skills required and the complexity of individual roles. The remuneration of the Chief Executive Officer is approved by the Board. For all other staff the process, including the award of annual pay uplift, is approved by the People Committee.

Public benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. In reviewing our aims, objectives and planning future activities, the Trustees have taken into account the Charity Commission's general guidance on public benefit. The Trustees ensure that activities undertaken are always in line with the charitable objectives and aims of Cystic Fibrosis Trust.

Open Strategic Research Centres (SRC) and Development Awards (DA) Awards – April 2025

SRC/DA Award	Lead applicant and host institution	Research goal	Title	Cystic Fibrosis Trust commitment
SRC012*	Dr Daniel Peckham, St James' Hospital	Symptoms throughout the body	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC014*	Professor Jane Davies, Imperial College London	Diagnosis and treatment of lung infections	Personalised Approach to *Pseudomonas Aeruginosa* (PAPA)	£750,000
SRC015*	Dr Darius Armstrong-James, Imperial College London	Diagnosis and treatment of lung infections	TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis	£750,000
SRC016*	Professor Pietro Cicuta, University of Cambridge	Effective treatments for all	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC018	Professor Steven Renshaw, University of Sheffield	Living longer healthier lives	Preventing gastrointestinal cancer in cystic fibrosis	£749,214
SRC019	Professor James Shaw, University of Newcastle	Symptoms throughout the body	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes	£750,000
SRC020	Professor Stephen Hart, University College London	Effective treatments for all	Therapeutic gene editing of CFTR. Co-funded with CFF	£375,000 (Total award; £749,924)
SRC021	Professor David Sheppard, University of Bristol	Effective treatments for all	The CFTR Folding and Function SRC	£747,972
SRC022	Professor Jo Fothergill, University of Liverpool	Diagnosis and treatment of lung infections	An evidence-based preclinical framework for the development of antimicrobial therapeutics in cystic fibrosis (PIPE-CF). Co-funded with CFF	£374,689 (Total award: £749,373)
SRC023	Professor Alan Smyth, University of Nottingham / Queens University Belfast	Symptoms throughout the body	Gut Research Advancing a Mechanistic and Personalised Understanding of Symptoms in cystic fibrosis: A strategic research centre: The GRAMPUS-CF SRC	£749,592
SRC024	Dr Paola Vergani, University College London	Effective treatments for all	Restoring the fizz: Pharmacological repair of bicarbonate transport in cystic fibrosis. Co-funded with CFF	£374,987 (Total award: £749,973)
SRC025	Professor Jim Wild, University of Sheffield	Diagnosis and treatment of lung infections	Pulmonary magnetic resonance imaging for cystic fibrosis. Co-funded with CFF	£366,536 (Total award: £733,072)
SRC026	Dr Mike Gray, University of Newcastle	Effective treatments for all	PTSuppress – Novel lead compounds as potential suppressor drugs for CFTR PTC mutations	£799,808

*** Grant issued extension due to COVID-19 related delays**

Open Strategic Research Centres (SRC) and Development Awards (DA) Awards – April 2025

SRC/DA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment
SRC027	Dr Imogen Felton and Professor Jane Davies, Royal Brompton Hospital	Living longer healthier lives	MATRIARCH_CF – MATeRnal, InfAnt, Reproductive and Child Health in CF	£799,089
SRC028	Professor Andres Floto, University of Cambridge	Diagnosis and treatment of lung infections	Developing better treatments for *Mycobacterium abscessus*	£800,002
DA001	Professor Nicholas Simmonds, Royal Brompton Hospital	Effective treatments for all	ADVANCE-CFTR: Advanced Diagnostic Validation and Novel Clinical Evaluation across the CFTR spectrum	£299,536
DA002	Dr Freddy Frost, University of Liverpool	Living longer healthier lives	ITCH-CF: Investigating The Cardiovascular Health of people living with cystic fibrosis	£173,487
DA003	Dr Ildem Akerman University of Birmingham	Symptoms throughout the body	Developing autologous stem cell-derived therapies for cystic fibrosis diabetes	£300,000
DA004	Dr Mike Gray, Newcastle University	Effective treatments for all	Novel role for succinate chemosensing in the pathogenesis of CF airway disease	£275,265

Open Venture Innovation Awards (VIAs) – April 2025

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA036	Dr Fred Piehl, Imperial College London	Diagnosis and treatment of lung infections	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data	£42,500	£42,500 Imperial College London
VIA062	Prof Miguel Camara, University of Nottingham	Diagnosis and treatment of lung infections	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000	£50,000 University of Nottingham
VIA098	Dr Jonathan Cox, Aston University	Diagnosis and treatment of lung infections	Discovery of new and repurposed ß-lactamase inhibitors for improving *Mycobacterium abscessus* treatment	£25,000	£25,000 ANTRUK (Antibiotic Resistance UK)
VIA105	Professor Alan Smyth, University of Nottingham	Living longer healthier lives	Core Outcome Set Taskforce for Cystic Fibrosis (COST-CF): a patient-initiated core outcome set for CF	£93,089	£105,652 NIHR Biomedical Research Centre and Programme Development Grant
VIA107	Dr Rian Griffiths, University of Nottingham	Diagnosis and treatment of lung infections	Development of a rapid and highly sensitive analytical method for the detection of biomarkers of infection in samples from people with CF	£37,726	£886,437 BBSRC

Open Venture Innovation Awards (VIAs) – April 2025

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA115	Dr Freddy Frost, University of Liverpool	Diagnosis and treatment of lung infections	Postal Sputum Testing for Early Detection of *Pseudomonas aeruginosa* in CF: POSTED-CF	£17,215	£97,570 Asthma & Lung UK
VIA116	Professor Jane Davies, Imperial College London	Diagnosis and treatment of lung infections	Repurposing the multiple sclerosis drug, Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections	£99,999	£2,500,000 LifeArc Collaborative Discovery Programme call
VIA117	Professor Janis Shute, Ockham Biotech Ltd	Diagnosis and treatment of lung infections	Investigating anti-pseudomonal effects of roneparstat, a non-anticoagulant derivative of heparin with multiple anti-microbial, anti-inflammatory and mucolytic activities	£50,000	£2,500,000 LifeArc Collaborative Discovery Programme call
VIA118	Dr Paul McNally, Our Lady's Children's Hospital	Living longer healthier lives	ENHANCE – Establishing Natural History in an Advanced New CF Care Era	£96,424	£4,800,000 CFF
VIA119	Dr Mina King, University College London	Diagnosis and treatment of lung infections	Understanding Regional Lung Physiology in Cystic Fibrosis Using Advanced MRI	£49,994	£1,800,000 MRC Career Development Award
VIA121	Professor Ruth Keogh and Dr Emily Granger, London School of Hygiene and Tropical Medicine	Diagnosis and treatment of lung infections	Target trial emulation in cystic fibrosis: optimising methods for evaluating long term antibiotic treatment using registry data	£18,077	£150,000 – pending peer review NIHR Research for Patient Benefit
VIA123	Professor Ineke Braakman, Utrecht University, Netherlands	Effective treatments for all	Understanding hypo- and hyper-responding phenotypes of CFTR mutants for therapeutic use	£75,000	£64,000 Nederlandse Cystic Fibrosis Stichting (NCFS)
VIA124	Gerry McCauley, OmniSpirant Limited	Effective treatments for all	Cell engineering optimisation and electrophysiology assessment of OS001 CFTR Extracellular Vesicles (EVs)	£21,242	£22,360 OmniSpirant Limited
VIA126	Professor Laura Ashley, Leeds Beckett University	Living longer healthier lives	Cancer risk, screening, and surveillance for people with cystic fibrosis: a national co-designed survey of awareness, perceptions, and behaviours, and information and support needs	£20,920	£56,609.17 Leeds Beckett University
VIA127	Dr Malcolm Brodlie, Newcastle University	Diagnosis and treatment of lung infections	Tracking the mucosal immune response to viral respiratory tract infection in children with cystic fibrosis	£50,000	£160,000 Vertex Innovation Award

Open Venture Innovation Awards (VIAs) – April 2025

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA128	Professor Martin Welch, University of Cambridge	Diagnosis and treatment of lung infections	Investigating the impact of pathoadaptive mutations on the fitness of *Pseudomonas aeruginosa* in a polymicrobial airway environment.	£64,500	£90,000 BBSRC
VIA129	Professor Chris van der Gast	Symptoms throughout the body	Impact of respiratory infection antibiotics upon the gut microbiomes of children with CF	£55,226.00	£55,226.00 Northumbria University
VIA130	Dr Ewart Kuijk	Effective treatments for all	AIR max: 3D AIRway organoids to define and MAXimize the efficacy of CFTR gene therapy	£75,000	£150,000 Nederlandse Cystic Fibrosis Stichting (NCFS)
VIA131	CEO Lindsay Easton – Bowel research UK	Living longer healthier lives	Optimising bowel cancer screening and surveillance for people with cystic fibrosis: a qualitative study to identify and understand clinician and patient challenges and needs and ways to address these	£24,966.34	£49,932.68 Bowel Research UK
VIA132	Action Medical Research – Guy Moss	Effective treatments for all	New therapeutic approaches for treating cystic fibrosis	£99,999	£100,000 Action Medical Research
VIA133	Prof Camilla Godlee, University of Cambridge	Diagnosis and treatment of lung infections	Characterising the host-pathogen interactions required for intracellular *Pseudomonas aeruginosa* infection of people with cystic fibrosis	£59,000	£134,000 BBSRC

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

Registered office: 33 Creechruch Lane, London EC3A 5EB.

Uniting for a life *unlimited*