Cystic Fibrosis Trust

Unstoppable together

Annual Report and Financial Statements
for the year ended 31 March 2024

Uniting for a life *unlimited*

Contents

We won't stop until CF does.

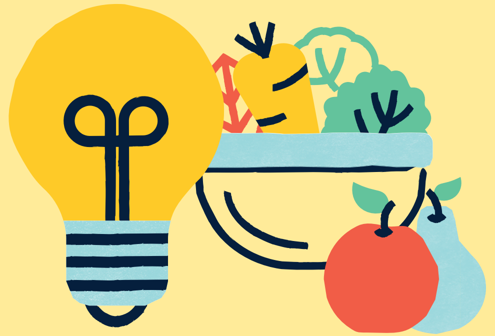
Thanks to you, in 2023/24...

Over 2,000 people with CF enrolled on to a CTAP clinical trial, helping to develop new treatments for everyone with CF.

Two new Strategic Research Centres (SRCs) and two new grants in a newly created Development Award (DA) scheme launched to address top research priorities.

We helped people with CF to access over £1.9million 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 continued our time-limited cost of living fund, providing 324 grants over the winter period to support those on low incomes to afford food and essentials.

Our #CFTruths campaign continues to raise awareness with a reach of over 18 million through media and OOH advertising. We won bronze in the people's choice awards in the 2024 Smiley Charity Film Awards 2024!

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2024. 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 66 to 107 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 2023/24 Annual Report 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 our successes possible.

The report documents a year of intense activity, during which we were committed to uniting with all of our partners to achieve our vision of a life unlimited by cystic fibrosis.

As in recent years we have continued to fund innovative research. Two new Strategic Research Centres were established as well as our first two commitments under our new Development Award scheme, all informed by the research priorities set by the CF community.

A key focus over the year has been supporting the NICE appraisal process for the modulator treatments now available and we were delighted to receive the news, shortly after the year end, that they had been formally approved for long-term use on the NHS. This was a very significant moment. However, we also never forget that these medicines are not a cure and are not a treatment available for everyone with CF.

Wider access to highly effective treatments has meant an increased focus on the opportunities as well as challenges of growing older with CF. For example it has been great to see our Work Forwards programme supporting people into employment develop significantly and it has now worked with 59 people in the CF community. We have also increased our focus on the wider health consequences of longer lives and the risks that may arise from other conditions.

> **"Our 'Your Life and CF' report has provided vital information about the reality of living with CF in 2024 and it informed our advocacy efforts to ensure that people with CF get as much of the help and support that they need."**

Richard Hunt CBE

It is not just about the future, as we are also committed to helping with the challenges of the present. Our 'Your Life and CF' report has provided vital information about the reality of living with CF in 2024 and it informed our advocacy efforts to ensure that people with CF get as much of the help and support that they need.

The latter part of the year has also seen rising concern about the availability of the vital CF medicine, Creon. We have devoted considerable effort to providing information and advocacy to do all we can to address this important issue. This effort continues.

We have continued our efforts to raise wider public awareness of CF with press and wider media coverage. This is also the third year of our #CFTruths campaign as well as the second series of the CForYourself podcast.

The year has also seen the most in-person and hybrid events since before the pandemic. We held a very successful UKCF Conference in October, a Clinical Trials event in March and our first ever multi-disciplinary team share and learn day.

We have provided 1,242 welfare grants and helped to secure almost £2million in benefits income for c.300 people we supported.

Our Helpline remained a vital link and resource for the CF community responding to c.4,500 enquiries over the 12 months. In addition, our UKCF Registry is a world-leading source of health information and it passed a significant milestone, with its 500th data request in March.

It has been another year of progress and I would like to thank my fellow Trustees for their time and commitment and the whole Trust for all of the effort they have put in.

Finally, this year we mark 60 years since the formation of the Trust in February 1964. We know a great deal has been achieved, but we know there is also much more to do. We won't stop doing all we can to support people with CF and we know our inspirational community will be with us on every step of this challenge.

Thank you.

Richard Hunt CBE
Chairman of Trustees

Uniting for a life *unlimited*

Objectives and activities

Our vision is to deliver a life unlimited for people with cystic fibrosis, and our objectives, as stated in the 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. Over 11,000 people in the UK live with the condition, having to undergo a brutal daily regimen of physiotherapy and take more than 30 tablets a day just to stay healthy. Despite these treatments, many people with CF will go on to require a double lung transplant. The median age of death for someone with CF in 2022 was 33.

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 for 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.

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 equality, diversity and inclusion strategy.**

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.

Uniting in research

Over the past year, our research has reflected the refreshed research priorities of the CF community. At the beginning of 2023, our research funding call highlighted the need to address these research priorities. Four new research awards as a result of this call were approved in March 2024, each addressing a top research priority. These included two new Strategic Research Centres (SRCs) and two new grants in a newly created Development Award (DA) scheme.

Addressing the CF community's top research priority

An SRC titled 'Novel lead compounds as potential suppressor drugs for CFTR Premature Termination Codon (PTC) mutations' will be led by Dr Mike Gray at the University of Newcastle – with an international collaboration of researchers based in Portugal, the Netherlands and Italy. The team will focus on designing compounds that could be CF medicines of the future for those with rare, 'Class 1' CFTR mutations who are not able to benefit from CFTR modulator medicines. This research addresses the CF community's top research priority.

The effects of modulators on areas of the body outside of the lungs

Another top 10 CF research priority was to understand more about the effects of modulators on areas of the body outside of the lungs. The second SRC awarded this year, 'MATeRnal, InfAnt, Reproductive & Child Health in CF (MATRIARCH)', will address one aspect of this.

The research programme will examine the impact of pregnancy, childbirth, and breastfeeding for those with CF. Access to modulators has increased the number of people with CF having children, but currently little is known about the impact of these medicines during pregnancy and breastfeeding.

The SRC will also examine important reproductive health decision-making for women and girls with CF throughout their lives. This SRC will be led by Dr Imogen Felton and Professor Jane Davies of Royal Brompton Hospital, part of Guy's and St Thomas's NHS Foundation Trust, and Imperial College in London.

Our new Development Awards scheme

The aim of our new Development Awards (DA) scheme is to allow researchers to undertake preparatory work prior to developing future applications for further funding. The preparatory work might include generating preliminary data, strengthening collaborations and developing new partnerships.

The 'Advanced Diagnostic Validation and Novel Clinical Evaluation across the CFTR spectrum (ADVANCE-CFTR)' Development Award will investigate alternative ways of diagnosing people with cystic fibrosis who have rarer mutations. This research may also be able to predict whether modulator medicines could work for rare CF mutations. This DA will be led by Professor Nick Simmonds of Royal Brompton Hospital, and Imperial College London.

Zoë Elliot, mum to twins with CF

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

Growing older with CF

We know that there are few ongoing research studies addressing the research priority, 'How do we manage an ageing population with cystic fibrosis?' As a first step to address this, we held a one-day, in-person workshop in December 2023 with the aim of building networks in this area and to understand more about some of the topics and challenges involved. 51 people attended the workshop, including researchers, clinicians, healthcare professionals, representatives from the CF community and funder representatives. Our 'Growing older with CF' report explores the discussions at the workshop.

The 'Investigating the Cardiovascular Health of people living with cystic fibrosis (ITCH-CF)' DA will be led by Dr Freddy Frost from Liverpool Heart and Chest Hospital, and will focus on one of the topics discussed at the growing older with CF workshop. Focusing on understanding more about the risk of developing heart disease for people with CF, one study will look at whether full-body imaging scans could be used to assess future risk of heart disease. Another study within the project will examine existing health records for statistical information about heart disease risk.

> "We hope the workshop and our report will generate new networks with ideas and opportunities for research proposals to address this priority."
>
> Dr Lucy Allen


Cystic Fibrosis Trust

Since 1964 | We won't stop until CF does

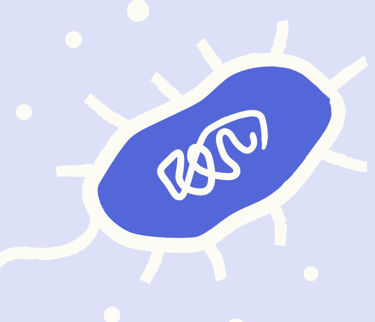
Growing older with CF report – February 2024

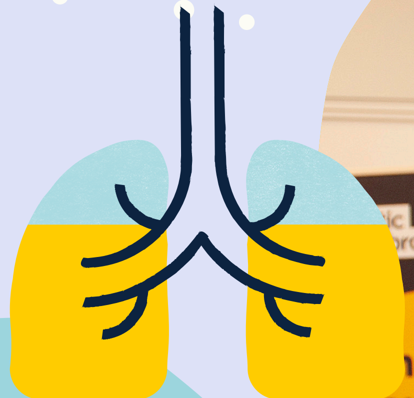
Publication date
February 2024

Uniting for a life unlimited

What is the best way to diagnose lung infections when there is no sputum?

The second highest research priority for the CF community was 'What is the best way to diagnose lung infections when there is no sputum?'. It is a topic that the CF AMR Syndicate have recently been focusing on. The Syndicate is a partnership between Cystic Fibrosis Trust, Medicines Catapult and LifeArc which aims to accelerate the translation of CF antimicrobials and diagnostics to the clinic to bring new and effective treatment options to people with CF. This year saw the publication of the Syndicate's patient-centred Target Product Profiles (TPPs) on diagnostic tests for CF lung infections. This will be used to support and advance diagnostic research and development, focusing efforts where they are needed the most. Discussions are underway on how the Syndicate will use these TPPs to bring better diagnostics for CF infections to the clinic.





> "Being invited to contribute to the development of the TPPs has provided much-needed reassurance that the demand for new or improved antibiotics for people with CF is still recognised as a critical requirement."
>
> Simon, who has CF

Dr Lucy Allen speaking at the 2023 UKCFC

> "It was inspiring to see the passion in the room, and the depth and breadth of ongoing research which will help improve the lives of people with CF."
>
> David Ramsden

UK CF Conference

At our UK CF Conference in October 2023, we were delighted that Professor Jane Davies agreed to give a plenary presentation on 'Re-learning CF', informed from members of the Trust's involvement group. The event was an opportunity to explore and showcase the Trust's research portfolio and was attended by 146 people in London, with a further 73 people joining online.

Included within the programme was a celebration of the CF Innovation Hub on lung health partnership at the University of Cambridge and our developing relationship with LifeArc, as well as the CF AMR Syndicate partnership. Trust-funded early career researchers gave fun and high energy elevator-pitch style presentations throughout the day. With support from CF community mentors, four early career researchers presented their research to the CF community in an online event a few weeks after the conference.

More people with CF taking part in research

The UK CF Clinical Trials Accelerator Platform (CTAP) is part of a highly successful global trials network. In the UK, we have established a robust clinical research infrastructure designed to support and deliver a diverse portfolio of CF studies with speed and efficiency. The majority of CF care centres in the UK are either an active member of CTAP or have pathways in place to refer patients to CTAP centres for study participation.

The CTAP network of 25 centres from across the UK is led by research-focused clinicians and trial coordinators with a range of experience, knowledge and skills in CF care and running clinical trials. **Collectively, the network covers ~90% of the UK CF community.**

Early phase clinical trial programme

The CTAP early phase trials programme funds six CTAP centres with a highly skilled early phase trial coordinator to oversee the set-up and delivery of early phase trials, which are often more resource intensive and time consuming than later phase trials. The early phase trial portfolio in the UK is steadily growing. The first early phase trial supported by funded early phase CTAP centres opened late in 2023, with two more opening later in 2024. This will create exciting opportunities for the UK and the CF community to support new and emerging CF therapies, such as genetic therapies, currently being developed and researched.

> **"I try to be a participant in as many trials as I can. The feeling of helping others with CF by putting myself forward for research makes me feel closer to our community, even if we cannot meet each other in person."**
>
> Sarah, who has CF

Since CTAP's official launch in September 2017...

- **over 4,000** babies, children and adults have enrolled on to a CTAP study
- **over 70** CF studies have been supported by CTAP so far
- study set-up times have **decreased by 73%** across the CTAP network
- more than three quarters of studies have exceeded **90% of their recruitment target**
- the average **retention rate** for CTAP studies is **98%**.

Sarah

> **"It's such a joy to speak with people with CF outside the normal clinical environment where there is actually the time to really get a handle on what research means to them and listen to their valuable lived experience."**
>
> Emma, Clinical researcher

Involving the CF community in shaping our research

Our community involvement group is made up of **almost 300 people with CF** and parents of children with CF. It gives people the chance to directly engage with sponsors to give meaningful feedback about trial design, from the conceptual stage onwards. This helps make future CF trials more patient-centred and less burdensome, with the aim of improved trial recruitment and retention rates.

Over the last year there have been a total of 24 research-related involvement activities, including 14 focus groups, covering everything from new diagnostics for lung infections to looking at the mental health effects of Kaftrio.

Delivering the UK CF Clinical Trials Conference

The sixth annual UK Cystic Fibrosis Clinical Trials Conference took place in Leeds in March 2024. It was an opportunity to bring together people working across CF research to talk about what's next in clinical trials. This year's event was titled 'Addressing research priorities through clinical research – the when and how'. With Cystic Fibrosis Trust celebrating its 60th anniversary this year, the conference was also an opportunity to look back on the past 60 years in clinical trials.

> **"When we meet next year, let's hope all of us have moved forward in this field and brought more answers to the CF community."**
>
> Dr Tim Lee

Dr Tim Lee

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 representatives from the specialist disciplines providing CF care and treatment, provides expert input into the Trust's information resources and clinical programmes. The Chair of CAG oversees the successful Clinical Fellowship scheme, which has run for a number of years. The scheme provides a unique opportunity for a fellow to start a career in CF, and has seen multiple candidates become prominent members of the CF clinical landscape.

The Trust sponsors and provides secretariat duties for the UK Cystic Fibrosis Medical Association, a group open to all doctors who deliver clinical care to people with cystic fibrosis in the UK.

The Trust's clinical guidelines continue to promote best practice in CF care provision. In 2023/24 work continued on several guidelines, including:

- the overarching standards of care
- psychological guidelines
- antibiotic treatment
- infection control.

We work directly with clinical teams to review and improve quality of care at a local level. We continue to influence NHS clinical policy; for example we provided providing input on the CF toolkit developed by NHS England.

Improving quality of care in CF

In September 2023, we published the latest findings from our patient experience survey in children's CF services. With over **800 responses from children with CF and their families**, the findings show that CF care is generally rated highly by those who receive it. However, the survey also reveals persistent gaps in access to specialist pharmacists, social workers and psychologists within paediatric CF teams. We are working to understand how this could be improved in future.

In November 2023, we initiated the second cycle of our patient experience survey in adult care, collecting new insights that will be reported later in 2024. We continue to monitor staffing levels in CF services using our staffing tool, creating bespoke staffing summaries for participating CF centres, and publishing an updated report on UK CF service resourcing in March 2024.

This year,we engaged over 150 CF professionals in our virtual, peer-led QI Share and Learn events, and ran bespoke quality improvement sessions with several paediatric CF teams to help them plan and deliver improvement projects.

Panel attendees at the new MDT Share and Learn conference

Collaborating for better care conference

In March 2024, the Trust hosted a new conference for CF professionals, covering hot topics in CF such as patient-centered care, the impact of neurodiversity in CF, and adherence to treatment. The event provided opportunities for clinicians to network and collaborate, with many reflecting on how the event supported them to improve their own practice. **100% of those who completed our post event evaluation told us that the event met their expectations.**

Supporting the CF community through issues that affect them

Creon

We've been monitoring issues with Creon supplies across the UK since late 2023 and have seen worrying fluctuations in the availability through early 2024. Many hospital and community pharmacies have struggled to maintain their usual supply, leading to increased demand for alternatives like Nutrizym and Pancrex. These supply issues prompted the Department of Health and Social Care to implement a Medicines Supply Notification specifying that access should be prioritised for those who need Creon the most, including people with CF.

The Trust and CF clinicians, dietitians and pharmacists have been working hard to ensure that the impact of shortages of Creon on the health and wellbeing of people with CF is minimised.

We're meeting regularly with Viatris and the NHS to ensure that all possible measures are being taken to resolve these issues. We've written to the Secretary of State for Health, calling for better communication to the community about what is happening, as well as long-term solutions, including research into alternative enzyme sources and new product development to reduce dependency on current raw materials.

We continue to keep our community informed through a dedicated hub on our website, blogs, videos, emails, social media, wider media and through our Helpline.

Our social media posts regarding the Creon shortages had a combined reach of 117,550 across Facebook and Instagram.

> "I would not be where I am today without the Trust. The grants that were offered to us during our crisis period and after moving to our new home has been lifesaving."
>
> Rita*

Carlie, who features in *Rita's story*

Cost of living crisis

Although inflation has slowed in the UK, costs remain high, and the ever-present additional costs of living with cystic fibrosis means day-to-day living continues to present difficult financial choices. **84% of respondents from our 2024 'Your Life and CF' survey told us they were worried about the cost of living, with 1 in 5 going without food.**

In the past year, we've seen more people turning to us for assistance in bridging financial gaps caused by circumstances beyond their control. And we're seeing more complex issues, including family breakdown, domestic abuse, and concerns for the welfare of children, as the financial strain on households has continued to bite. These financial, social and emotional obstacles impact mental and physical health for people with cystic fibrosis and those who care for them, making it more difficult to maintain good health and manage the challenges that CF presents.

We continue to offer financial support through our grants, and information and support through a dedicated hub on our website, supporting content, and our Helpline, all aimed at helping those with CF safeguard their health.

In October 2023, we released ***Rita's story***, told by Carlie who has CF, which demonstrates the complex and challenging situations people affected by CF can be put in, as highlighted in our ***Support in crisis: the unseen costs of cystic fibrosis report***.

NICE appraisal

In 2020, landmark interim deals for access to life-saving modulator treatments Orkambi, Symkevi and Kaftrio were reached between the NHS in England, Wales, Scotland and Northern Ireland and the pharmaceutical company Vertex. As part of these agreements, the UK Cystic Fibrosis Registry, in partnership with NHS England, NICE and Vertex collected real-world evidence, looking at the effectiveness of the therapies ahead of a formal appraisal from the National Institute of Clinical Excellence (NICE).

In 2022, the formal NICE appraisal began, with the Trust engaging proactively at all stages and keeping the CF community updated and supported through a variety of channels. In May 2023, **over 1,100 people from the CF community shared their views to inform our evidence submission to NICE**, ensuring the voices of the CF community were heard.

In November 2023, NICE's draft guidance said that while Orkambi, Symkevi and Kaftrio were clinically effective treatments, they were too expensive at the current price for them to be able to recommend them for use on the NHS. This was a distressing and challenging time for the community, with the Trust providing essential information and support.

We were pleased that NICE, Vertex and the NHS confirmed unequivocally that access would be protected for those already on treatment, and that people could continue to start taking the medicines while the process was ongoing. In January 2024, NICE announced a pause to allow for commercial negotiations between Vertex and the NHS to take place.

Following sustained action from the whole CF community over months and years, we were delighted that in June 2024, NICE finally gave approval for modulator drugs to be made available on the NHS in England, following a deal between NHS England in Vertex. Similar deals have followed between NHS Wales, NHS Northern Ireland, and NHS Scotland.

We know that not everyone can benefit from Orkambi, Symkevi and Kaftrio, which is why we continue to invest in cutting-edge CF research for effective treatments for all. We won't stop until everyone with CF can live a life unlimited.

Our social media posts regarding the NICE appraisal had a combined reach of 327,440 across Facebook and Instagram.

> "When we found out initially that these drugs weren't available in Northern Ireland it was like someone dangling a carrot in front of you and then taking it away. It was like a kick in the stomach for us, as parents, and that's why I campaigned for it. It is just so reassuring that Robyn can now access this – it's life changing."
>
> Laya, mum to Robyn who has CF

Laya and Robyn

> "Those living with CF, or caring for those that do, know the condition better than anyone. Involvement provides an opportunity for people to use that experience to help shape the development, delivery and communication of research for the benefit of the wider CF community. Being part of the involvement group gives you a real insight as to the sorts of research projects taking place and provides lots of different ways to get involved. It's also really nice to be able to connect with other members of the community and share experiences."
>
> Dan, who is part of our involvement group

From 1 April 2023 to 31 March 2024, cystic fibrosis was mentioned in parliaments across the UK 127 times.

Making sure our community is heard

Our community involvement group has grown to over **300 members**, consisting of people living with CF of all ages, parents of children with CF and other family members and loved ones, offering diversity of social profiling as well as CF profiling. On average, we induct 3 new registrations per month, ensuring perspectives are truly representative.

Due to the rapid changes being experienced in the clinical care and presentation of CF, recognition of the value and power of the patient voice has grown demand for activity as we prioritise the needs and requirements of the community we represent. The continuous engagement of the involvement group members enables us to meet this demand, reacting in timely manner to a diverse portfolio of activity.

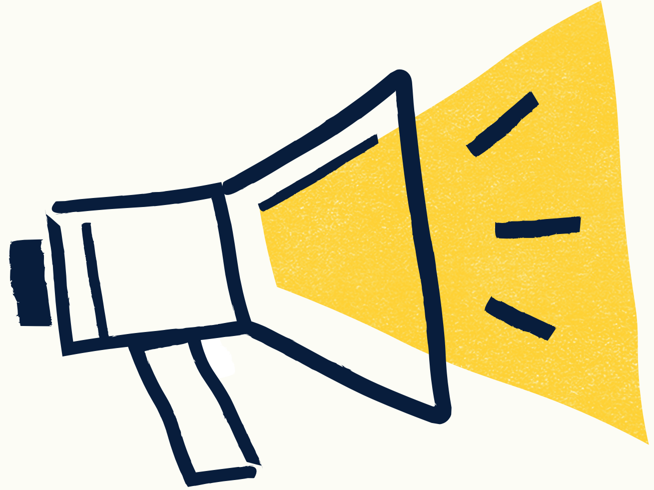
However, the true power and reach of collective community insights and themes lies in proactively encouraging investment in CF, both in financial and career terms, securing the both the future of CF research and clinical provision. Community involvement has ensured the success of applications to national funding streams, provided income generation opportunities and the power to leverage industry investment.

Campaigning hard

Prescription charges remains high on the agenda for people with cystic fibrosis in England, with the Trust working to influence parliamentarians through a number of debates and parliamentary questions. We have made sure the voices of people with cystic fibrosis are heard, with a leading role in the Prescription Charges Coalition. We have also written to key ministers and gained media traction for a review of the exemption list.

Underpinning the Trust's key campaign asks has been the annual ***Your Life and CF*** survey, now informed directly **by over 10% of the CF community**, which has included policy recommendations on the cost of living, Statutory Sick Pay (SSP), and air quality.

As we navigate the post-election landscape, our advocacy priorities remain firmly grounded in the needs of the CF community. The general election ushers in a period of significant change, presenting both opportunities and challenges. Building robust relationships with newly elected MPs is essential so that we are able to effectively champion the needs of the CF community, and make sure that our voices are heard in the new Parliament.



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

> "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

The UK CF Registry

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

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

In 2023/24 we have:

- concluded three drug safety studies, generating total income of over **£1.7 million**
- received up to **£160,000** from NHS contracts for generating public reports and supporting the commissioning of CF services in England
- submitted anonymised 2022 data to the European CF Society Patient Registry (ECFSPR)
- **received 51 data requests:**
  - **7** requests from ECFS Patient Registry requesting UK data
  - **7** requests withdrawn prior to review by Committee
  - **37** requests were submitted to the Registry Research Committee for review; **31** were approved and **6** were declined.

We're seeing a steady increase in the number and complexity of data requests received, reflective of the increasing richness of the Registry data. In March 2024, we received our 500th data request.

> "The UK CF Registry is the envy of many disease conditions, and I believe it has been really important in helping to drive forward research and quality of care in the field of CF. We are grateful that over 99% of people with CF in the UK contribute to this powerful data resource which researchers from across the globe can apply to use in an anonymous or pseudonymous format."
>
> Dr Jamie Duckers

Dr Jamie Duckers

Data Validation Programme

- From September to December 2023, CF centres with more than 55 patients participated in a virtual data validation visit to check the accuracy and validity of data submitted to the Registry.
- The Data Validation Programme (DVP) has confirmed a high level of data accuracy and completeness of UKCFR data; the process has provided further evidence that the Registry is fit for purpose for use in research, pharmacovigilance studies, and ongoing NHS commissioning requirements.
- The UK CF Registry DVP has been adopted as a model of best practice by other CF Registries in Europe. For the 2022 data, a report has been sent to the ECFSPR to be added to their European Data Validation Report.

Annual Registry report

The UK CF Registry report 2022 was published in October 2023. We reported that 7,950 people were taking a CFTR modulator by December 2022. As we continue to gather data on the use of CFTR modulators, a clearer picture of the health impact of the modulators will be formed.

An accessible highlights summary was also published, helping people with CF and their families to understand the data contained in the report. Both reports can be found on our website at **cysticfibrosis.org.uk/registry**

Annual Registry meeting

In October 2023, we held our Registry annual meeting in Birmingham. Around 60 Registry users from CF centres across the UK attended to hear from the team and clinical colleagues about the latest Registry updates, projects, and current research, as well as contributing to workshops looking to the future of the Registry.

Uniting for the CF community

Day-to-day support

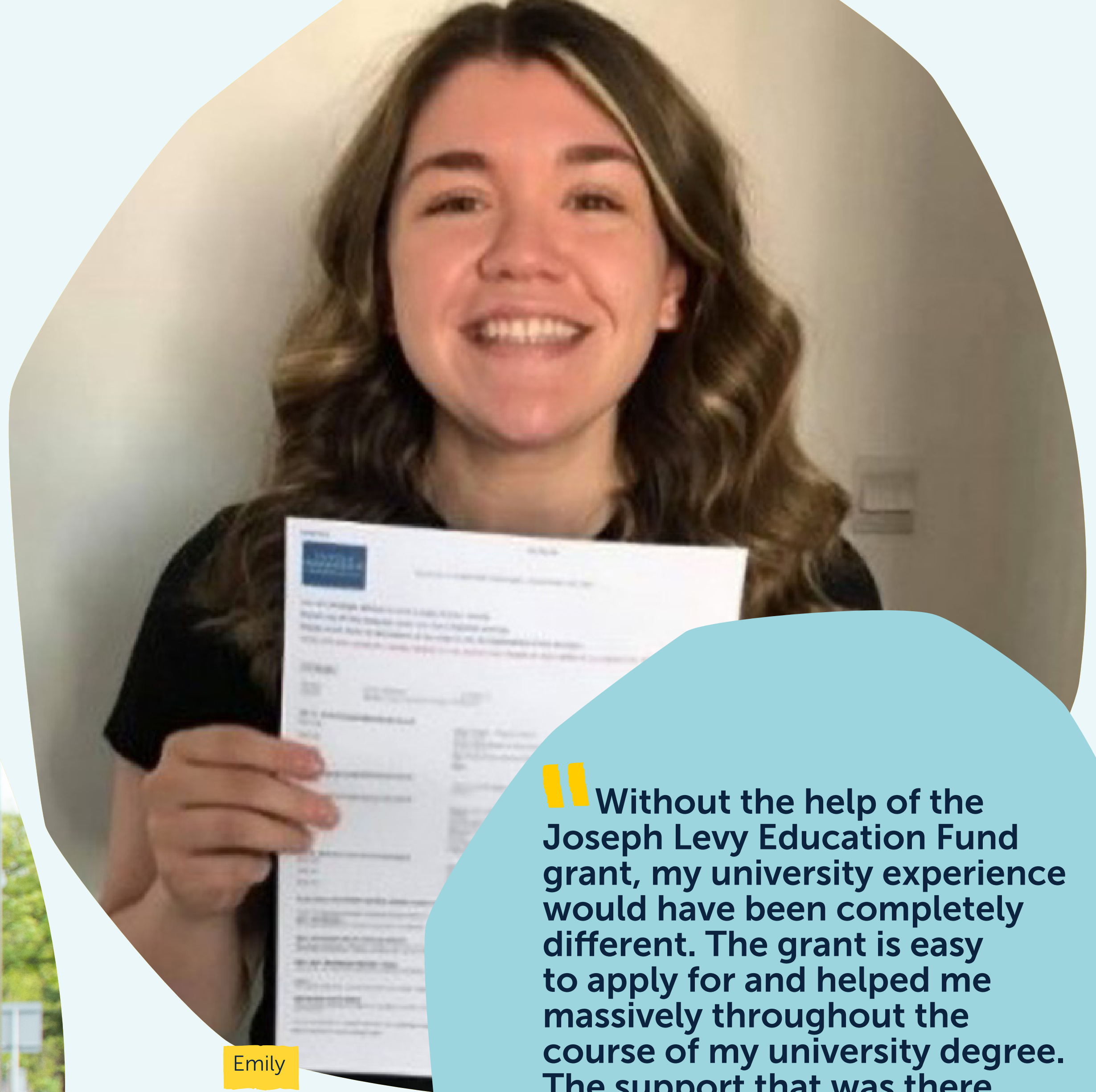
We have continued to deliver support to the CF community when it matters most. This year has included some challenging times, including the draft NICE appraisal announcement in November and medicines shortages, particularly for Creon. We have provided vital information and support, helping the community to understand what's happening and listening and responding to questions.

Alongside this reactive work, we've continued to provide a range of support services to help people with CF manage day to day life, with the ultimate aim of protecting CF health and helping people affected by CF to live the lives they want. This has included expanding our peer support offering by providing a safe space in our online community and training a new cohort of volunteers for CF Connect, our peer support service for parents with children with CF.

Many of those contacting us for support this year are experiencing complex emotional, social and financial issues, which impact on their physical and mental health. Through our individualised and holistic approach, we have been able to provide responsive, flexible support to help them move forward and support their long term health.

> **"Being involved in reviewing Cystic Fibrosis Trust's Ramadan resource was really rewarding for us. It felt good to provide our personal experience on something close to us and help those from less represented backgrounds with CF."**
>
> Kareem, who has CF and reviewed our Ramadan resources


Kareem


Emily

> **"Without the help of the Joseph Levy Education Fund grant, my university experience would have been completely different. The grant is easy to apply for and helped me massively throughout the course of my university degree. 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

Grants

This has been another busy year for our grants programme, and we've provided **1,242 welfare grants, totalling over £310,000**. This included **324 Cost of Living Fund grants**, supporting low income households with the basics needed to stay well over the difficult winter months.

We also provided **61 grants to support people with CF** in higher or further education through the Joseph Levy Education Fund. And through our Helen Barrett Bright Ideas Awards we've supported **9 people with CF with £20,000 of grants** to support them to take a step forward in running their own business.

Thanks to the support of the Joseph Levy Foundation, we've been able to open for applications for Rest & Relax holiday grants, enabling people who have been through a particularly challenging time to have a holiday.

We've also increased impact reporting across all our grant types this year. Over 90% of those who responded to our surveys told us the grant they received had a positive impact on their physical and mental health.

Benefits advice

We have continued to deliver expert benefits advice, income maximisation and student support to help secure financial stability for people affected by CF.

Our benefits advice service has been busy with detailed casework, particularly around Personal Independence Payments (PIP) this year, with more people needing support at tribunals. The impact of this support is evidenced by the staggering **£1.9 million in benefits income** we have secured for the 300 people supported through benefits advice.

We've helped a further **70 people with income maximisation and 23 students with CF** to identify all the financial and practical support available to them. Across both these services, we've been able to identify on average £5,000 per year of additional income, per household.

Helpline

Our Helpline service has continued to provide practical support and information and a listening ear. We've been able to meet people in the CF community where they are, by providing our service across a range of channels. We've handled over 4,500 enquiries across phone, email, WhatsApp and social media. The Helpline has acted as the gateway to all our support services, often dealing with our most complex enquiries and 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.

> **"When I called the Helpline, the adviser at Cystic Fibrosis Trust went over and above his responsibilities and signposted me to ensure I had all the support and advice I needed but didn't know I could access. We are so grateful."**
>
> Rob, Helpline user

James, who has CF

> **"Cystic Fibrosis Trust are fantastic, and they have contributed to my life in different key moments. They offered me support when I was diagnosed, and I received a grant of £1,000 toward my first office space when I started my first business."**
>
> James, who has CF

Trusted
Information
Creator

Patient Information Forum

Empowering the CF community through high-quality, accessible information

We retained our accreditation with the PIF TICK, a quality kitemark demonstrating the Trust's strict adherence to best practice in the production of health information. Last year we added several new and updated resources to our extensive information offering, covering topics such as inhaled therapies, hearing loss, vaping, CFSPID (inconclusive CF diagnosis), CF diabetes and the sweat test. We also responded to ongoing and emerging topics such as the NICE appraisal and Creon shortages, publishing regular updates to ensure the community was kept up to date on these important issues. Looking ahead, a key focus for the coming year will be developing information to meet the needs of an ageing CF population.

> **"A new diagnosis is incredibly overwhelming and tough, which is part of the reason Cystic Fibrosis Trust is so important to us, because the first resource you're given is information written by the Trust specifically for parents of a child with new diagnosis."**
>
> Chris, whose son Ambrose has CF

Ambrose, who has CF

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 **88 children attending 32 courses** and one-off events, including baking sessions, resilience workshops and exploding science experiments!

Our Youth Advisory Group (YAG) of 14–25 year olds with CF **held 17 meetings**, continuing work on a new dictionary of CF terms as well as helping steer the Trust's work for young people. We also piloted Strong Beginnings, a support programme for parents of children with CF aged 0–6, running peer support events, music sessions and parent and baby yoga. **Almost 40 parents** have attended these events so far, and shared positive testimonies of how the events helped them cope at the start of their CF journey.

> **"The best part of YAG is meeting people who also have CF. I think it's really important that we're able to connect online with the people we relate to most, as we can't meet in person due to cross-infection and this can get incredibly isolating. So, it's great that we can just have a chat and a catch up as well as working on upcoming projects."**
>
> Tilly, who's a member of YAG and has CF


Tilly

> **"I contacted the Work Forwards team to see how they could help and what advice they could offer. With the help of the team, I learned how to deal with my anxiety and not let my nerves control me – and after a few months, I was offered a job! I know this wouldn't have been possible without the help of Work Forwards. They have been imperative in offering advice and helping me prepare for interviews. Because of them, I feel more confident, and I am incredibly excited to start the next chapter of my life."**
>
> Jonathan, who has CF

Work Forwards

Work Forwards employment programme

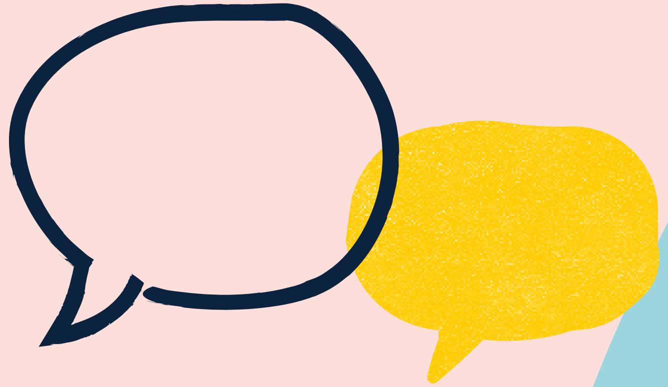
Following its formal launch in early 2023, our Work Forwards employment programme has continued to support people affected by CF towards secure, fulfilling work. This year, we've provided detailed one to one support to 59 people and delivered a range of online group sessions on topics including transferable skills and rights and adjustments at work.

We've shared a range of stories from people with CF in different jobs and careers and we'll be building on this in the year ahead. The project has also included work with our Youth Advisory Group to look at how we can equip young people with knowledge of their rights and the delivery of this year's Helen Barrett Bright Ideas Awards, which provide grants and support around self-employment.

We're grateful to National Lottery Community Fund and Scope for their funding which has made this programme possible.

COMMUNITY FUND

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. From growing our presence on TikTok and experimenting with social media advertising, to launching our third co-created awareness campaign and the second series of our CForYourself podcast.

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, CF Week and #CFTruths have been shaped and influenced by people with CF and their families via our active involvement groups.

Learning more about our community through insights and market research

We conducted a crucial market research project with Humankind Research to understand the different needs of our community following the introduction of modulator treatments, and the challenges of the pandemic and the cost of living crisis.

We found that:

- we have incredibly high levels of positive brand sentiment, which to a large extent is driven by our excellent provision of information
- there are high levels of connection with research, and a desire to keep hearing updates in this area
- Kaftrio has bought new opportunities and a new sense of optimism for many, but this is, by no means, 'job done' and if anything the sense of anxiety and uncertainty has increased
- the fears and anxieties we might have seen before around mortality are still present
- and the uncertainty drives people to the extremes: either inward or outward facing
- especially for those who are more outward facing there is a frustration around low CF awareness.

This leads to a new set of needs and opportunities, particularly in finding ways to mitigate the uncertainty:

- helping our different stakeholders build a road map for a new future with CF, focusing on what growing older with CF looks like
- providing practical and emotional tools to help them along this journey
- providing reassurance (and research) around the future of Kaftrio
- providing platform(s) for the people who go 'outwards' – and tools to help them raise awareness and empathy
- providing support and understanding to those who go 'inwards'

To support this work, we have four key work streams to focus on what we can enhance, promote and develop around life stages, bereavement, awareness of CF and emotional support to ensure we remain relevant and continue to enhance and target our offer.

Our EDI strategy

At the Trust, we recognise that everyone's experience of CF is unique, with many people facing different barriers and challenges to being able to live a life unlimited. Over the last year, we've been consulting on and developing an Equity, Diversity and Inclusion (EDI) strategy, to ensure we put EDI at the heart of everything we do and recognise the full range of needs across the community.

Events

For our community
This year we ran four online and two hybrid CF Live events, which brings together the CF community, people involved in CF care, researchers and others with an interest in CF. The series spanned a range of topics including genetic therapies, a recap of our annual CF conference (UKCFC) and involvement and paediatric CF care.

We were also thrilled to be able to hold hybrid CF Live community events in Belfast and Glasgow, enabling us to engage with the wider community across the UK.

CF Live

For CF professionals
We supported the delivery of four key conferences and events for CF professionals. A one-day hybrid UKCFC event attended by over 150 individuals working in CF research, followed by another one-day event focusing on growing older with CF.

We hosted two further one-day conferences in Leeds: the Annual Clinical Trials Conference and the MDT Share and Learn Conference.

60th anniversary

In February 2024, landmarks across the UK lit up yellow to recognise 60 years of Cystic Fibrosis Trust. We launched new content and materials under the banner of 'we won't stop until CF does', 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. 10,000 posters were donated to us to raise awareness on bus shelters across the UK, totalling around £500,000 media value.

Since 1964

Hazel, 58, and Harvey, 60, who both have CF

> "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

CF Week

CF Week is our annual awareness and fundraising week, ending with our brightest fundraising day of the year – Wear Yellow Day. CF Week 2023 focused on some of the incredible progress we've already made in CF research, and looked forward to the breakthroughs we can make in the future. Together as one united community. We shared stories from across the CF community, went inside the lab with some CF researchers, and hosted a series of live events across our social media channels. This year:

- Wear Yellow Day raised a fantastic £78k
- media coverage during and after the week had a **potential audience of 1.7m**. Highlights included a James Dunmore interview in Fabulous magazine and an awareness piece in Take a Break magazine
- the ***Your Life and CF*** survey was continuously promoted via BBC Access All social media and syndicated to all BBC local radio station with **a combined reach of over 4.6m**
- we had a combined reach of over 450,000 across our social channels and over 1m impressions through our paid social media advertising
- we received 'out of home' (OOH) advertising coverage worth over **£115,000 with a reach of over 800,000 people**
- we visited two research centres, creating a range of video and blog content as well as adding to our growing suite of brand photography
- we empowered the CF community to tell their story and share their #CFTruths through our own platforms – including guest editing of CF News and Instagram stories takeovers
- eight celebrities got involved with CF Week including Nick Mohammed, Lyndall Grace, Jenny Agutter and Richard Madeley
- we engaged with politicians across the UK to share our resources and show their support, with:
  - **47 parliamentarians** wearing Trust pin badges
  - **22 CF parliamentary** mentions
  - Welsh First Minister, Mark Drakeford, publicly supporting CF Week.

Lyndall Grace

77%
of respondents felt their CF or caring responsibilities have an impact on their employment opportunities.

1 in 5
ran out of food before they had money to buy more in the last 12 months.

1 in 3
borrowed money for basic essentials, such as food, clothing, heating, and internet.

9 out of 10
respondents were worried about their future, with 1 in 3 worrying about it every day.

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Cystic Fibrosis Trust
Since 1964
We won't stop until CF does

Your life and CF
2024 report
Kieran Earlam
June 2024

Uniting for a life unlimited

Jonathon

> "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

#CFTruths

Our annual awareness campaign leaned into our 60th anniversary this year by recognising that improvements over the past 60 years have made life better for many, but as old problems diminish, they can bring new challenges and fears. And there is still no cure. No day off from CF.

The campaign is still live, but so far has achieved:

- over £450k donated for OOH advertising with a reach of over 7m
- over 479,000 impressions across paid social media
- over 4,000 clicks to the website through paid social media
- over 18,000 impressions and over 1,800 clicks to our website with over 700 conversions – including 10 purchases in our online shop, totalling almost £350 through a Google Performance Max campaign
- national coverage in the Mirror and syndicated across 11 regional outlets, with an editorial reach of over 11m.

Our *You don't see CF* campaign won bronze in the people's choice awards in the 2024 Smiley Charity Film Awards 2024.

Celebrity engagement

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

- Roger Black appearing on The Celebrity Chase and recording a video of support for participants of Great Strides
- James Dunmore and Married at First Sight Australia's Lyndall Grace featuring as guests on our podcast CForYourself
- Lyndall Grace taking part in an Instagram Live
- James Dunmore supporting us through media in Fabulous Magazine
- Jenny Agutter helping us to promote Carols by Candlelight on Loose Women. She also did a reading at Carols by Candlelight alongside James Dunmore, and actor David Haig
- Jenny Agutter and Vincent Franklin both taking part in an Instagram Reel to support our FeBREWary campaign
- a host of celebrities supporting Wear Yellow Day, including Richard Madeley, Jack Kinsey, and Nick Mohammed.

A huge thank you to all of our celebrity ambassadors and influencers who continue to support our 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, poverty, mental health, travel, growing a family and the relentlessness of living with an invisible condition. 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.

> "The amazing strides that have been made in treatments in the time since my sisters passed away is astounding and a true reflection of what is possible with increased awareness and funds."
>
> James Dunmore

James Dunmore ran London Marathon for the Trust in 2024


Spotlight

Mama Mia!

Back in 2021, a group of amazing mums, led by Pamela Millward-Browning, wanted to do something to help make a difference for their children and all those affected by cystic fibrosis (CF). With COVID-19 restrictions still in place, options were limited, but the group of 14 'CF Mamas' decided to each cover 100km over a six-week period, raising over £16,000 for the Trust in the process.

The group reunited the following year for another exercise-based challenge, and their fundraising again exceeded expectations, reaching the dizzy heights of £60,000 across the two years.

As parents, we'll do anything for our children, but the CF community is something else. Due to what our little ones have to go through with treatments, medications, constant infections, procedures and surgeries, we fight harder than most have to.

Paediatric CF care

Paediatric CF care – Insights from the UK CF Registry and our patient experience survey

At Cystic Fibrosis Trust, we regularly collect data and insights from the CF community. We use these to help inform our work with clinicians, policymakers and other stakeholders, to make recommendations about improvements in care, and to support vital research.

One incredibly important data source is the UK CF Registry. Since 2007, the Registry has been sponsored and hosted by Cystic Fibrosis Trust and collects information about the health, treatments and demographics of people with CF in the UK. Almost everyone who has CF in the UK has agreed to have their data entered into the Registry, and we are incredibly thankful for this.

The data has an extraordinary impact on CF care, as it helps clinical teams to understand their own paediatric centres better and allows them to compare themselves against the national figures. The Registry data can also be used to monitor overall health trends in the CF community across the UK, to support novel research, and to provide an evidence base for new medicines.

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Cystic Fibrosis Trust

Since 1964 | We won't stop until CF does

Issue 16

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CFLife

CF care
The UK CF Registry and experiences of paediatric CF care

Fly on the wall
Ten years of exciting innovative research

Your stories
Yvonne Hughes talks stand up and her life with CF

Uniting for a life unlimited

Access to modulators

Deciding to keep fighting

Knowing how hard it was for us to initially get access in the UK, and then the impact Kaftrio has had not only on my daughter but so many others across the UK, has spurred me on to keep fighting and campaigning for global access to the drug.

Seeing how much harder it is for other countries, especially lower-income countries, to gain access when we struggled so much as a high-income country left me with a strong sense of moral responsibility.

Setting up Vertex Save Us

Three of us launched Vertex Save Us in October 2020. We could see that high drug pricing was a major block to access in many countries around the world, and as a result, we wanted to put pressure on Vertex rather than governments and health systems to pay these high prices.

Within a few months, we had 3,000 members from more than 60 countries on our mailing list. It was incredible. There are thousands of families out there without access to Kaftrio and other modulators, and I just wanted to use my experience to help them.

I could see the huge potential for this campaign as we had so much patient support and backing from families and clinicians worldwide. With all these voices, I knew that we could bring people together to make a difference.

We launched the Right to Breathe campaign with coordinated actions in four countries across four continents on the same day.

Gayle (middle) and members of Right to Breathe

During our latest call with Vertex representatives in October, we were deeply concerned to hear of the lack of progress with agreements for access in lower middle and low-income countries. So, we've again asked them to drop their patents in those countries to allow cheaper generic manufacturers to supply the drugs. However, at the moment, they won't agree to do that.

Instead, they say they are piloting a donation programme in a small number of countries and we are waiting for more information on how this will work. This also leaves some higher-income countries without access.

We are appealing to Vertex to take immediate action to ensure all patients have access as soon as possible. It's been more than four years since the US regulator, the FDA (US Food and Drug Administration), approved Kaftrio, so the fact that many countries still don't have access is not good enough.

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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.

In 23/24, CF Life covered topics including:

- transition from paediatric to adult care
- an interview with the founder of Vertex Save Us about the campaign for global access to Kaftrio
- diversity in clinical trials
- genetic therapies and CF.

Following the spring edition of CF Life magazine, we received a £5,000 donation in the post from a supporter. After reading Tilly's piece about what YAG means to her, the supporter wrote: **"Many things had me in tears... Say thank you to Tilly and tell her the donation is partly due to her!"**


Young voices

What YAG means to me

Hi everyone, my name is Tilly. I'm 15, and I have CF and CF diabetes. Today, I want to talk to you about the Trust's Youth Advisory Group (YAG) and what it means to me.

One year ago, I entered my first YAG Teams call... and it made me see my conditions in a whole new way.

Living with CF comes with so many obstacles, but personally, I think one of the hardest things for a young child to understand is that you can't go near people exactly like you because people with CF are advised not to meet. It sounds dystopian, doesn't it? Six feet apart from the only people who will ever truly understand your health. It's really difficult to embrace your life, health and ultimately your future when you feel so completely isolated.

"CF is the biggest part of my life, and I've never had it in common with anyone before. It's a strange and exciting feeling to finally have that."

Tilly

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Young voices

In most cases, that loneliness could be fixed by meeting someone who understands how difficult it is to live with this condition. But with CF, it's not that easy. Cross-infection gets in the way and makes our lives difficult – haunting us with promises of bacteria, infection, and hospital.

But some people know exactly how I feel every day, and they live through the same experiences as me, but until now, I didn't know how to connect with them.

This is where YAG comes in and makes the loneliness disappear. Suddenly, I have a beautiful support network and community of young people exactly like me – and I can actually talk to them! Every meeting comes with feelings of relief and happiness. It's something that I'm excited to talk about and share. CF is the biggest part of my life, and I've never had it in common with anyone before. It's a strange and exciting feeling to finally have that.

Along with a mixture of feeling supported and listened to, I also feel incredibly proud because we use our meetings to help other people living with CF. The projects we do are all varied and interesting, and everyone works together to create something we're all proud of. One of our previous projects was called 'When I Grow Up', where we got adults with CF and cool jobs to talk to us about how they followed their dreams. We wanted to inspire young children with CF to do anything their heart desires, and it was a very successful project. I also took over YAG's Instagram account to promote the project, and it was really fun!

YAG has inspired me to look for the positives in my condition and not be afraid to complain about the negatives. I'd always put on a brave face in front of my family and friends because I was scared of stressing them out. However, YAG has lifted a weight from my shoulders, and I can laugh and let it all out. I can just be myself with no worries.

After a year, it's taught me so much about myself, my conditions and how I should take care of myself. It's truly an honour and a pleasure to be part of it!

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

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CForYourself podcast

Our podcast launched in June 2022 with host Lucy having a cup of tea and a chat with others in the cystic fibrosis community, talking openly and honestly about a whole range of topics. In series 2 of the podcast, we covered everything from dating with CF to the menopause, and we also featured some well-known voices, including Made in Chelsea star James Dunmore and Lyndall Grace, star of Married at First Sight Australia.

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. Whilst most of our listeners are in the UK, we've also reached the CF community across the world, from Australia to Argentina.

> **"The episode was the first I have ever heard and it was great to listen. Keep going strong on the podcasts... not only are you helping those listening, you are helping your guests talking through their difficulties and triumphs."**
>
> Tim, Podcast listener

Series 2 highlights

- 8 episodes
- 1,050 downloads
- Most popular episode: #CFTruths: Living with an invisible condition

12:33

Cystic Fibrosis Trust

CFor Yourself

16 NOVEMBER 2023

CForYourself: CF and dating wi

CForYourself: A podcast from Cy

8:41

-28:47

1x

Lucy Baxter, host of the CForYourself podcast

10:36

Cystic Fibrosis Trust

What I learned about cystic fibrosis while working on EastEnders

Hi, I'm Elizabeth Green

Jade, played by actress Lizze Green, who appears in Eastenders

CF in the media

We've had an incredible year for media coverage and 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 saw amazing coverage of our London Marathon stories and reached national audiences through the BBC Access All podcast for the ***Your Life and CF*** survey. We also launched our cost-of-living campaign, raising awareness of the difficulties people with CF were facing, which received amazing coverage across the Express.

Once the NICE consultation began, and we had the news about Kaftrio being approved for 2-5 year olds, the Trust was in hundreds of national and regional outlets. Jenny Agutter, our celebrity ambassador, also appeared on Loose Women speaking about Carols by Candlelight. It was also incredible to see a CF storyline in EastEnders.

CF News

Our monthly newsletter is sent to over **10,000 opted in subscribers** sharing the latest CF research breakthroughs, stories from our community and wider news from the Trust. Over the past year, the newsletter

- averaged over **37% unique open rate**
- averaged over **1,000 click throughs** to our website
- covered popular articles such as CF Life magazine, our awareness campaign and topics important to our community such as the NICE appraisal.

We had 1,453 pieces of coverage over the last year with a huge potential editorial reach of 7.8 billion

Website

During 2023/24 we have delivered a number of projects to strengthen our website, led by the needs of the CF community and championing accessibility to ensure everyone can engage with the information they need.

These include:

- reducing the number of links in the main navigation menu
- introducing personalisation on the homepage to make it more engaging and relevant for repeat users
- redesigning the CF Trials Tracker
- implementing Google Analytics 4 to support our data collection and analysis.

Another highlight has been the growth of our online community forum, which has had over 500 new sign ups, over 400 posts and 34,000 page views.

> "At the beginning, there were so many questions I had to ask. I went on Cystic Fibrosis Trust's online forum and absorbed so many different people's stories and different walks of CF life. It brings you so much hope and made me feel like, 'it's going to be okay'."
>
> Shanique, CF parent

Shanique and Thiago, who has CF

Social media

From the beginning of 2023, we saw the continuation of our successful weekly social media initiatives: Research Wednesday, Thanking Thursday, and Fundraiser Friday, which aims to give space on a weekly basis to share CF research news and opportunities to get involved, as well as celebrate the amazing achievements of our supporters.

Our social channels allow us to respond to the CF community in a timely fashion on key themes such as the NICE process and ongoing Creon issues. Our ability to turn around video content quickly, direct from our Chief Executive, enabled us to reassure our community during some challenging moments.

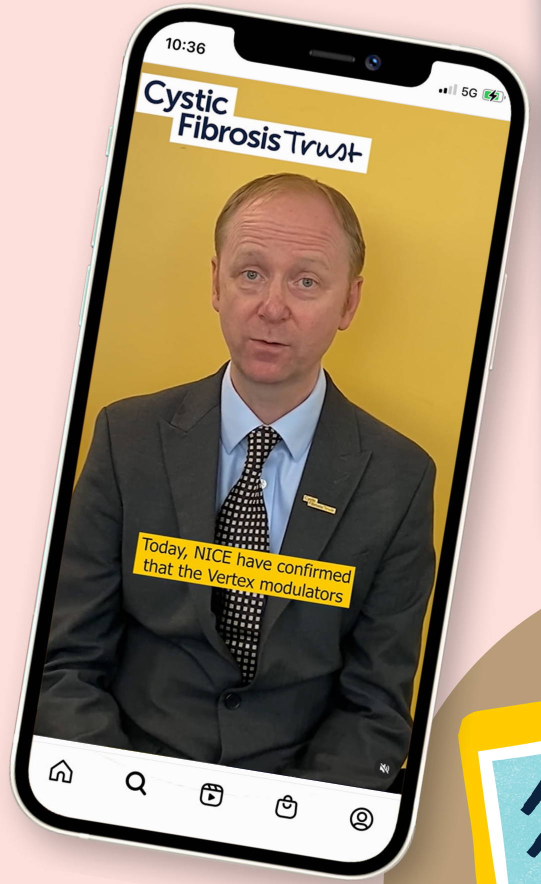
Across Facebook, Instagram and TikTok we had an incredible combined reach of **6.9m** and **1.9m** impressions across LinkedIn and X.

Our video content continues to perform incredibly well across all of our channels with over half a million views in the past year.

CF Connect

CF Connect is our peer support service for parents of children with CF, helping them connect with one another without the risk of cross-infection. We trained a new group of volunteers this year.

Recently we put Helena, who has a young baby with CF, in touch with one of our trained parent volunteers. Helena had been through a difficult time, figuring out her new routine and keeping her baby well, and she had questions about the future. Helena found solace in talking to one of our trained volunteers who had been there herself, and understood her worries. We provided a safe, nonjudgemental space for Helena to get things off her chest and talk her concerns through.



Today, NICE have confirmed that the Vertex modulators

First up is a Strategic Research Centre (SRC)

cftrustuk • Follow
Original audio

cftrustuk For #ResearchWednesday we've got some really exciting news to share!

We are delighted to announce that we are funding over £2 million to four new research projects:

💛 An SRC led by Dr Mike Gray focusing on people who can't benefit from modulator drugs, and looking at designing chemicals that could be used as future CF medicines.

💛 An SRC looking at the impact of pregnancy, childbirth, and breastfeeding on those with CF, led by Dr. Imogen Felton and Prof. Jane Davies at the Royal Brompton Hospital in London.

Liked by **thefullshilling** and **others**
May 29

Log in to like or comment.

Uniting in fundraising

We would like to thank all our amazing individual donors and supporters, organisations, charitable trusts, foundations and corporate partners who support our work to make sure everybody with CF can live a life unlimited. We really appreciate everything you do for the CF community, particularly when we know everyone is feeling the financial pressure. It makes your support so incredibly special to us.

We couldn't do what we do without you.

In 2023/24, total income of £7.9 million gross income was raised compared to £6.45 million in 2022/23 (+£1.4m) and £5.7 million net income. There were increases in many areas of fundraising including Community and Events income, In Memory income, Corporate Partnerships, Trusts and Foundations, and in particular income from gifts in wills of £2.6m which had an increase of £1.6m versus 2022/23. However, this still represents a 24% reduction in net income compared to pre-pandemic income in 2019-20 as our voluntary income at the Trust continues to be impacted by the cost of living crisis.

This year marks the final year of our groundbreaking CF Innovation Hub on lung health with the University of Cambridge, which started in 2018 under the leadership of Professor Andres Floto. We successfully raised £5 million for the Innovation Hub thanks to the incredible generosity of our supporters over these six years. Every pound raised was match-funded by the University of Cambridge.

We continue to innovate and adapt our fundraising plans. Examples of new innovations launched this year include a new gaming proposition #Game4CysticFibrosis, our winter wander and virtual event 60 for 60 for our 60th anniversary.

Our trustees agree and regularly review our fundraising strategy. We adhere to Data Protection Law and the Fundraising Preference Service. We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice and, as such, commit to their Fundraising Promise.

- We aim to exceed the standards included in our promise to our supporters:
- We will be transparent about our work
- We will be respectful
- We will listen and respond
- We are committed to high standards
- We are fair and responsible

Jamie

> "The Trust has been a huge part of my journey for as long as I can remember. They have supported me, helped me find support in tough times and included me in their campaigns. I've been so glad to be able to raise money for them when competing in events such as London Marathon, as it's so important the Trust can continue their research."
>
> Jamie, who has CF

Supporter experience

The Trust received 29 complaints in 2023/24. This is broadly in line with the 19 received in 2022/23, and 24 in 2021/22 and lower than our pre-pandemic average, 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.

Community and event fundraising

This year our aim has been to continue to grow income year on year and thanks to you, over **£2.27 million** has been raised.

Our unwavering fundraisers continue to take part in activities across our event portfolio including London Marathon, London Landmarks Half Marathon, Edinburgh Marathon Festival, London to Brighton Cycle Ride, skydives, and overseas treks. We have also seen an increase in fundraisers signing up to events that capture their imagination as a DIY activity. Together, our challenge event participants have raised over **£1 million**.

The CF community have been very busy fundraising through amazing events and activities such as Wear Yellow Day events, FeBrewary activities, balls, boxing matches, football matches, quiz nights, games nights, and the impressive list goes on. These fantastic endeavours **have raised over £1.08 million**. Our annual Wear Yellow Day **raised over £78,000**.

Our dedicated branches and groups located all over the United Kingdom **raised £100,000**.

Nell

> "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

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.
>
> Greater awareness of CF is essential to help raise money for future medications and research, and that's why Stuart and I do a lot of fundraising for Cystic Fibrosis Trust. My sister teaches hot yoga, so we have held classes on the beach to raise money for CF, and last year, we also put on a silent disco using headsets that the Trust kindly lent us. This year, we held a fundraising event at Jacob's nursery during CF Week, and everyone dressed up in yellow and raised a lot of money. We are hoping to do that again next year."

Morag, whose son Jacob has CF

Regular gifts

We'd like to express our gratitude to our loyal regular donors who provide invaluable ongoing support that enables us to plan effectively for the future. These supporters contributed **just over £800,000** in 2023/24, including Gift Aid. During this year, we carried out a direct mail appeal and a telemarketing campaign through Ethicall, our professional telephone fundraising agency. Ethicall have a respect and dignity policy that turns marketing calls into 'thank you' calls if they suspect the person that they are speaking to is vulnerable. These campaigns (a regular giving upgrade via both direct mail and telemarketing, and a direct debit recruitment campaign) resulted in an additional annual income of £18,000.

Gifts in Wills

During 2023/24 we were privileged to receive **legacies from 88 supporters** who generously chose to include a gift in their Will to support the Trust. These special gifts will help us to continue our vital work for years to come. In 2023/24, 42 supporters informed us of their commitment to leaving a legacy gift. We remain committed to promoting legacy giving through various channels and providing a free Will service to our supporters all year round.

In memory

We continue to honour and remember all those with cystic fibrosis who have lost their lives and thank everyone who donates in their memory. In 2023/24, **more than £320,000 was donated in memory of loved ones** and they will always stay in our thoughts. Our Book of Remembrance, tribute funds and dedication wall remain special places where these individuals can be remembered.

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

Natalie and her brother Sam, who is remembered through our Book of Remembrance at Holy Trinity Church in South Kensington

Corporate partnerships

Building partnerships with existing and new corporate partners is vital to both raising funds and awareness for the Trust.

We would also like to highlight the continuing support we have had this year from longstanding partner AJN Steelstock for the Innovation Hub. Crane CPE provided the opportunity to apply and receive funding from their 'Crane Widows and Children Fund', and the skills and expertise of the Bip Group assisted us in ensuring that our Helen Barratt Bright Ideas Awards continues to go from strength to strength.

We were delighted to be named as charity of the year by C-Stem, Orlo, McLemore Konschnik LLP, and SHS Drinks, and the benefitting charity for the Britannia Stakes race at Ascot thanks to the Betting and Gaming Council and their members.

Events such as the UK CF Clinical Trials Conference, UKCFC and the Annual Registry Meeting are essential in showing the work we do within the cystic fibrosis sphere and we would like to thank our sponsors once again for the support they have given us, many of whom have supported the events in previous years.

We value all the support that our corporate partners have given us and the wonderful enthusiasm and dedication that comes with it.

Philanthropy

Philanthropic support from charitable trusts, foundations and individual supporters is key to the sustainability of our mission to improve the lives of those affected by cystic fibrosis.

We would like to thank the generous and committed support of trusts, foundations, the National Lottery Community Fund and BBC Children in Need who provide donations and multi-year grants. This is critical to the Trust's provision of services to our CF community and world-leading research. In this 60th anniversary year of the Trust, we are particularly grateful for our long-term partners, the Robert Luff Foundation and the Joseph Levy Foundation.

This year marks the final year of our groundbreaking CF Innovation Hub on lung health with the University of Cambridge, which was established in 2018 under the leadership of Professor Andres Floto. Thanks to the incredible generosity of our supporters, Cystic Fibrosis Trust successfully raised £5 million for the Innovation Hub, which was match-funded pound for pound by the University of Cambridge. As the programme draws to a close, we want to thank all our funders who supported us and enabled world class advances in our knowledge of CF lung infections.

We deeply appreciate the dedication of our Sixty Five Roses Club, a group of supporters **who commit to donating £1,000 a year** or more. Longstanding support from these members and other donors who pledge sustained giving is so important to our ability to deliver sustainable programmes. Members of the Sixty Five Roses Club have been on this journey every step of the way, **raising over £760,000 over the last decade** in support of our mission to ensure everybody with CF can live a life unlimited.

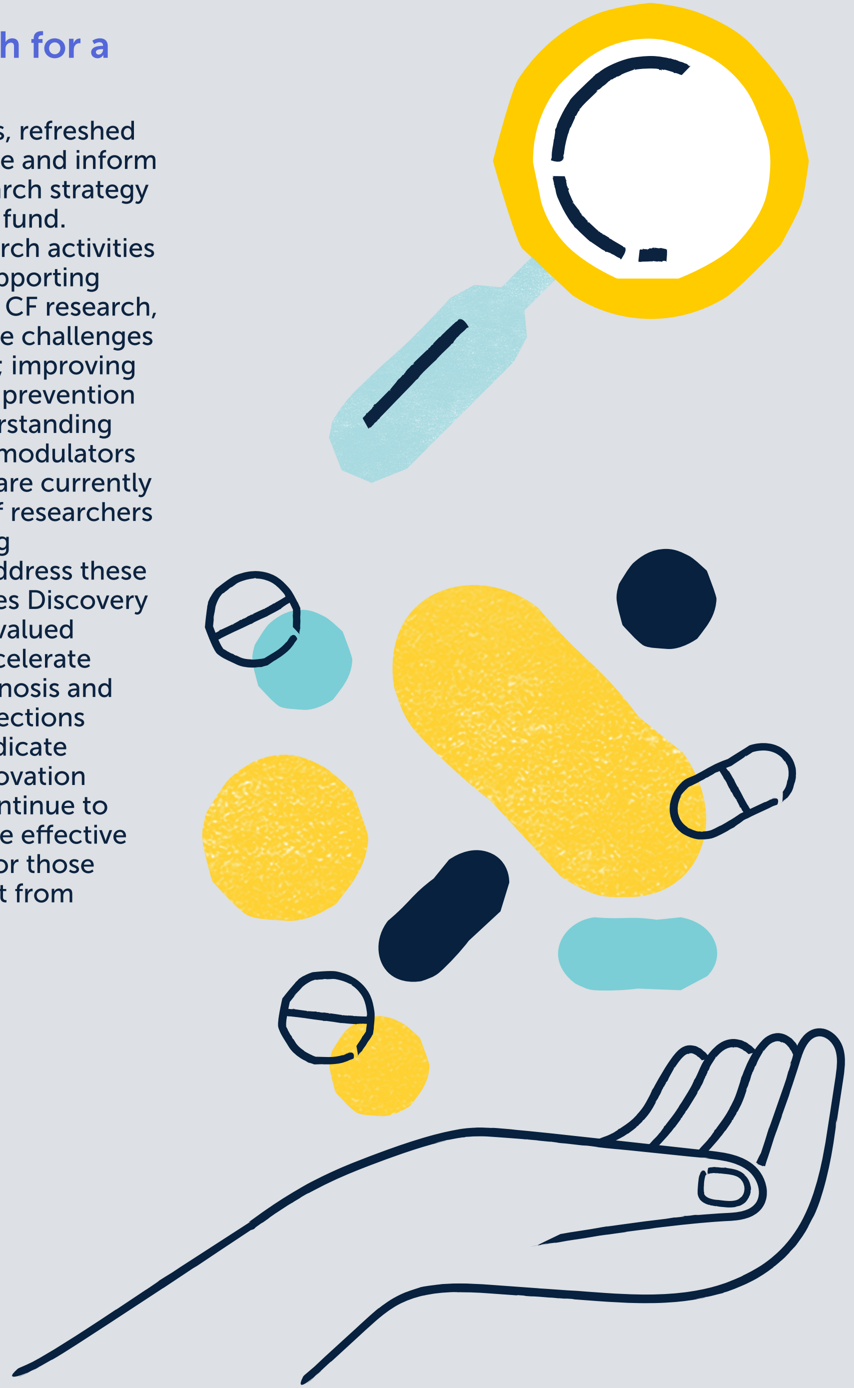
As the CF community faces post-pandemic adjustments and the cost of living crisis rolls on, philanthropic support has allowed us to extend our Cost of Living Support Package programme which launched in 2022. This year **we have supported 324 people with CF** in low-income households with grants for energy bills, food and basic essentials over winter.

Professor Andres Floto and his team working in the laboratory at the Cambridge LMB (Laboratory of Molecular Biology).

Looking to the future

Uniting in research for a life unlimited

The CF research priorities, refreshed in 2022, continue to guide and inform the direction of our research strategy and the research that we fund. Mapping of current research activities has led us to focus on supporting under resourced areas of CF research, such as understanding the challenges of growing older with CF; improving diagnosis, treatment and prevention of CF diabetes; and understanding the long-term effects of modulators outside of the lungs. We are currently building new networks of researchers and new research funding partnerships to help us address these new challenges. Medicines Discovery Catapult and LifeArc are valued partners in our aim to accelerate research to improve diagnosis and treatment for CF lung infections through the CF AMR Syndicate and the Translational Innovation Hub Network. We will continue to support research for more effective treatments, particularly for those who are unable to benefit from current modulators.



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

> “I know my fundraising has contributed to CF research over the years and that’s really important to me because I’ve seen firsthand what a difference Kaftrio has made.”
>
> Sharon

Whatever you do, do it in yellow

Being great fundraisers

Growing our income is vital to enabling us to expand our research programme and support everyone with CF to live a life unlimited. The continued support of our CF community is so incredibly special to us.

Throughout 2024, we look forward to celebrating our 60th anniversary and all that has been achieved with our incredible CF community. Some of the activities will include a special Wear Yellow Day in June, a campaign to promote leaving a gift in your will in September and our 60th Awards in November; shining a light on some of the incredible people who have made a difference to the CF community.

We will continue to work closely with our incredible supporters, branches and groups, and with our trusts, donors and corporate partners. In order to provide the very best experience when supporting the Trust, we will continually review and update our engagement and how we communicate with our supporters.

Innovation remains a key pillar of our fundraising strategy to develop new products and engage new supporters in order to diversify our income.

Building on the success of our first Innovation Hub with the University of Cambridge, we will launch our £15 million Translational Innovation Hub Network which is co-funded by the Trust and medical research charity LifeArc; to fast track new research and treatments to improve lung health and quality of life for people with CF over the next five years. We are delighted that the Robert Luff Foundation have continued their support for the new Hub Network.

Campaigning hard

Our advocacy will continue to emphasise critical issues such as air quality, which significantly impacts those with respiratory conditions like CF. The Government’s focus on enhancing the UK’s science and innovation sector provides unique opportunities for advancing CF research and treatment. We will advocate for policies that support research, innovation, and improved mobility for scientists, which can accelerate progress in CF treatment where needed.

With a new legislative agenda taking shape, we will remain flexible and proactive, diligently monitor announcements, ensuring we leverage every opportunity to advance our mission. Upcoming policy reviews and budget announcements will further shape our strategies as we advocate for sustained and increased investment in healthcare and research.

We will seize every opportunity to advocate for improved CF care and support. Our advocacy work puts the needs of people with CF, their families, and professionals working in CF care at the heart of everything we do.

Day-to-day support

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

This year, we formed a partnership with Home-Start UK, a national charity who support families with children under 5, to develop support for new parents who have CF. We have seen a significant increase in people with CF becoming parents in recent years, and we want to put support in place to enable them to make the most of early parenthood while also maintaining their own CF self-care.

We have piloted this project in Glasgow, training a cohort of Home-Start volunteers in cystic fibrosis, so that when new parents need support they can access this in the knowledge that the person supporting them understands the condition. This programme has shown how, as needs in the CF community change, we can work with other organisations to balance their experience and knowledge with our understanding of cystic fibrosis.

We have also been developing our work to support those in the CF community who are neurodivergent, and those bereaved by CF.

HOME START

> "Accessing Kaftrio was a game changer for me and turned the clock back around 10 to 15 years in terms of my overall health. This was obviously great, but it did also bring some challenges. I had always preferred to live in the moment and never really thought much about saving for a pension, because as morbid as it sounds, I thought it was never going to be a problem I'd need to worry about."
>
> Jimmy, our Work Forwards Programme Manager who has CF

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

Quality improvement and clinical engagement

In 2024/25, we will report on findings from the second cycle of our patient experience survey in adult services and will provide bespoke feedback to all adult CF centres that took part.

In the autumn, new data will be collected on staffing levels in CF services. We also plan to develop and launch a new survey for CF professionals, which will look at how CF care and workload is evolving from the perspective of those working in the specialty.

We are continuing to roll out and expand our holistic follow-up offer for CF centres, to support them to explore their data insights and plan targeted quality improvement activities. This offer will be extended to adult CF services in 2024.

The UK CF Registry

Registry data will continue to help NICE as they evaluate the impact of CF modulator therapies on the health and wellbeing of people with CF.

We plan to present at CF Live events in 2024/25, taking advantage of the opportunity to explain the meaning behind collection of data and answer questions from the community.

We will be reviewing and expanding the types of data we collect to further support our community as CF care and the needs of people with CF evolve.

Financial review

Results for the year

The final result for the year, excluding movements on investments, was a deficit of £0.4m (2023: surplus of £1.9 million).

Whilst total income of £14.7m is the same as in 2023, total expenditure has increased by 18% (£2.3m), which is principally due to an increase of £1.9m in grants to support innovative research projects that we hope will help us achieve our goal of a life unlimited for everyone living with cystic fibrosis. This increase in expenditure was funded by unrestricted reserves held by the Trust in March 2023.

Although, following the cost of living crisis, generating voluntary income remains challenging, the Trust still retains strong reserves and is committed to maintaining charitable expenditure in 2024/25 whilst continuing to take appropriate cost control measures.

In subsequent years we anticipate the need to make some reductions in expenditure and focus on income growth to ensure that unrestricted reserves are within the Trusts' reserves policy range.

Income

The Trust's income from normal activities for the year to March 2024 was £14.7m. This total income is unchanged from the previous year although the mix of income has changed significantly, with strong legacy income balancing lower income generated in other areas.

Voluntary and trust income of £7.7m (2023: £7.8m) 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.

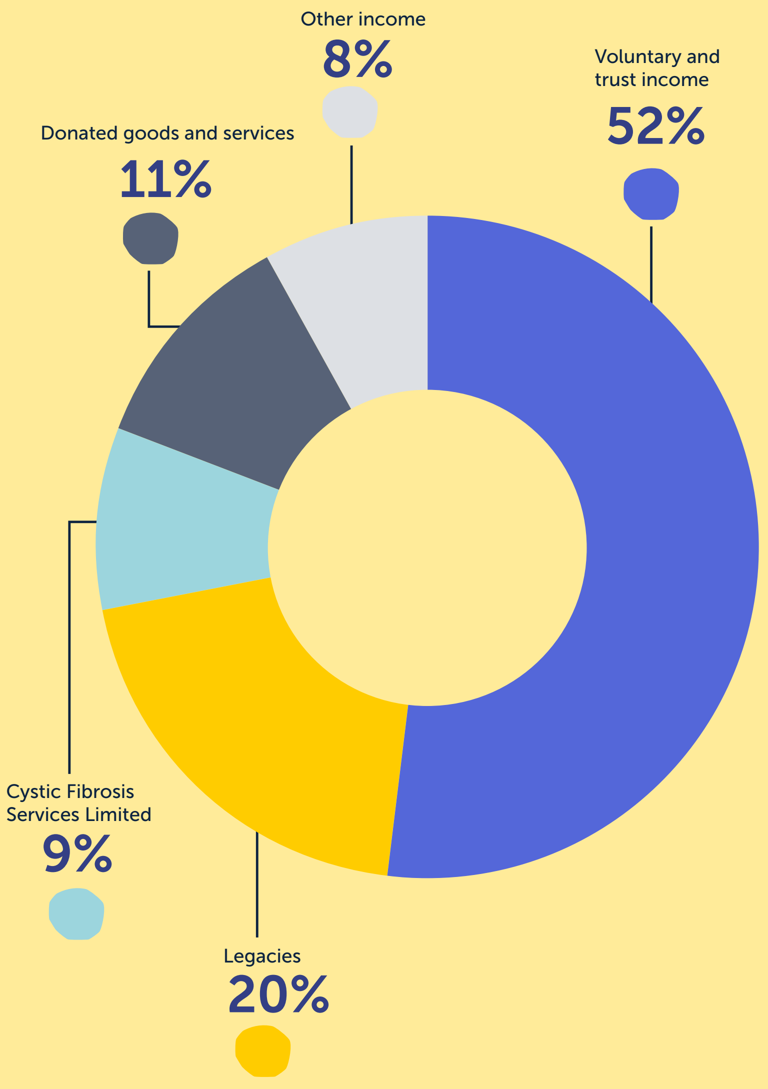
In addition, Legacy and In Memory income of £2.9m (2023: £1.2m) was raised which included several large gifts in wills. Income in the prior year was impacted by pressures in the housing market, meaning property left in estates was difficult to sell, and by processing delays at the Probate Office. The additional income in 2023/24 reflects some reduction in these pressures.

We benefit from generous corporate donations in kind including outdoor advertising and advice supporting our campaigns. The value of these services was £1.5m (2023: £1.2m). The corresponding cost value of this donation is shown included in the information, advice and support costs.

Income generated by Cystic Fibrosis Services Ltd ("CFSL"), the Trust's trading subsidiary, was £1.3m (2023: £2.9m). 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. Several contracts came to an end at the beginning of the financial year. Confirmation of the NICE approval of Kaftrio in 2024 and the pipeline of potential new treatments is likely to lead to new studies being commissioned and we expect revenues will increase over the next two years.

Other income of £0.3m in the year (2023: £1.1m) includes recoverable VAT. In the prior year the Trust received £1.0m income from a revenue share agreement with the Gene Therapy Consortium.

Income 2023/24



Expenditure

The Trust's total expenditure for the year was £15.1m, a £2.3m increase compared to the previous year.

Expenditure on charitable activities in the year was £12.0m (2023: £9.5m). This includes funding research, providing information and advice and support and supporting clinical care. The increase in expenditure is mainly grants to support research.

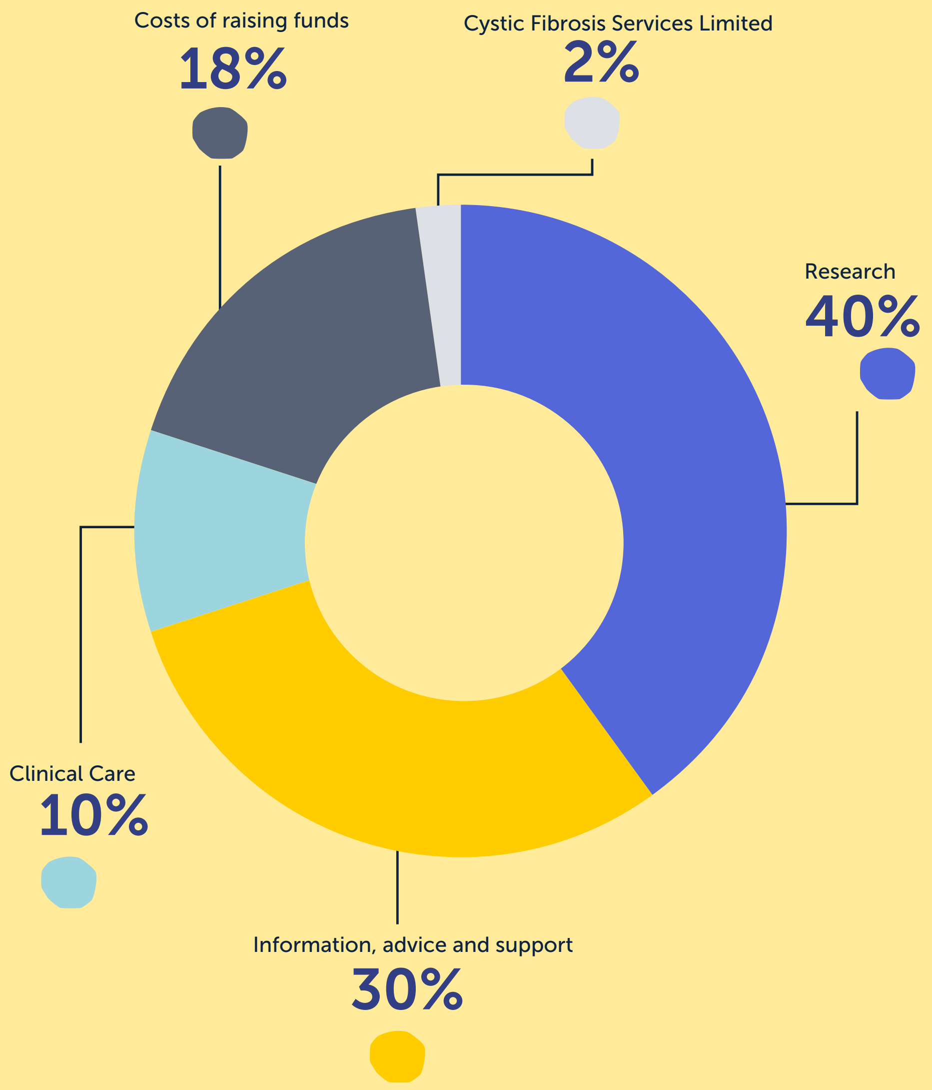
Grants to support charitable activities include:

- £3.9m (2023: £2.0m) 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 releasing £0.3m (2023: £nil) made in previous years
- £0.4m (2023: £1.0m) to fund the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme
- £0.3m (2023: £0.6m) 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 £3.07m (2023: £3.32m) and includes direct fundraising costs of £2.73m (2023: £2.65m) and the costs of CFSL of £0.34m (2023: £0.67m). CFSL costs include UK CF Registry Support grants.

Expenditure 2023/24



Investment policy

The Finance Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to adopt a balance between generating a 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 general fund portfolio is kept in liquid Funds although there is some exposure to less liquid assets such as property. Approximately 83% 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 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 Committee.

Review of investments in the year

The value of the investment portfolio (including endowment funds) was £5.8m as at 31 March 2024 (2023: £5.4m). This increase of £0.4m is mainly due to investment gains in year.

No change was made to the allocation between amounts held as stocks and shares and that held as cash. Income generated on investments totalled £0.6m which is £0.3m more than in 2023 and reflects increased interest rates compared to prior year.

Reserves

The Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, at a level that mitigates the risks associated with fluctuations in fundraised income and cost pressures and ensure funds are available to maintain operational activity and invest in key strategic areas to support future impact and growth.

The Board believes an appropriate level of reserves is in the range of above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £4m and £6m.

At 31 March 2024, after adjusting for the designated reserves explained below, the Trusts' Unrestricted Reserves were £8.7m (2023: £8.6m). This level reflects the impact of a number of exceptional items in recent years which have acted to limit the impact of deficits from core activities.

The Trustees have approved a business plan and substantial deficit budget for the next financial year which maintains services and grant awards at a level similar to previous years despite the continued challenge of the wider economic climate and therefore Unrestricted reserves are forecast to fall to £7.5m at March 2025 and reduce further to £5.9m by March 2026 which will bring the Trust within the range detailed in its reserves policy.

The Trustees have opted to designate unrestricted reserves for the following purposes:

- Organisational reserve: £1.0m (2023: £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 and for the costs associated with moving to a new office in early 2025.
- Fixed asset reserve of £0.13m (2023: £0.16m). The reserve is maintained as fixed assets cannot be readily realised as cash.

The trust also holds Endowment and restricted funds:

- Endowment funds – The Trust maintains a number of endowment funds where the donor require 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 2024 the endowment funds totalled £1.0m (2023: £1.0m). See note 21 for information about the individual endowments.
- Restricted funds – Restricted funds 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 2024 restricted funds totalled £0.5m (2023: £0.7m). Note 22 lists the individual restricted funds and their movement in the year.

Total reserves at 31 March 2024 were £11.3m (2023: £11.4m).

The Trustees will continue to keep the Trusts' reserves policy under regular review to ensure it is set at the appropriate level to reflect changes in the business outlook as they materialise.

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 means we might not be seen as relevant and will not reach widest possible audience • Failure to Influence key external stakeholders and decision makers could 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 • We are developing a new Equity Diversity and Inclusion Strategy to ensure relevance to all stakeholders across community • Audience insight research analysis was completed in 2024 and we are implementing the findings • We continually develop strategies on emerging priorities, including Air Quality, Housing, Poverty, CF Care resourcing, and benefits & welfare reform • 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

Strategic risk	Strategies/plans for managing risks
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 and budget for 2024/25 and beyond includes measures to closely track income and expenditure and is scrutinised by the Finance Committee • We have commissioned an external broad review of Fundraising and will implement changes based on this. • We continue to have a strong focus on business development and partnerships in research and other areas • Our business planning has strong focus on prioritisation, and additional cost savings are actively explored • Our plans ensure that we will maintain unrestricted retained reserves within policy

Strategic risk	Strategies/plans for managing risks
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 DPO. There is ongoing staff training and oversight from Data Governance Group • 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 • In the last year we have made improvements to our data security including access controls (multifactor authentication) and further automated monitoring and reporting
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. • 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 pharmaceutical, academic institutions and funding partners 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 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

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 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 Cystic Fibrosis 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 2023/24 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £1.3m (2023: £2.9m) 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

We seek sponsorship and grants from partners that include other charities and pharmaceutical companies to enable us to run events so important for both healthcare professionals and people affected by cystic fibrosis. These events enable us to keep these audiences informed on all aspects of clinical care and research.

We would like to thank LifeArc, Vertex, Nordic Pharma and Optic 11 Life sponsorship for the UK Cystic Fibrosis Conference (UKCFC) held in October 2023. We also received sponsorship from Vertex for the Annual Registry Meeting held in October 2023.

The Trust organised the UK CF Clinical Trials Conference in March 2024 at the Royal Armouries Museum in Leeds. We again received an Independent Medical Education (IME) grant from Vertex towards the cost of the event along with sponsorship support from Recode Therapeutics.

> **"Enjoy your newborn and keep planning that big, bright future you want for them."**
>
> Jade, mum to Penelope, age 7

Jade and Penelope, who has CF

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 **29 October 2024** 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 2024 which the comprise the consolidated statement of financial activities, consolidated income and expenditure account, the consolidated and charitable parent company balance sheets and 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 2024 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.

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.

Responsibilities of trustees for the financial statements

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.

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 requires us to report to you if, in our opinion:

- 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.

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. 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 LLP

Shachi Blackmore (Partner)
For and on behalf of Buzzacott LLP, Statutory Auditor

130 Wood Street,
London
EC2V 6DL

Date 10 - TBA

Cystic Fibrosis Trust

Consolidated statement of financial activities

For the year ending 31 March 2024

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2024 £'000**	Total Funds 2023 £'000
Income and endowments from:						
Donations and legacies	2	8,715	3,687	-	**12,402**	10,417
Charitable activities						
Other trading activities		1,304	-	-	**1,304**	2,873
Investments	3	628	-	-	**628**	279
Other income		332	-	-	**332**	1,097
Total income		10,979	3,687	-	**14,666**	14,666
Expenditure on:						
Raising funds	4	3,068	6	-	**3,074**	3,322
Charitable activities						
Research	4	4,075	2,008	-	**6,083**	3,766
Clinical care	4	655	822	-	**1,477**	1,947
Information, advice and support	4	4,082	378	-	**4,460**	3,737
Total charitable activities		8,812	3,208	-	**12,020**	9,450
Total resources expended	4	11,880	3,214	-	**15,094**	12,772
Net income/(expenditure) before investment gains/(losses)		**(901)**	**473**	**-**	**(428)**	1,894
Realised investment (losses)/gains		(2)	-	-	**(2)**	(32)
Unrealised investment (losses)/gains		353	-	60	**413**	(176)
Net investment (losses)/gains		**351**	**-**	**60**	**411**	(208)
Net income/(expenditure)		**(550)**	**473**	**60**	**(17)**	**1,686**
Transfers between funds	20	679	(679)	-	**-**	-
Net movement in funds		129	(206)	60	**(17)**	1,686
Reconciliation of funds:						
Total funds brought forward		9,711	674	972	**11,357**	9,671
Total funds carried forward	20	**9,840**	**468**	**1,032**	**11,340**	11,357

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 23).

The notes on pages 82 to 105 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated and charity balance sheets

For the year ending 31 March 2024

	Notes	**Consolidated**		**Charity**	
		Total 2024 £'000	Total 2023 £'000	**Total 2024 £'000**	Total 2023 £'000
Fixed assets					
Tangible assets	7	**132**	155	**132**	155
Investments	8	**5,796**	5,388	**5,796**	5,388
		5,928	5,543	**5,928**	5,543
Current assets					
Debtors	9	**5,076**	6,589	**5,041**	5,396
Cash held as short term investment		**12,024**	11,485	**12,024**	11,485
Cash at bank and in hand		**4,046**	3,430	**4,036**	2,734
		21,146	21,504	**21,101**	19,615
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	10	**(6,065)**	(2,799)	**(6,065)**	(2,799)
Creditors and accrued charges	11	**(2,772)**	(2,257)	**(3,625)**	(2,500)
		(8,837)	(5,056)	**(9,690)**	(5,299)
Net current assets		**12,309**	16,448	**11,411**	14,315
Creditors: amounts falling due after one year					
Grants payable	10	**(6,727)**	(10,464)	**(6,727)**	(10,464)
Provisions: amounts falling due after one year	15	**(170)**	(170)	**(170)**	(170)
Total net assets		**11,340**	11,357	**10,442**	9,224

Continued on the next page

Cystic Fibrosis Trust

Consolidated and charity balance sheets (continued)

For the year ending 31 March 2024

	Notes	Consolidated Total 2024 £'000	Consolidated Total 2023 £'000	Charity Total 2024 £'000	Charity Total 2023 £'000
The funds of the charity:					
Endowment funds	21	**1,032**	972	**1,032**	972
Restricted income funds	22	**468**	674	**468**	674
Unrestricted funds					
Designated reserves					
Organisational reserves	20	**1,000**	1,000	1,000	1,000
Fixed asset reserve	20	**132**	155	132	155
Total designated funds		**1,132**	1,155	**1,132**	1,155
Retained reserves		**8,708**	8,556	**7,810**	6,423
Total unrestricted funds		**9,840**	9,711	**8,942**	7,578
Total charity funds	20	**11,340**	11,357	**10,442**	9,224

The notes on pages 82 to 105 form part of these financial statements.
As permitted by Section 408 of the Companies Act 2006, no separate Statement of Financial Activities or Income and Expenditure account has been presented for the charity alone.

Approved and authorised for issue by the Trustees on **29 October 2024** 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 2024

	2024 £'000	2023 £'000
Net cash provided by/(used) operating activities (Note A)	**565**	(1,669)
Cash flows from investing activities:		
Dividends and interest	**628**	279
Purchase of property, plant and equipment	**(41)**	(161)
Purchase of investments	**(255)**	(417)
Movement in cash awaiting investment	**(21)**	(16)
Proceeds of sales of investments	**279**	437
	590	122
Increase in cash held as short term investments	**(539)**	(220)
Increase/(decrease) in cash (Note B)	**616**	(1,767)

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

	2024 £'000	2023 £'000
Net income for the reporting period (as per the statement of financial activities)	**(17)**	1,686
Adjustment for:		
Depreciation charges	**64**	25
Dividends and interest from investments	**(628)**	(279)
(Gains)/losses on investments	**(411)**	208
Decrease/(increase) in debtors	**1,513**	(2,641)
Increase/(decrease) in creditors	**44**	(838)
Increase in provisions	**-**	170
Net cash provided by/(used in) operating activities	**565**	(1,669)

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

	2024 £'000	2023 £'000
Cash and cash equivalents at the beginning of the reporting period	**14,915**	16,462
Change in cash and cash equivalents in the reporting period	**616**	(1,767)
Increase in short-term investments	**539**	220
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)	**16,070**	14,915

	2024 £'000	2023 £'000
Analysis of cash and cash equivalents:		
Notice deposits (less than 3 months)	**12,024**	11,485
Cash at bank and in hand	**4,046**	3,430
Total cash and cash equivalents	**16,070**	14,915

Cystic Fibrosis Trust
Notes to the Financial Statements
For the year ending 31 March 2024

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 106. 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 surplus of the parent charity was £853,000 (2023: £1,496,000).

Cystic Fibrosis Services Limited's results for the year ended 31 March 2024 are summarised in note 13. The net surplus for the year of £899,000 (2023; £2,134,000) 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.

1. Accounting policies

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 from 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 & 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).

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 forecasts and projections to the year ending 31 March 2028, 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.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ending 31 March 2024

2. Income from donations and legacies

	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	Total 2024 £'000	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	Total 2023 £'000
Branches, Groups and Community	2,224	45	**2,269**	2,147	44	2,191
Legacies	2,745	196	**2,941**	1,240	3	1,243
Individual donations	309	40	**349**	383	74	457
Corporate	267	5	**272**	149	51	200
Regular giving and appeals	1,204	2	**1,206**	1,232	2	1,234
Trusts	187	3,093	**3,208**	13	3,056	3,069
Appeal for Innovation Hub	-	306	**306**	-	610	610
Donations in kind	1,543	-	**1,543**	1,234	-	1,234
NHS National Services England and Scotland	236	-	**236**	179	-	179
Total income from donations and legacies	8,715	3,687	**12,402**	6,577	3,840	10,417

Total income from donations and legacies includes gift aid of £455,000 (2023: £411,000).

Donations in kind refer to non-monetary donations received from partner organisations. In 2024 £1,543,000 (2023: £1,234,000) was donated in the form of 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 below.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ending 31 March 2024

3. Investment Income

	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	**Total 2024 £'000**	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	**Total 2023 £'000**
Income from listed investments	607	-	**607**	279	-	279
Bank interest	21	-	**21**	-	-	-
Total investment income	628	-	**628**	279	-	279

4. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2024 £'000**	**Total 2023 £'000**
Raising funds						
Fundraising	-	-	2,297	438	**2,735**	2,649
Trading and merchandising	-	326	13	-	**339**	673
Total raising funds	-	326	2,310	438	**3,074**	3,322
Charitable activities						
Research	1,976	1,636	1,499	972	**6,083**	3,766
Clinical care	454	77	711	235	**1,477**	1,947
Information, advice and support	149	167	3,432	712	**4,460**	3,737
Total charitable activities	2,579	1,880	5,642	1,919	**12,020**	9,450
Total resources expended	**2,579**	**2,206**	**7,952**	**2,357**	**15,094**	12,772

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 & OD £'000	HQ & Facilities £'000	**Total 2024 £'000**	**Total 2023 £'000**
Fundraising	108	42	128	59	101	**438**	**431**
Research	240	93	285	130	224	**972**	**638**
Clinical care	58	22	69	32	54	**235**	**318**
Information, advice and support	176	68	208	96	164	**712**	**609**
Total costs	**582**	**225**	**690**	**317**	**543**	2,357	1,996

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2023 £'000**
Raising funds					
Fundraising	-	-	2,218	431	**2,649**
Trading and merchandising	-	609	64	-	**673**
Total raising funds	-	609	2,282	431	**3,322**
Charitable activities					
Research	601	1,345	1,182	638	**3,766**
Clinical care	999	58	572	318	**1,947**
Information, advice and support	164	103	2,861	609	**3,737**
Total charitable activities	1,764	1,506	4,615	1,565	**9,450**
Total resources expended	**1,764**	**2,115**	**6,897**	**1,996**	**12,772**

4. Expenditure (continued)

Analysis of allocated support costs – prior year

	Governance £'000	Finance £'000	IT Support £'000	People & Organisational Development £'000	HQ & Facilities £'000	**Total 2023 £'000**
Fundraising	41	59	140	60	131	**431**
Research	61	87	207	89	194	**638**
Clinical care	30	44	103	44	97	**318**
Information, advice and support	58	84	197	85	185	**609**
Total costs	190	274	647	278	607	**1,996**

Net income for the year is stated after charging

	2024 £'000	2023 £'000
Auditors remuneration excluding VAT	**29**	28
Depreciation	**64**	25
Operating leases – building	**269**	271
Operating leases – other	**3**	7
Trustees' travel expenses	**1**	2

5. Grants

Grants were awarded during the year as follows:

	2024 £'000	2023 £'000
Grants to institutions	**4,453**	3,565
Grants to individuals	**332**	414
	4,785	3,879

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:

	2024 £'000	2023 £'000
University of Cambridge	1,210	121
Imperial College London / Royal Brompton Hospital	1,116	100
Newcastle University	850	20
University of Liverpool	182	17
Action Medical Research	105	-
Innovation Hub Cambridge	100	241
Medical Research Council	100	50
Utrecht University, Netherlands	75	-
UCL	50	-
Medicines Discovery Catapult Limited	42	81
OmniSpirant Limited	21	-
Leeds Beckett University	21	-
Queen's University Belfast	8	26
University of Nottingham	-	115
UCL Great Ormond Street	-	46
University of Sheffield	-	753
Cystic Fibrosis Canada (Fibrose Kystique)	-	116
Royal College of Surgeons in Ireland	-	96
MDC (CF AMR Syndicate)	-	20
Western General Hospital	-	78
Medusa Pharmaceuticals	-	50
Ockham Biotech Limited	-	50
Other Institutions (less than £20k)	68	28
	3,948	2,008
Trial Coordinator commitments made to CTAP centres (see note)	436	953
Registry support grants made to various CF centres	326	609
Release of grants made in previous years (see note below)	(257)	(5)
Total grants made to institutions	**4,453**	3,565

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme.

Various grants totalling £257,000 (2023: £5,000) 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

	2024 £'000	2023 £'000
Salaries	**5,107**	4,481
Temporary Staff	**23**	80
Social security costs	**547**	493
Other pension costs	**318**	270
	5,995	5,324

The average number of staff employed by the Trust:	**2024 No.**	2023 No.
Research	**22**	17
Clinical care	**8**	8
Information, advice and support	**43**	38
Fundraising	**38**	36
Management	**2**	2
Finance	**6**	6
IT and project management support	**8**	8
HR and organisation development	**6**	5
Facilities	**1**	1
Total average monthly headcount	**134**	121

The number of employees whose gross salary exceeded £60,000 in the year was:	**2024 No.**	2023 No.
£60,001 – £70,000	**4**	1
£70,001 – £80,000	**3**	2
£80,001 – £90,000	**1**	2
£120,001 – £130,000	**-**	1
£130,001 – £140,000	**1**	-

Pension contributions to defined contribution pension schemes for employees noted above totalled £44,083 (2023: £33,525).

The total remuneration paid to key management personnel, including social security and employer pension contributions, was £657,196 which relates to 8 individuals who served on the Senior Leadership Team during the year (2023: £621,941 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. £1,201 of expenses were settled on behalf of 5 Trustees (2023: £4,684 was paid to 5 Trustees) as meetings were held equally in person and remotely during the period.

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 2023	630	929	286	462	183	2,490
Additions	-	41	-	-	-	41
Disposals	-	-	-	-	-	-
At 31 March 2024	630	970	286	462	183	2,531
Depreciation						
At 1 April 2023	630	871	243	408	183	2,335
Disposals	-	-	-	-	-	-
Charge for the year	-	33	11	20	-	64
At 31 March 2024	630	904	254	428	183	2,339
Net book value						
At 31 March 2024	-	66	32	34	-	132
At 31 March 2023	-	58	43	54	-	155

8. Investments

Group and Charity	**Total 2024 £'000**	Total 2023 £'000
Opening market value	5,388	5,604
Adjustment to brought forward balance	-	12
Additions at cost	255	417
Disposals at opening book value	(230)	(469)
Net gains/(losses) on investments	362	(192)
	5,775	5,372
Change in cash	21	16
Closing market value	5,796	5,388

Represented by:	**Total 2024 £'000**	Total 2023 £'000
Equities	587	589
Fixed Interest and multi-asset funds	4,909	4,513
Property	184	162
Cash	116	124
	5,796	5,388

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 2024 was £4,809,000 (2023: £4,417,000).

The historical cost of investments held within the Trust portfolio at 31 March 2024 was £4,853,000 (2023: £4,853,000).

9. Debtors

	Group 2024 £'000	Group 2023 £'000	**Charity 2024 £'000**	Charity 2023 £'000
Trade debtors	35	1,225	-	32
Prepayments and accrued income	4,981	5,293	4,981	5,293
Other debtors	60	71	60	71
	5,076	6,589	5,041	5,396

10. Grants Payable

Group and charity	**2024 £'000**	2023 £'000
Opening grant creditor	13,263	13,654
Grants paid during the year	**(4,924)**	(5,827)
Trial Coordinator commitments made to CTAP centres and payable within one year	**436**	953
Registry support grants made to various CF Centres and payable after one year	**326**	609
Release of grants made in previous years	**(257)**	(5)
Research grants approved and payable within one year	**1,380**	2,792
Research grants approved and payable after one year	**2,568**	1,087
Closing grant creditor	**12,792**	13,263
Represented by		
Grants committed and awaiting claim		
Grants due within one year	**6,065**	2,799
Grants due after one year	**6,727**	10,464
	12,792	13,263

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 2024 £'000	Group 2023 £'000	**Charity 2024 £'000**	Charity 2023 £'000
Trade creditors	**857**	610	**857**	600
Other creditors	**41**	36	**41**	36
Other taxation and social security	**147**	137	**147**	137
Amounts owed to subsidiary undertaking	**-**	-	**932**	257
Accruals and deferred income	**1,727**	1,474	**1,648**	1,470
	2,772	2,257	**3,625**	2,500

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12. Financial Instruments

	Group 2024 £'000	Group 2023 £'000	**Charity 2024 £'000**	Charity 2023 £'000
Financial assets measured at amortised cost	**16,109**	16,145	**14,224**	14,224
Financial assets measured at fair value	**5,796**	5,388	**5,796**	5,388
Financial liabilities measured at amortised cost	**(15,063)**	(15,338)	**(15,142)**	(15,352)
Net financial assets measured at amortised cost	**6,842**	**6,195**	**4,878**	**4,287**

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 subsidary 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 medical services, information and data system support and the merchandising of marketing materials.

Summary profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March 2024:

	Total 2024 £'000	Total 2023 £'000
Sales and sundry income	**1,304**	2,873
Cost of sales and administration	**(339)**	(673)
Intercompany recharges	**(66)**	(66)
Net contribution to parent charity	**899**	2,134

13. Interest in subsidary undertaking (continued)

	Total 2024 £'000	Total 2023 £'000
Current assets		
Debtors	**968**	1,450
Cash at bank	**10**	696
	978	2,146
Creditors: amounts falling due within one year	**(79)**	(12)
Net assets	**899**	2,134
Capital and reserves		
Called up share capital (£2)	**-**	-
Profit and loss account	**899**	2,134
Shareholder's funds	**899**	2,134

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 the 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	
	2024 £'000	2023 £'000	**2024 £'000**	2023 £'000
Within one year	**271**	271	**2**	5
Between two and five years	**-**	271	**6**	18

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

15. Provisions

The Trust's office at One Aldgate, London is under a lease that expires on 31 March 2025. Under the terms of the lease the Trust must restore the property to the condition prior to the Trust taking possession of the office. After seeking advice from surveyors, the Trust has maintained a provision of £170,000 (2023: £170,000) for this work.

16. Contingent assets

As at 31 March 2024, the charity had been notified of a further four 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 £360,000 which has not been accrued.

17. 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 £16,701 (2023: £11,911). In addition, 6 of the trustees (2023: 7 trustees) were involved in fundraising activities carried out by regional fundraising branches.

Five trustees claimed expenses totalling £1,201 in the year (2023: four trustees totalling £2,000). These expenses related to travel and subsistence.

18. Post balance sheet events

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

19. Analysis of net assets between 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**
Current liabilities	(8,837)	-	-	**(8,837)**
Liabilities due in more than one year	(6,727)	-	-	**(6,727)**
Provisions due in more than one year	(170)	-	-	**(170)**
	9,840	1,032	468	**11,340**

Prior year

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2023 £'000**
Tangible fixed assets	155	-		155
Investments	4,416	972	-	5,388
Current assets	20,830	-	674	21,504
Internal obligations	(5,056)	-	-	(5,056)
Current liabilities	(10,464)	-	-	(10,464)
Liabilities due in more than one year	(170)	-	-	(170)
	9,711	972	674	11,357

20. Current year fund movements 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 (Note 21)	972	60	-	-	-	**1,032**
Restricted funds (Note 22)	674	-	3,687	(3,214)	(679)	**468**
Unrestricted funds						
Designated reserves						
Organisational reserve	1,000	-	-	-	-	**1,000**
Fixed asset reserve	155	-	-	-	(23)	**132**
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**

Movements in funds for prior periods are presented in note 24.

Designated Funds

- Organisational reserve: is designated for investment in process improvement and our digital/data strategy, including implementation of a new Customer relationship management (CRM) system and for the costs associated with moving to a new office in early 2025.
- The designated fixed assets reserve matches the net book value of the Trust's tangible fixed assets. These assets support the Trust's ongoing work and are not readily convertible to cash.

As explained on page 68, the Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, at a level that mitigates the risks associated with fluctuations in fundraised income and cost pressures and ensure funds are available to maintain operational activity and invest in key strategic areas to support future impact and growth.

The Board believes an appropriate level of reserves is in the range of above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £4m and £6m.

At 31 March 2024, after adjusting for the designated reserves explained below, the Trusts' Unrestricted Reserves were £8.7m (2023: £8.6m). This level reflects the impact of a number of exceptional items in recent years which have acted to limit the impact of deficits from core activities.

The Trustees have approved a business plan and substantial deficit budget for the next financial year which maintains services and grant awards at a level similar to previous years despite the continued challenge of the wider economic climate and therefore Unrestricted reserves are forecast to fall to £7.5m at March 2025 and reduce further to £5.9m by March 2026 which will bring the Trust within the range detailed in its reserves policy.

Transfers between funds

The following transfers were made between funds:

- 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.

21. 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**

Movements in funds for prior periods are presented in note 24.

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.

22. 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						
Gene Therapy Research	-	-	3	(3)	-	-
General medical research	-	-	260	(260)	-	-
Sport England – Helping the active stay active	32	-	-	-	-	**32**
University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis	-	-	34	(34)	-	-
UCL Great Ormond Street Institute of children	-	-	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)	-	-
Life Arc	-	-	62	(38)	-	**24**
Quality Improvement Project	35	-	-	-	-	**35**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**437**	**-**	**2,181**	**(2,002)**	**(679)**	**243**

22. Restricted 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						
Clinical Trials Accelerator Platform (CTAP)	-	-	804	(804)	-	-
CTAP Clinical Trials Conference	14	-	7	(16)	-	**5**
Gut symptoms	39	-	27	-	-	**66**
Carols by Candlelight	6	-	3	(4)	-	**5**
HDRUK2023-Improving Transparency of Processes	-	-	15	(5)	-	**10**
Other older funds	36	-	-	-	-	**36**
Total other funds	**95**	**-**	**856**	**(829)**	**-**	**122**
Total restricted funds	**674**	**-**	**3,687**	**(3,214)**	**(679)**	**468**

Movements in funds for prior periods are presented in note 24.

Restricted income funds are donations received during the year to support the Trust's commitment to contribute £3.5m to Cambridge University as part of the Innovation Hub flagship programme are recorded as restricted income funds. The funds are used to fund any additional commitments to the Innovation Hub made during the year.

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 BBC Children in Need.
- **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.

23. Prior year consolidated statement of financial activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2023 £'000**
Income and endowments from:					
Donations and legacies	2	6,577	3,840	-	**10,417**
Charitable activities					
Other trading activities		2,873	-	-	**2,873**
Investments	3	279	-	-	**279**
Other income:		1,097	-	-	**1,097**
Total income		10,826	3,840	-	**14,666**
Expenditure on:					
Raising funds	4	3,301	21	-	**3,322**
Charitable activities					
Research	4	3,122	644	-	**3,766**
Clinical care	4	696	1,251	-	**1,947**
Information, advice and support	4	3,360	377	-	**3,737**
Total charitable activities		7,178	2,272	-	**9,450**
Total resources expended	4	10,479	2,293	-	**12,772**
Net income/(expenditure) before investment gains/(losses)		**347**	**1,547**	**-**	**1,894**
Realised investment gains/(losses)		(32)	(32)	-	**(32)**
Unrealised investment gains/(losses)		(102)	-	(74)	**(176)**
Net investment gains/(losses)		**(134)**	**(32)**	**(74)**	**(208)**
Net (expenditure)/income		**213**	**1,547**	**-**	**1,686**
Transfers between funds	23	1,144	(1,144)	-	**-**
Net movement in funds		1,357	403	(74)	**1,686**
Reconciliation of funds:					
Total funds brought forward		8,354	271	1,046	**9,671**
Total funds carried forward	**23**	**9,711**	**674**	**972**	**11,357**

24. Prior year movements in funds

Summary

	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
The funds of the charity:						
Endowment funds (note 21)	1,046	(74)	-	-	-	**972**
Restricted funds (note 22)	271	-	3,840	(2,293)	(1,144)	**674**
Unrestricted funds:						
Designated reserves						
Organisational reserve	-	-	-	-	1,000	**1,000**
Fixed asset reserve	19	-	-	-	136	**155**
Appeal deficit	(1,285)	-	-	-	1,285	**-**
Total designated funds	(1,266)	-	-	-	2,421	**1,155**
Operating reserves	3,411	-	-	-	(3,411)	**-**
Retained reserves	6,209	(134)	10,826	(10,479)	2,134	**8,556**
Total unrestricted funds	**8,354**	**(134)**	**10,826**	**(10,479)**	**1,144**	**9,711**
Total chairty funds	**9,671**	**(208)**	**14,666**	**(12,772)**	**-**	**11,357**

Endowment funds	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2023 £'000
Ena Bennie Endowment	530	(39)	-	-	-	491
EW Joseph Endowment	175	(13)	-	-	-	162
Joseph Levy Endowment	293	(22)	-	-	-	271
Sally Wrigley Memorial fund	20	-	-	-	-	20
Other endowment funds	28	-	-	-	-	28
Total endowment funds	**1,046**	**(74)**	**-**	**-**	**-**	**972**

24. Prior year movements in funds (continued)

Restricted funds

	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
Restricted income funds						
Appeal: Innovation Hub at Cambridge	-	-	1,270	(241)	(1,029)	-
Restricted funds related to research:						
Genetic therapies	-	-	3	-	(3)	-
General medical research	-	-	34	(34)	-	-
Sport England – Helping the active stay active	7	-	25	-	-	**32**
Imperial SRC: *Pseudomonas aeruginosa*	-	-	10	-	(10)	-
SRC013-M GRAY Newcastle	-	-	1	-	(1)	-
Sheffield SRC: Gastrointestinal cancer	-	-	57	-	(57)	-
UCL/GOSH SRC: Therapeutic gene editing	-	-	16	-	(16)	-
SRC022 – Co Funded with CFF	-	-	-	-	-	-
SRC Costed Extensions	-	-	186	(186)	-	-
SRC025 – University of Sheffield (Co Funded with CFF)	-	-	366	-	23	**366**
UK CF Infection Biorepository	-	-	32	(32)	-	-
Carols by Candlelight 2022	-	-	12	(6)	-	**6**
CF Active Programme	-	-	5	(50)	45	-
Transition Information Resources	15	-	-	-	(15)	-
Quality Improvement Project	35	-	-	-	-	**35**
Aberdeen Unit	-	-	-	-	-	-
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**61**	**-**	**2,107**	**(549)**	**(1,086)**	**443**

24. Prior year movements in funds (continued)

	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
Restricted funds related to Information and Support						
E W Joseph/Homecare grants	3	-	-	(3)	-	-
Joseph Levy/Education Grants	4	-	53	(46)	-	**11**
Young Lives programme	29	-	26	(39)	-	**16**
Support services (inc. welfare grants)	112	-	240	(192)	(45)	**115**
Helpline	-	-	5	(5)	-	-
Forum	22	-	-	(9)	(13)	-
Young Entrepreneurs	3	-	16	(19)	-	-
Total funds related to Information and Support	**173**	**-**	**340**	**(313)**	**(58)**	**142**

Other funds						
Coombe Hill	8	-	5	(13)	-	-
Clinical Trials Accelerator Platform (CTAP)	-	-	1,262	(1,262)	-	-
Digital Health Programme	-	-	134	(134)	-	-
CTAP digital conference	(7)	-	43	(22)	-	-
Gut Symptoms	-	-	39	-	-	**39**
Other older funds	36	-	-	-	-	**36**
Total other funds	**37**	**-**	**1,483**	**(1,431)**	**-**	**89**
Total Restricted Reserves	**271**	**-**	**3,840**	**(2,293)**	**(1,144)**	**674**

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)**
- Professor Rosalind Smyth CBE FMedSci (resigned 30 November 2023)
- Sean Collins
- Anne Byrne
- Richard Hoey
- Michelle Shore
- Joanna Barrett
- Sophie Pierce
- Sonya Trivedy
- Professor Martin Walsh
- Jane Wainwright (appointed 29 September 2023)
- Neil Priscott (appointed 29 September 2023)
- Dr Maya Desai (appointed 23 May 2024)

Engagement Committee

(Previously Marketing, Communications & Income Generation Committee)

- Richard Hoey **(Chair)**
- Sean Collins
- Joanna Barrett
- Sophie Pierce
- Neil Priscott (appointed February 2024)

Finance Committee

- Sean Collins **(Chair)**
- Anne Byrne
- David Sawer (Independent member)
- 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 September 2024)

Senior Leadership Team

- David Ramsden – Chief Executive
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research and Healthcare Data
- Simon Hawkins – Director of Finance and Resources (resigned June 2023)
- Alex Fowles - Director of Finance and Resources (appointed June 2023)
- Dr Sarah Clarke - Associate Director, Data and Quality Improvement

Company Secretary

- Alex Fowles

Principal and Registered Office

One Aldgate
London
EC3N 1RE

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 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 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 SRC Awards (April 2024)

SRC Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment
SRC012*	Dr Daniel Peckham, St James' Hospital	Managing GI Symptoms	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC014*	Professor Jane Davies, Imperial College London	Reducing negative affects of antibiotics	Personalised Approach to *Pseudomonas Aeruginosa* (PAPA)	£750,000
SRC015*	Dr Darius Armstrong-James, Imperial College London	Diagnosis of lung infections	TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis	£750,000
SRC016*	Professor Pietro Cicuta, University of Cambridge	Improving lung health, including tackling infection	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC018	Professor Steven Renshaw, University of Sheffield	Growing older with CF	Preventing gastrointestinal cancer in cystic fibrosis	£749,214
SRC019	Professor James Shaw, University of Newcastle	Preventing CF diabetes	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	Options for those not able to take modulators	Therapeutic gene editing of CFTR. Co-funded with CFF	£749,924
SRC021	Professor David Sheppard, University of Bristol	Options for those not able to take modulators	The CFTR Folding and Function SRC	£747,972
SRC022	Professor Jo Fothergill, University of Liverpool	Reducing negative affects of antibiotics	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	Managing GI Symptoms	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	Options for those not able to take modulators	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	Improving lung health, including tackling infection	Pulmonary magnetic resonance imaging for cystic fibrosis. Co-funded with CFF	£366,536 (Total award: £733,072)
SCR026	Dr Mike Gray, University of Newcastle	Options for those not able to take modulators	PTSuppress – Novel lead compounds as potential suppressor drugs for CFTR PTC mutations	£799,808
SRC027	Dr Imogen Felton and Professor Jane Davies, Royal Brompton Hospital	Physical health	MATRIARCH_CF – MATeRnal, InfAnt, Reproductive and Child Health in CF	£799,089

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

Open Development Awards (April 2024)

Development Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment
DA001	Professor Nicholas Simmonds, Royal Brompton Hospital	Options for those not able to take modulators	ADVANCE-CFTR: Advanced Diagnostic Validation and Novel Clinical Evaluation across the CFTR spectrum	£299,536
DA002	Dr Freddy Frost, University of Liverpool	Growing older with CF	Investigating The Cardiovascular Health of people living with Cystic Fibrosis (ITCH-CF)	£173,846

Open VIA Awards (April 2024)

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA035	Dr Fred Piehl, Imperial College London	Improving lung health, including tackling infection	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data	£42,500	£42,500 Imperial College London
VIA036	Dr Fred Piehl, Imperial College London	Improving lung health, including tackling infection	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	Improving lung health, including tackling infection	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000	£50,000 University of Nottingham
VIA068	Professor Jane Davies, Imperial College London	Improving lung health, including tackling infection	The idealised LCI (i-LCI): tuning in on the 'silent years' of paediatric CF	£98,595	£550,000 EPSRC & Imperial College London
VIA070	Dr Laura Nolan, Imperial College London	Improving lung health, including tackling infection	Understanding interbacterial competition in the cystic fibrosis lung to identify opportunities for intervention	£30,000	£206,000 Imperial College London
VIA072	Dr Elizabeth Crone, Papworth Hospital	Diagnosis of lung infections	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis	£36,000	£108,000 Owlstone Medical & Papworth Hospital
VIA081	Dr Anand Shah, Imperial College London	Improving lung health, including tackling infection	FREAL – Fungal Resistance Evolution and Acquisition in chronic lung disease	£38,000	£247,350 MRC – Clinical Academic Research Partnership Award
VIA083	Dr Paul McNally, Our Lady's Children's Hospital	Long-term and non-lung effects of CF treatments	RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in people with CF)	£97,297	£3,000,000 CFF & CF Ireland

Open VIA Awards (April 2024)

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA092	Dr James Reihill, Queen's University Belfast	Options for those not able to take modulators	The ubiquitylation system as a therapeutic target in CF	£15,000	£101,127 Almac Discvoery, UKRI Innovation Scholars Secondment
VIA098	Dr Jonathan Cox, Aston University	Reducing negative effects of antibiotics	Discovery of new and repurposed ß-lactamase inhibitors for improving *Mycobacterium abscessus* treatment	£25,000	£25,000 ANTRUK (Antibiotic Resistance UK)
VIA104	Dr Beverley Isherwood, Medicines Discovery Catapult	Improving lung health, including tackling infection	Support for the UK CF Infection Biorepository	£95,000	£300,000 CFF
VIA105	Professor Alan Smyth, University of Nottingham	Long term and non-lung effects of CF treatment	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 of lung infections	Development of a rapid and highly sensitive analytical method for the detection of bio-markers of infection in samples from people with CF	£37,726	£886,437 BBSRC
VIA111	Professor Lorraine Martin, Queen's University Belfast	Options for those not able to take modulators	Developing a novel regenerative gene therapy platform technology for inhaled CF therapy	£26,000	£220,000 Emily's Entourage
VIA115	Dr Freddy Frost, University of Liverpool	Diagnosis 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	Reducing negative affects of antibiotics	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	Reducing negative affects of antibiotics	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	Long term and non-lung effects of CF treatment	ENHANCE – Establishing Natural History in an Advanced New CF Care Era	£96,424	£4,800,000 CFF
VIA119	Dr Mina King, University College London	Improving lung health, including tackling infection	Understanding Regional Lung Physiology in Cystic Fibrosis Using Advanced MRI	£49,994	£1,800,000 MRC Career Development Award

Open VIA Awards (April 2024)

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA121	Professor Ruth Keogh and Dr Emily Granger, London School of Hygiene and Tropical Medicine	Reducing negative affects of antibiotics	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	Options for those not able to take modulators	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	Options for those not able to take modulators	Cell engineering optimisation and electrophysiology assessment of OS001 CFTR Extracellular Vesicles (EVs)	£21,242	£22,360 OmniSpirant Limited
VIA125	Dr Claire Edmondson, MRC Clinical Academic Research Partnerships	Improving lung health, including tackling infection	The effects of sex hormones and menstruation on lung function and respiratory exacerbations in adolescents with cystic fibrosis	£99,990	£255,224 – pending peer review Wellbeing of Women
VIA126	Professor Laura Ashley, Leeds Beckett University	Growing older with CF	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 Leeds Beckett University

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

Uniting for a life *unlimited*