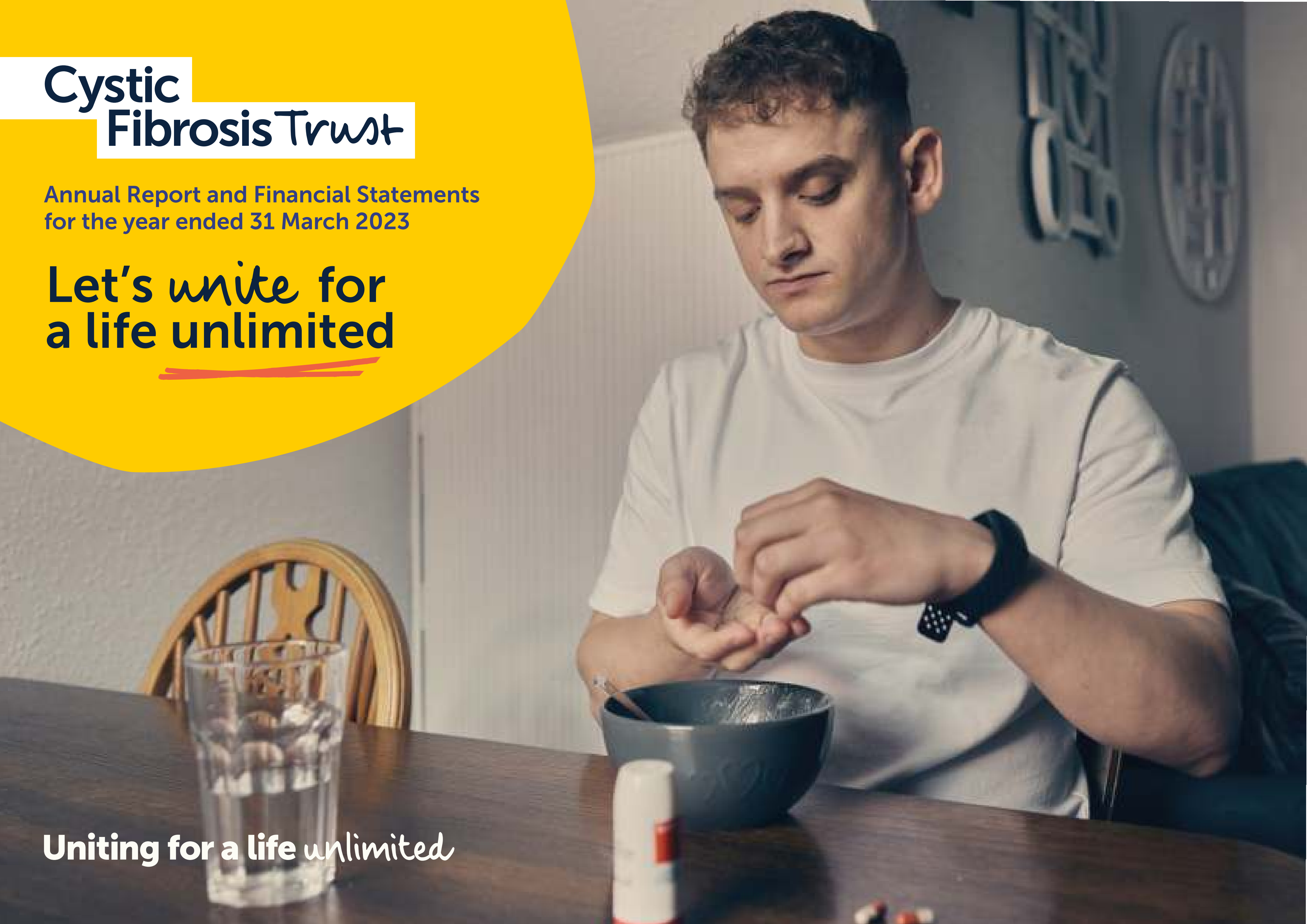
Annual Report and Financial Statements for the year ended 31 March 2023

Let's unite for a life unlimited



Jamie Fox, who has CF and is a fundraiser for the Trust

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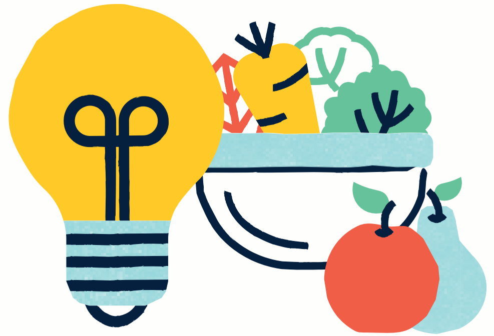
Thanks to you, in 2022/23...

1,202 people with CF enrolled on to a CTAP clinical trial, helping to develop new medicines for everyone with CF. This is nearly four times greater than last year.

We co-funded a new Strategic Research Centre (SRC) to understand in detail what happens to bicarbonate transport in CF, with the hope that the lab-based studies could lead to ideas about new ways to treat CF in the future – tailored to individuals, based on the form of CF they have.

We helped people with CF to access over £900,000 in benefits through our Welfare and Benefits Advice service.

Our Helpline responded to 4,799 enquiries, making this the busiest year on record. We continued to provide support to our community through the cost of living crisis.



We launched a new time-limited cost of living fund, providing 342 grants over the winter period to support those on low incomes to afford food and essentials.

The second year of our #CFTruths campaign reached over 10 million through out of home advertising and had a reach of over 11 million via a combination of national and regional news.

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2023. 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 60 to 103 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 2022/23 Annual Report.

As this report demonstrates, the past year has been one of wide-ranging activity and innovation as we continue to focus on achieving our vision of a 'Life Unlimited' by cystic fibrosis (CF).

The year started with optimism that we had left the worst challenges of the COVID-19 pandemic behind us. However, as we all know we were then faced with new concerns led by a war in Ukraine, a cost of living crisis and some domestic political turmoil.

Against this everchanging backdrop, throughout the year, we have continued to see the impact Kaftrio is having on the lives of many people with CF in our community. We have come to understand more about the scale and scope of the drug's positive impact as well as the various challenges that some people have experienced.

We recognise that the current available drugs are not a cure, and that too many people still have no therapies that work with their specific mutations. There is still much to do until everyone with CF can live a life unlimited.

These factors have helped to inform what has been a key area of focus for us this year, the James Lind Alliance Research Priority Refresh. This involved consulting the CF community on their priorities for research, which will now help direct research investments by the Trust and others in the years ahead.

> "Our benefits and income maximization advice has continued to be vitally important and we have helped people to access around £900,000 in social support that they were eligible for during the year."

A further element of our research activity has been the continued development of the involvement of people with CF in clinical trials through the CTAP (Clinical Trials Accelerator Platform) programme. Over the year we have seen an exciting increase in the level of early phase trial activity, which includes a focus on new approaches to genetic therapies.

Richard Hunt CBE

We have continued to fund high quality research through our Strategic Research Centre programme covering areas such as Magnetic Research Imaging (MRI), and whether this could be used to track changes in lung health over time and how the flow of bicarbonate in different organs is affected by CF.

As the needs of people with CF change, so have the ways in which we offer information and support. Mindful of the particular financial challenges that some people within our community are facing, we have been advocating hard for their fair treatment. This includes the ending of all prescription charges in England for those living with CF. We also launched a specific Cost of Living Fund, which awarded 342 grants to people in our community who urgently need help.

Our benefits and income maximisation advice has continued to be vitally important and we have helped people to access around £900,000 in social support that they were eligible for during the year.

This year saw the launch of our brand-new podcast CForYourself. In each episode our host Lucy has a virtual 'cup of tea and a chat' with others in the CF community. They talk openly and honestly about a whole range of topics, from exercise regimes and employment to parenting and mental health.

We entered the second year of our awareness campaign, #CFTruths. This is a vital way we are telling the real story of life with CF to the widest possible public audience. We want to ensure that people with CF can live their lives to the fullest, in a world that understands them and understands that despite progress there is still no cure.

We must acknowledge that we can only do our work and everything mentioned within this report, due to the incredible commitment of our supporters and the CF community. Thank you. Your determination and passion motivates us every day and we won't stop until that vision of a life unlimited is a true reality for everyone with CF.

Finally, I must also express my thanks to the whole Trust team and my colleagues on the Board for their commitment and support over the last year. Sincere thanks to you all.

As I have said we won't stop until we have achieved our vision and I know our inspirational community will be with us every step of the way.

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.

More than 10,900 people in the UK live with the condition, having to undergo a brutal daily regimen of physiotherapy and take up to 60 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.

We're uniting for a life unlimited.

Our goals

Physically well

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

Mentally well

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

Fulfilment

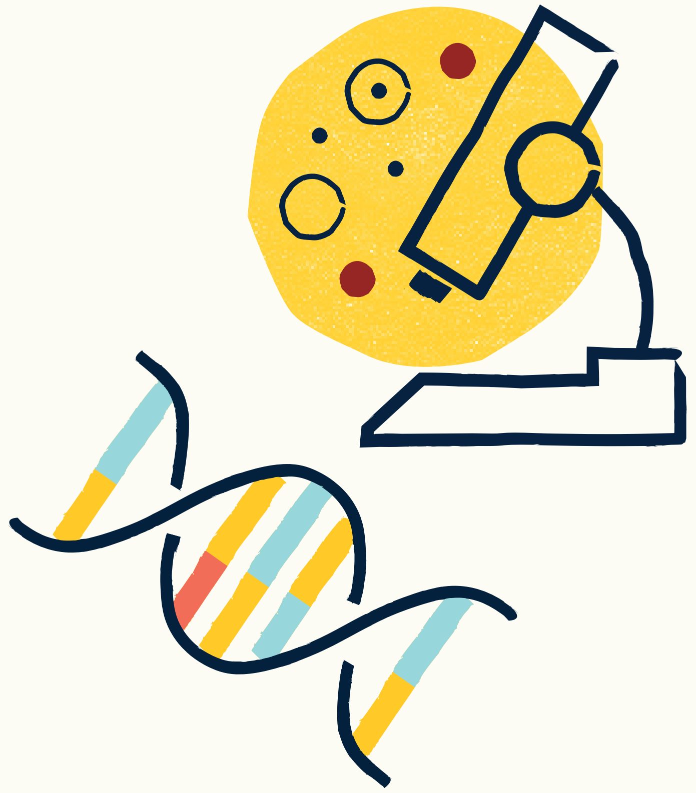
Together, we can lead the life we want as part of a connected community

Measuring success

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

Uniting in research

Over the past year, we've invested in innovative research projects across a wide range of areas to help us achieve our goal of a life unlimited for everyone living with cystic fibrosis.



Research into more detailed ways to monitor the lung health of people with CF

With the changing nature of cystic fibrosis, it is important that we continue to develop new ways to monitor people's health. This information could be used to manage their condition from day to day and also to find out the effectiveness of new treatments being tested in CF clinical trials.

People with CF on CFTR modulators medicines, such as Kaftrio, have fewer lung symptoms than before they had access to these medicines. This can make it much harder to spot any flare-ups of lung infection or changes in lung function.

New types of CF treatment, such as CF genetic therapies that have the potential to benefit everyone with CF, are starting to be tested in clinical trials. Doctors and researchers need to be able to see any changes in lung function due to these medicines as soon as possible.

A new Strategic Research Centre approved for funding by Cystic Fibrosis Trust this year will investigate whether Magnetic Resonance Imaging (MRI) could be used to track changes in lung health over time. New MRI methods have been developed by Professor Jim Wild, the Principal Investigator of this SRC, who is based at the University of Sheffield. The programme is co-funded by the Trust and the CF Foundation in the United States.

> **"I have taken part in over 20 trials throughout my life. Put it this way, if there is a trial, I'm going to agree to be part of it because it's my way of giving back and returning some of the help and support I've had over the years with my CF. I feel I have a responsibility to help the community as they have helped me"**
>
> Emma

Professor Wild will lead a collaborative, multidisciplinary programme of research to investigate how and whether these MRI methods can be incorporated into CF clinical practice, including developing easy-to-use software to process the MRI data and working out the best ways to support CF clinicians and the people with CF and families they care for, in understanding the significance of this new information for people's lung health.

If successfully adopted into CF care, these new MRI methods could give a much more detailed assessment of the lung health of people with CF and reduce their exposure to X-rays (as they may require fewer lung CT scans that require X-rays).

Restoring the Fizz: Pharmacological repair of bicarbonate transport in cystic fibrosis

Some people will be familiar with the chemical sodium bicarbonate, sometimes known as 'bicarbonate of soda'. It can be used to help make cakes rise and is also used for cleaning things around the house. If you add hot water to a teaspoon of sodium bicarbonate in a bowl or a mug, it will fizz, and it's the 'bicarbonate' part of the chemical that causes this.

Bicarbonate is an important chemical in the body, too. It can help keep fluids at the right acid-alkali balance and has a job in the production and movement of mucus. For bicarbonate to do its job in the body, it relies on being moved by the CF protein that is damaged or missing in CF.

The CF protein is found in different parts of the body, including in the lungs, intestines, pancreas and liver. It acts as a gate allowing the movement or transport of two chemicals - chloride and bicarbonate - out of cells. Researchers have conducted many studies to understand how chloride transport is affected in cystic fibrosis, but they know less about how bicarbonate transport defects lead to the symptoms of CF.

In October, a new Strategic Research Centre (SRC) led by Dr Paola Vergani, based at UCL in London, will begin a programme of research to understand in detail what happens to bicarbonate transport in CF. They will investigate it in different forms of CF (where people have rarer CF mutations) and in different tissues, particularly the liver. They hope that their lab-based studies could lead to ideas about new ways to treat CF in the future – tailored to individuals based on the form of CF they have – and could lead to drugs that treat CF in a different way than the current medicines. This research is co-funded by the Trust and the Cystic Fibrosis Foundation in the United States.

> **"Cystic Fibrosis Trust is a huge support when it comes to raising awareness and making medical and treatment miracles happen. Without the Trust, the CF community would not have seen the incredible, life-changing advancements in medicine, education and care that have been made possible."**
>
> Siobhan, who has CF

Your bugs are helping researchers in the lab

When people with CF develop lung infections, the bacteria that cause them adapt themselves to living within the thick sticky mucus in the CF lungs. In order to test whether new medicines to treat CF infections are likely to work, lab-based researchers need access to the adapted forms, or 'strains' of these bugs. However, getting access to CF strains of bugs can be very difficult for scientists, holding up their research. It is a problem that members of the CF Antimicrobial Resistance (AMR) Syndicate wanted to address.

The CF AMR Syndicate is a partnership between Cystic Fibrosis Trust, Medicines Discovery Catapult (MDC) and LifeArc, a national medical research charity, to accelerate the development of new medicines to treat CF infections. It is a cross-sector initiative which enables the CF community to gain awareness of and timely access to these trials. People with CF are involved in all of the Syndicate's activities to ensure their needs and priorities are at its heart.

Following Venture and Innovation Awards (VIAs) from the Trust to pilot the scheme in the last few years, this year saw the launch of the Syndicate's UK CF Infection BioRepository, creating a central source of CF strains of infection-causing bugs. Coordinated by Medicines Discovery Catapult (MDC), the BioRepository brings together a network of eight centres in the UK who can work with researchers around the world, from universities, hospitals, and biotech and biopharmaceutical companies, to speed up CF research. The BioRepository is now supported by a grant from the CF Foundation in the United States.

More people with CF are taking part in research

Across the UK, the Trust has established a clinical trials network of 27 adult and paediatric CF centres. The Clinical Trials Accelerator Programme (CTAP), which is funded by the CF Foundation (CFF), provides invaluable support to sponsors (organisers of trials) with their delivery and a platform which enables the CF community to gain timely access to these trials. The Trust recently secured a further five years of funding, over $6m, from the CFF to maintain and further develop this network, which is a key part of the UK's CF research landscape.

The CTAP network of 27 centres from across the UK comprises a mix of research-focused clinicians and 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.

27 Centres form the CTAP network providing coverage of **~90% of the UK CF population**

Since CTAP's official launch in September 2017,

3,585 people with CF have been screened for a trial within the CTAP network (2,207 in the last 12 months)

2,270 enrolled on a trial (1,306 adults and 964 babies & children) - 1,202 were enrolled in the last 12 months which is nearly 4 times greater than the previous year

50 CF trials have been supported by CTAP, with 15 studies open to recruitment in the last 12 months

> **"It's very exciting to hear about potential clinical trials for genetic therapies. I try to stay positive that something will come along for my daughter that could be a game changer, but there are times when I can't help but feel despondent. This gives me real hope that a 'wonder' drug could help her and give her more of a 'normal' life with no limitations.**
>
> Rachel, mum to Anna who has CF

Rachel (right) and daughter Anna

> **"As a parent to a child with CF, it can feel like there are too many components that sit outside of your control. But being a part of QuestionCF has enabled us to feel like we're doing something proactive. It's refreshing to be part of a project that's actually giving those in the community a voice and a chance to share their own perspective. It's a really optimistic time to be part of the CF community, but there's a lot that needs to be done to make sure that the needs of everyone with CF are met. Those that have access to modulators, and those that don't."**
>
> Nicole and Martyn, parents to Arlo who has CF

CF genetic therapies

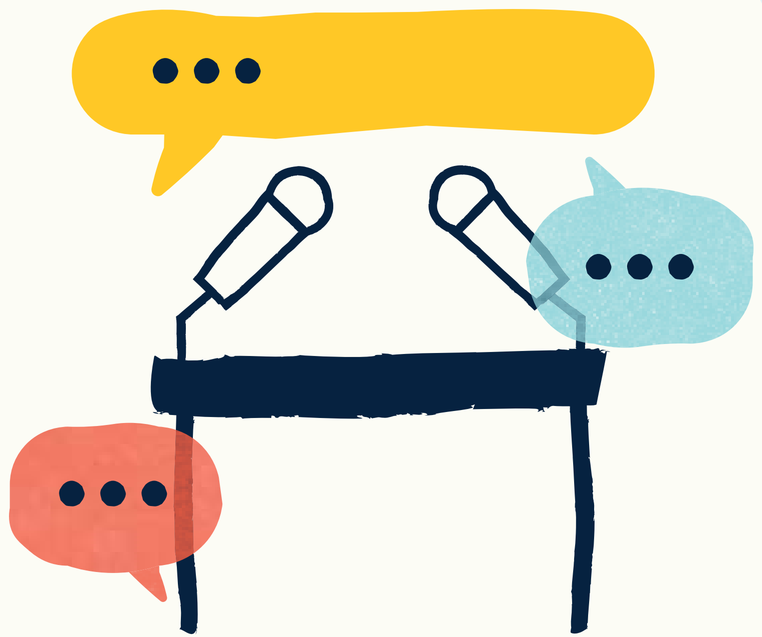
Over the next few years, we hope to run a number of early clinical trials on CF genetic therapies through the CTAP Early Phase Trials Network. These are therapies that would work in a completely different way to existing CF medicines, such as Kaftrio and other CFTR modulator medicines, and are particularly relevant and exciting for those people with CF who are unable to benefit from modulators. To support recruitment to these new trials, we have created some CF genetic therapy resources for our website: **cysticfibrosis.org.uk/genetictherapies**


Nicole, Martyn and Arlo, who has CF

Involving the CF community in shaping our research

In 2016 the Trust was a partner in the QuestionCF project, identifying the research priorities of people with CF, as well as their families, carers, and CF teams. Other partners in the project included the CF community and researchers at the University of Nottingham. The priorities were identified in the Priority Setting Partnership (PSP), facilitated by the James Lind Alliance (JLA) team at the National Institute for Health and Care Research (NIHR). The research priorities were published in January 2017. Since then, these priorities have helped us decide what research we fund; much of this research is ongoing, and you can read about some examples of the exciting work underway in a **review article from December 2021**.

In 2022, in partnership with the University of Nottingham, the JLA and members of the CF community, we led a project to refresh the CF research priorities. The project started with a survey that opened in January 2022, asking the CF, research and clinical communities to identify those 2017 priorities they felt were still important to them, and gave respondents the opportunity to submit up to two new research questions or priorities.



We received over 1,600 responses to this first survey from across the world, including Europe, Canada, North America and Australia. The second survey, launched in the summer, asked participants to identify their top 10 priorities from a short-list of 71 questions, and the final list of priorities was completed in an online workshop in November. The refresh CF research priorities are:

1. What options are available for those not able to take current CFTR modulators (including rarer mutations, not eligible and unable to tolerate)?
2. What is the best way to diagnose lung infection when there is no sputum e.g. children and those on modulators?
3. How can we relieve gastrointestinal symptoms, such as stomach pain, bloating and nausea?*
4. How do we manage an ageing population with CF?
5. Is there a way of reducing the negative effects of antibiotics e.g. resistance risk and adverse symptoms in people with CF?*
6. What are the long-term effects of medications (including CFTR modulators) in CF?
7. What are the effects of modulators on systems outside the lungs, such as pancreatic function, liver disease, gastrointestinal, bone density etc?
8. What are the effective ways of simplifying the treatment burden of people with CF?*
9. Can genetic therapies (such as gene editing, stem cell and mRNA technology) be used as a treatment for CF?
10. Is there a way of preventing CF diabetes in people with CF*

*denotes priorities that were included in the top 10 priority list in 2017.

Work is now ongoing to bring the research community and other potential funders together to accelerate research to address these priorities.

Find out the latest updates on the refreshed research priorities: **cysticfibrosis.org.uk/researchpriorities**

Putting people with cystic fibrosis at the heart of everything we do

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

Through working with clinicians and other experts to develop high-quality clinical guidelines, we can improve the standards of care received by everyone with CF. Last year we updated three key guidelines, all of which are written and reviewed by CF expert clinicians, scientists, and community representatives:

- We updated our guidelines on CF diabetes, a condition which affects more than 30% of adults with CF and can have a significant detrimental impact on health.
- We updated guidance on the laboratory management of CF microbiology samples, a critical part of ensuring prompt diagnosis and treatment of CF pathogens.
- We published the third edition of our pharmacy's standards of care, which help ensure people with CF get the best possible outcomes from their medicines.

The impact of the cost of living crisis on the CF community

The impact of rising living costs was felt across the CF community, particularly over the winter months – with more people struggling to buy the basic essentials they needed to manage their health and stay well. Others in the community may have been just about managing but were unable to make ends meet when faced with the cost of a broken home appliance or the loss of income that comes with a hospital admission.

We provided responsive, wide-ranging support, helping people with CF and their families access the basics they needed through our grants offer. We then worked to identify all the financial support available to claimants, supporting them to understand their rights and, importantly, were there to listen and offer emotional support when times were tough.

In response to the cost of living crisis, we launched a new time-limited cost of living fund, providing 342 cost of living fund grants of £225 over the winter period to support those on low incomes to afford food and essentials.

85% of people who received a cost of living fund grant told us that without the grant, they would have struggled to buy enough food over the winter.

To support our community with the cost of living crisis, we also:

- developed a new cost of living hub on our website, providing the latest updated information and advice tailored to each of the four nations
- introduced spot-check appointments for benefit checks
- shared template letters for our community to send to energy companies, explaining the importance of a warm, dry home for staying well with CF
- introduced our new grant category, the Home Essentials Fund, to provide streamlined access to essential white goods, like washing machines and fridges, to store medication.

> **“I never thought I'd be this financially fragile in 2023, but here I am. Last week I had pasta and rice as my dinner for three nights until I could borrow money. I find myself losing weight I've spent years putting on. I want to stay as healthy as possible. I need the extra nutrition now more than ever. This grant helps me ensure I've got food in my fridge to do that.”**
>
> Sam*, who has CF

* names changed for anonymity

Campaigning hard

We campaign hard to drive positive change for people with cystic fibrosis. We ensure policymakers have the evidence needed to pursue interventions which make a difference to those living with CF and their families.

> **“I think the Trust's Cost of CF campaign is really important as it will help people to understand that it's not just the condition that we live with, it's the actual cost of having the condition too.”**
>
> Chantelle, who has CF

Our cost of CF campaign

In spring 2022, we surveyed the CF community as part of our Cost of CF campaign to truly understand the additional cost of living with cystic fibrosis. Our report revealed that 87% of people with CF were worried about the cost of living and that 1 in 3 had missed a hospital appointment due to the cost.

In January 2023, we published research in partnership with the University of Bristol, which found that a typical family with CF will lose £564 per month – or nearly £6,800 per year because of the condition. We used this evidence to call on governments across the UK to act.

> **“I would like not to have to worry about money. I am forever trying to think of ways to make money whilst juggling my child, part-time work, nursery costs, family life, dog... My health ends up as an afterthought. I'd like to be able to have time to myself, to work on my health and wellbeing.”**
>
> **Jamie*, who has CF**

Carlie

> **"It's so important than every single one of us gets behind the campaigning work of the Trust because ten thousand of our voices are so much stronger, powerful, and louder than just one."**
>
> Carlie, who has CF

The Trust submitted evidence to a parliamentary inquiry on the cost of living, highlighting the need to address how the uprating of social security benefits did not keep pace with inflation, and that those who relied on this support were effectively worse off due to the challenges of living with a lifelong condition. Repeated lobbying of ministers and parliamentarians across the year prompted parliamentary questions and contributions to debates held by elected representatives across all four nations.

In early 2023, this culminated with a specific debate in the House of Commons on the financial cost of living with CF. We were pleased to see this advocacy work, and our partnership working through wider third-sector coalitions saw the Chancellor of the Exchequer confirm that uprating would occur in line with inflation rather than the proposed lower rate.

This debate on the cost of living with CF prompted further discussion in England around prescription charges. On behalf of the CF community, our CEO, David Ramsden, handed in a petition signed by 1,300 people to 10 Downing Street, calling for CF to be added to the list of conditions exempt from paying prescription charges.

Making sure the voices of our community are heard

In early 2023, the National Institute for Health and Care Excellence (NICE) launched the next stage of its assessment of modulator therapies. Over 1,000 people with CF shared their experiences of Kaftrio, Orkambi and Symkevi with us to inform our evidence submission to NICE for their appraisal of these medications.

Our community told us that living with CF can have a significant impact on their quality of life, and "there is no day off from CF" due to the high treatment burden and the challenging symptoms which can affect the whole body. They also highlighted how the introduction of modulator therapies, particularly Kaftrio, have transformed quality of life as well as hopes and aspirations for those who are able to benefit from them. The formal NICE committee hearing for this appraisal is due to take place later in 2023.

We continue to lobby hard on prescription charges and raised it with ministers ahead of the 2023 budget. We were part of the successful coalition working in partnership with financial advice expert Martin Lewis which campaigned to scrap the planned increase in the Energy Price Guarantee.

We will continue to raise awareness of the financial challenges people with CF are facing, campaign for greater support from the Government and strengthen the direct support that we provide to those in our community who need it most. Our community will always inform our advocacy work for the year ahead based on what they tell us in our annual 'Your life and CF' survey.

CEO David Ramsden and Cystic Fibrosis Trust staff members at 10 Downing Street

Dr Jamie Duckers

> **"The UK CF Registry is like gold dust; we're so lucky to have it. It guides how we help people with CF to manage their condition now, and we can conduct research to answer their questions about the future."**
>
> Dr Jamie Duckers

The UK CF Registry

The UK CF Registry is a world-class database that includes data on over 99% of people with CF in the UK who have consented to their data being submitted by their CF team. This Registry team supported the running of three drug safety studies, generating over £1.7 million in income. A significant proportion of these funds was used as grants to support centres in their data entry to the Registry. All three studies will be completed by the end of 2023.

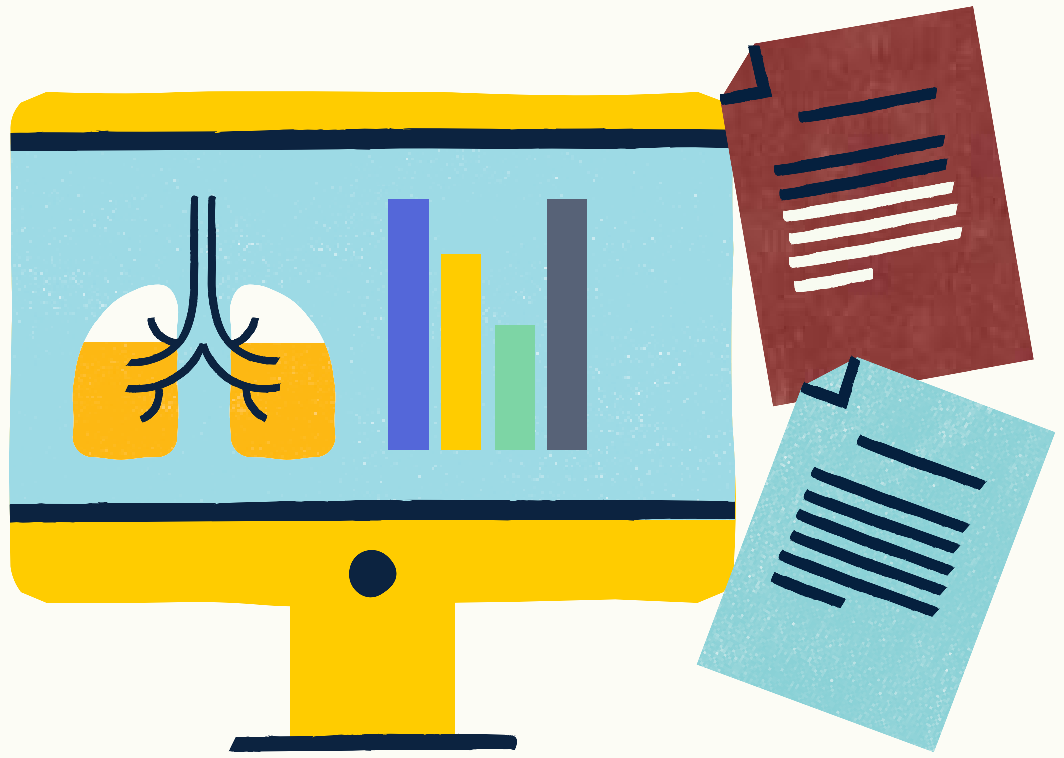
In 2022, the Board of Trustees approved investment in a new Registry role, Senior Health Studies Development Manager, to build on existing partnerships and nurture new partnerships with industry and academia.

More information about how we use Registry data to keep medicines safe can be found at **cysticfibrosis.org.uk/registry**.

This year the Registry will receive up to £160,000 from NHS contracts for generating public reports and supporting the commissioning of CF services in England.

Anonymised Registry data supports research, service improvement, and information materials. Between April 2022 and March 2023, the Registry received 37 data requests, of which 34 were reviewed by the Registry Research Committee and 29 were approved. The Registry Research Committee ensures that all data requests adhere to the Registry protocol and are meaningful to people with CF and the wider community.

The UK CF Registry continued to play a pivotal role in evaluating the effect of Orkambi, Symkevi and Kaftrio following interim access agreements across the UK.



Throughout 2022 100% of CF centres committed to opting in to enter three 'encounters' (records of height, weight and lung function) throughout the year, supporting additional data collection to enable a more robust analysis of the rate of change in lung function due to these new medicines. This Data Collection Agreement also boosted the Trust's annual Registry Support Grant programme for a third year. The final report of the observational study of Orkambi and Symkevi was submitted at the end of 2022, with the final analysis of Kaftrio following in summer 2023. These two reports will form an important part of the NICE appraisal of these medicines in 2023.

Recruitment to the Registry-based clinical trial CF STORM, which was launched in Summer 2021, is ongoing. This trial is designed to find out whether people with cystic fibrosis can safely withdraw mucolytic therapy once they have started taking CFTR modulators.

In November 2022, the first face-to-face Registry Annual Meeting was held following pandemic restrictions. Around 90 Registry users from CF centres across all four nations in the UK attended the meeting in Birmingham to hear from the team and clinical colleagues about the latest Registry updates, projects, and current research and contributed to workshops looking to the future of the Registry.

Annual data report

The UK CF Registry annual data report on 2021 data was published in September 2022.

It was found that 7,384 people were reported as being on a CFTR modulator by December 2021. 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 at-a-glance summary of infographics highlighting the main trends for that period 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**.

We submitted anonymised 2021 data to the European CF Society Patient Registry, which published its reports online.

Quality improvement (QI)

In June 2022, we published a series of reports, sharing insights from patient experience surveys and the Trust's staffing tool. It was the first time that findings from our patient experience surveys were shared publicly, and social media posts about the launch were viewed over a thousand times in the month following publication.

In autumn 2022, the QI team initiated the second cycle of the Trust's patient experience survey in children's CF centres, collecting new insights that will be reported on next year. The team also continued to monitor staffing levels in CF services through the staffing tool, creating bespoke staffing data summaries for participating CF centres and publishing an updated report on CF service resourcing in March 2023.

Coming together for the CF community

> "Our team introduced us to the Trust at diagnosis, and we have learnt so much. It has also given us a point to guide family and friends for information. It's an amazing charity which is so supportive; they create huge awareness around CF, providing information and support to those living with CF and their friends and family. They are constantly striving to fund research for the CF community."
>
> Jason, dad to Luca, who has CF

Jason and his son Luca, who has CF

Day-to-day support

We've continued to see high levels of demand for support in all aspects of life with CF; many in our community have had worries about the cost of living. Through our grant programme, backed by our welfare and benefits advice services, we've been able to offer support in immediate financial crises to put food on the table. We also work to offer support for longer-term financial security. Our Helpline team provide a knowledgeable, non-judgmental listening ear, offering emotional support while also signposting to practical help and advice.

> "All the leaflets and information that was given to us in the early days about CF were from the Trust and it made a big difference. The leaflet for family and friends was invaluable and made so much sense. We will still get strangers asking the wrong questions or saying the wrong comments, but at least we could equip our family and friends with the right things to say, making it a little easier when they did meet Rufus for the first time."
>
> Ben, dad to Rufus who has CF

Grants

This year, we've provided 1,190 grants totalling over £310,000. This includes over 400 emergency grants, funding basic essentials like food. These are often needed when there has been a sudden, unexpected loss of income. This frequently happens when a hospital admission means someone with CF, or parents/carers of someone with CF, have to take time off work and lose income. This is in addition to coping with the costs of travel and food at hospital. The impact of this can be felt for many weeks or months, leaving people struggling to afford the basics, impacting their physical and mental health. A small emergency grant can help to ease some of this pressure.

Following feedback from the CF community, we have adapted our grant programme, ensuring we can meet the needs of those who need our support most. This included the launch of the Home Essentials Fund, supporting households on low incomes to quickly replace broken-down appliances which are needed to protect CF health. Between October and March, we funded 113 vital appliances, including fridges needed to store medication and washing machines needed to keep clothes and homes clean and hygienic.

Our Cost of Living Fund grants launched in October 2022 and provided vital support to protect the health of those who were most vulnerable to rising living costs.

Thanks to the generosity of the Joseph Levy Foundation, we have also been able to provide 57 Joseph Levy Education Fund grants, helping people with CF with the costs of higher or further education.

We also provided 10 Helen Barrett Bright Ideas Awards, supporting people with CF to take a step forward in self-employment, building confidence and giving an opportunity to shape a career that fits around their health.

Benefits advice

Our welfare team supported 377 people this year and secured benefits income of over £900,000 for people affected by cystic fibrosis. 300 people received detailed, personalised one-to-one benefits advice, and 50 people were supported by our Income Maximisation Service, which works to check for any financial support or savings available. 27 young people with CF accessed our Student Support Service, which provides one-to-one support to identify financial and practical support to help at university. As well as supporting people with CF and those who care for them, the team also provided support to cystic fibrosis specialist social workers, often working in partnership to get the best possible outcomes, particularly in complex benefits situations.

> **"The gentleman I spoke to was extremely helpful and gave me the accurate and precise information I was looking for. He followed it up by email, sending me the information and answering my further questions. He was patient, kind and generous with his time and knowledge, and I appreciate that enormously."**
>
> Dave*, who called our Helpline for advice

Sangeeta Enright, welfare and rights advisor

Helpline

With a total of 4,799 enquiries, this has been the busiest year on record for our Helpline. The Helpline acts as the gateway to all of our support services, providing emotional support with a detailed understanding of cystic fibrosis and signposting to our other services as well as external support.

100% of people who responded to our Helpline survey told us they felt heard and understood, and 98% said that they felt more confident dealing with the issue they contacted us about. The majority of enquiries come into the Helpline by email, but in February 2023, we launched a WhatsApp service, and the Helpline is available over the phone as well as via social media, making sure our support is as accessible as possible.

> **"Searching anything CF-related on the internet can be overwhelming. Most of the information can be just statistics and facts. But the information provided by the Trust is reliable and helpful for day-to-day life, from how to deal with everyday bellyache to diet and lifestyle information."**
>
> Margherita, whose partner Pierre has CF

Empowering the CF community through high-quality, accessible information

In 2022, Cystic Fibrosis Trust was awarded the PIF Tick, – a widely recognised quality kitemark awarded by the Patient Information Forum, which identifies Cystic Fibrosis Trust as a trusted information producer. Achieving the kitemark involved an intensive assessment, during which the Trust had to demonstrate it meets 12 criteria for developing high-quality patient information.

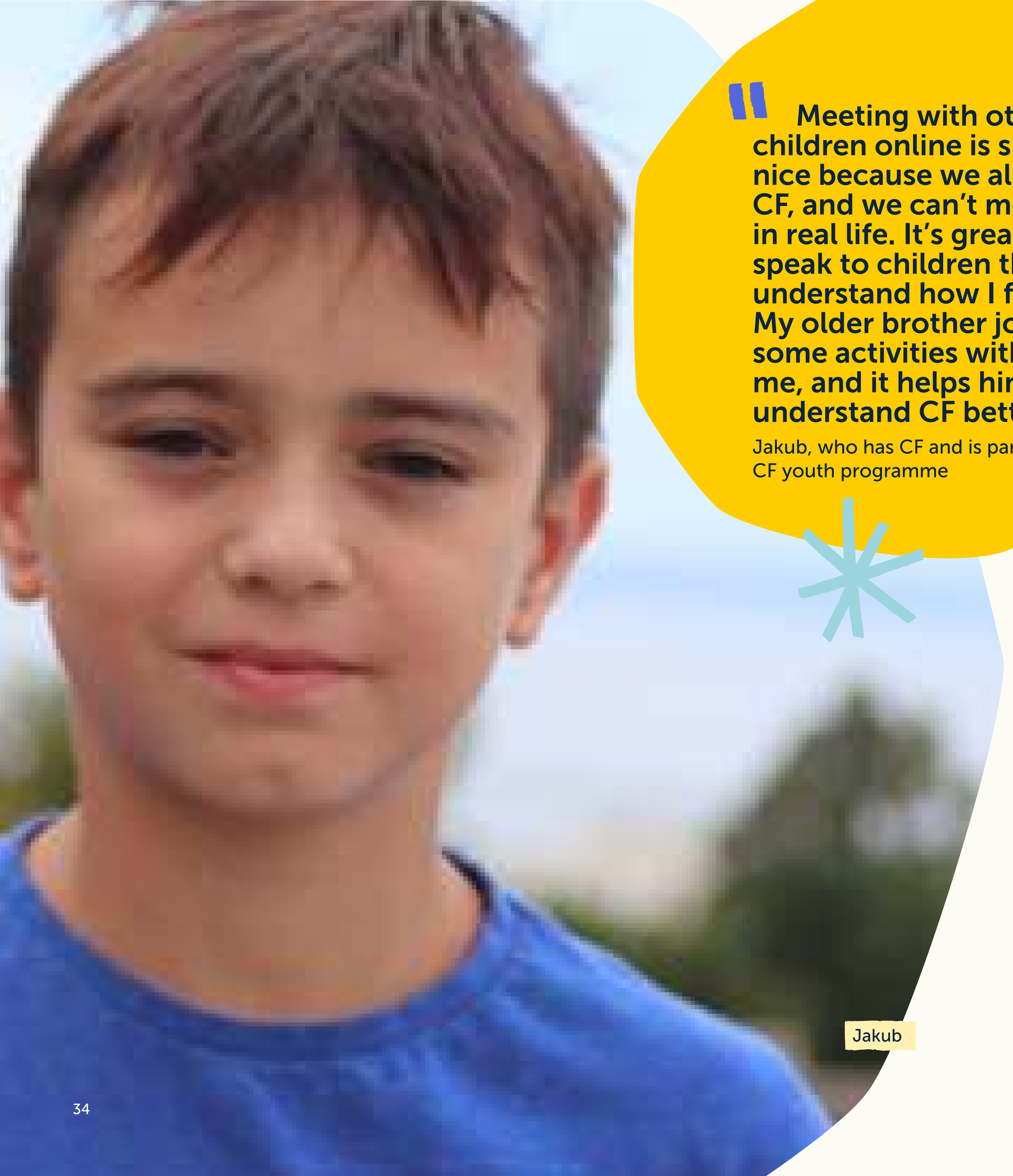
We published a significant new resource for younger audiences, featuring an animation voiced by children with CF and their siblings, as well as a fun activity pack. The animation quickly became one of the most-viewed videos on the Trust's YouTube channel.

For the first time, we published an Easy Read resource about cystic fibrosis, ensuring accessible, easily understood information about cystic fibrosis is available to those who need it.

Trusted
Information
Creator ✓
Patient Information Forum

We also developed and expanded our information in other key areas. We published new content on menopause in CF to coincide with Menopause Awareness Week 2022. Menopause is affecting increasing numbers of women with CF, and we provided information on treatment options and shared coping tips and personal stories. We also expanded our housing information in direct response to increasing challenges faced by some people with cystic fibrosis in their living situations, covering issues such as homelessness, housing discrimination and help with bills.

Layla (left) and Jason, two characters from our newest resources for young children



> "Meeting with other children online is super nice because we all have CF, and we can't meet in real life. It's great to speak to children that understand how I feel. My older brother joins some activities with me, and it helps him to understand CF better."
>
> Jakub, who has CF and is part of our CF youth programme

Dedicated support for children and young people

Our thriving youth programme continued to attract both new and returning children with a diverse range of online events and workshops – including arts and crafts, singing and songwriting, coding, and our ever-popular games nights. For people with cystic fibrosis, cross-infection can be very harmful. This is why people with CF should not meet face to face, and it's also why we hold these events online.'

We held 28 one-off events and three six-week workshops, with 84 children taking part – over half of whom attended more than one event. Children with CF and their siblings aged 6–18 are welcome to join these free events, generously funded by BBC Children in Need, which receive wonderful feedback from children and parents alike. Regular surveys show children's confidence increases after taking part in the workshops. They also develop new skills and benefit from informal peer support through meeting others with CF in a safe online space.

Meanwhile, our Youth Advisory Group, comprising young people with CF and siblings aged 14-25, aimed at supporting other young people with CF. This included a careers-focused project, 'When I grow up', which shared positive stories about CF and employment to encourage young people with CF to develop their own career aspirations.

> "I joined YAG to not only help other people with CF, but also to get to know other young people in the community and to have a support network that understood CF in its entirety. I loved the idea that it was a group of people with CF or a connection to CF making content and projects for those with the condition. It made so much sense!"
>
> Cicely, member of Youth Advisory Group

Being diverse and together as a community and an organisation

This year, we've continued to find new ways to engage with people affected by CF. From continuing to grow our presence on TikTok, to our youth programme and the launch of our new podcast, we have focused on reaching everyone affected by CF and connecting with people in the best way that works for them. We've also sourced a greater range of voices in the stories we tell on our website, the media stories we place, and in our fundraising packs. High-profile campaigns like CF Week and #CFTruths have been shaped and influenced by people with CF and their families via our active involvement groups.

CF Live and social media

CF Live, our series of online panel events with expert speakers, has continued to grow in popularity. Hundreds of attendees tuned in to our seven-part nutrition series, as well as our popular session on growing older with CF. As we increased our social media presence across all our platforms, we also jumped into CF-related conversations online to proactively offer help and support to people with CF who were struggling.

CF Week

CF Week is our annual awareness and fundraising week, with a focus on community engagement and sharing diverse stories from our community. The 2022 theme for CF Week was 'lifting the limits together', which we used as an opportunity to emphasise a message of togetherness and that we won't stop until everyone can live without the limits of CF.

This year:

- we raised over **£105,000**, with over **£53,000** being raised by CF Mamas' Wear Yellow Day Challenge through **74** incredible fundraisers
- had **290** signs ups with **66** identified school fundraisers
- media coverage during or just past the week had a potential audience of **1.7m**, including a feature in Women's Own which has a **76k** circulation
- received a donation of OOH coverage worth over **£50,000** with a reach of over **3 million**
- achieved over **20,000** views with our video content and over **387,000** impressions across our social platforms
- engaged with politicians across the UK to share our resources to show their support.

> **"A life unlimited to me means looking forward to a future with my husband and my son, and not worrying too much about how my health will decline or how it will impact me day to day."**
>
> Gillian, who has CF

Gillian

#CFTruths

Following the success of our #CFTruths campaign last year, we worked with Kieron, who has CF, and the wider CF community to launch the next phase. You can't see CF, which focuses on the invisible burden of the condition, was co-created with members of the community and tested carefully with those new to CF too.

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

- **£200,000** donated support for OOH advertising with a reach of **10 million**
- over **900,000** impressions across paid social media and display adverts
- over **700** clicks to the website through paid advertising
- over **115,000** impressions and over **41,000** views across social media
- over **11 million** via media with a combination of national and regional news.

> **"I always get told 'I didn't know you had CF'. I love this campaign so much; it means so much to me to know that people understand that life isn't 'normal' for people with CF as many would believe."**
>
> Ronnie*, commenting on social media

> "You don't see the hours coughing. Or the hours laughing. You don't see the mountain of pills I've taken. The hours of physio. You don't see me having to avoid meeting others with the same condition. The chance of catching an infection is simply too dangerous for us both. You'll just see me. See me grow. See me cough sometimes. See me try to live a life unlimited."

Kieron, who has CF and featured in our campaign posters and video

Celebrity engagement

Our celebrity ambassadors and supporters continued to help raise awareness and lend their support to key projects, including our big fundraising campaigns such as Wear Yellow Day and FeBrewary. Jenny Agutter, Richard Madeley and Vincent Franklin got behind our Cost of CF work by featuring in a video which told real-life stories from the CF community.

Jenny Agutter and Richard Madeley were interviewed for various publications across the year, including The Express, Candis Magazine and Fabulous Magazine. Olympian Roger Black and comedians Tim Key and Chris McCausland all appeared on celebrity editions of family favourite TV game shows, such as Mastermind and Pointless, to raise money for the Trust.

In March 2023, we were delighted to announce our newest official ambassador, James Dunmore.

A huge thank you to our celebrity ambassadors and supporters who help us to raise vital awareness.

CELEBRITY INTERVIEW

Back on track

Much-loved actor **Jenny Agutter** talks to Roz Lewis about her return to *The Railway Children* and the charity she espouses

From her home in London, Jenny Agutter is apologising for looking less than immaculate, while looking pretty much immaculate; wearing a soft grey polo neck, hair in a stylish bob.

This month sees the *Call the Midwife*, Hollywood and RSC actor back on the big screen in the film, *The Railway Children Return*. Based on the book by Edith Nesbit, the 1970 film *The Railway Children* tells the story of three children: Roberta (Bobbie), Phyllis and Peter, who move from London to a house near a railway in Yorkshire with their mother after their father unexpectedly goes away.

Reprising her famous role as Bobbie Waterbury – who she played in the BBC series and in the iconic Lionel Jeffries film – Jenny, now 69, was delighted to be given the chance to be in the sequel, the only actor from the original film to do so. "*The Railway Children* played an important part in my life," says Jenny. "I loved the idea of revisiting the role in a different time and liked the script, which pays tribute to Nesbit's story and Lionel Jeffries' film. This new film very much wanted to be in the same locations, so was filmed back in Haworth and at Oakworth station, which was a real trip down memory lane."

It is the fourth time Jenny has been involved in a *Railway Children* project, now part of the childhood of many generations. As well as the BBC television series in 1968, filmed when Jenny was just 14 and at ballet school,

Below Jenny Agutter and Sheridan Smith in *The Railway Children Return*

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CELEBRITY INTERVIEW

"I thought I had just done a film about a loss of innocence and I was growing up, so I was too old for *The Railway Children* – even though I was only 17!"

Chris McCausland appearing on Celebrity Mastermind

Sharing stories from our community

We strive to share diverse and new stories from our community through our blogs and video content, which continues to grow. This year, we've developed videos which cover a range of topics such as CF research, menopause, mental health, breastfeeding, and what it's really like 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.

> **"I'm in high school with CF and sometimes feel a bit different. It is a hard time for anyone being a teenager, but sometimes I feel no one understands me. But then I listened to your podcast and I felt you and the Trust understood. I feel like I'm in the room with you and you're my friend."**
>
> Lizzie, podcast listener

Lucy Baxter, host of the CForYourself podcast

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 where they talk openly and honestly about a whole range of topics, from exercise and employment to parenting and mental health. Each episode features a CF expert, who shares their knowledge and advice for everyone affected by CF.

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 the United States, Africa and beyond.

6 episodes, 1182 downloads, most popular episode: CF and mental health, demographic: (according to Spotify): 28-34 (32%) and 63% female, reach: worldwide

> **"From the moment that I was asked to host this podcast, I knew that I wanted it to be really special and open and vulnerable so that people with CF or help with people with CF can understand and relate to something."**
>
> Lucy Baxter, CForYourself podcast host

Website

We launched our new website in March 2021 and have continued to improve the user experience based on analysis, polling, user testing, and internal feedback. In March 2022, the website was redesigned in line with the overall brand refresh, and in June 2022, we launched a new community forum which now has over 700 active contributors and has been very positively received by our supporters.

We are continuing to improve the website with a current focus on navigation and personalising content for our different audience groups. We're also carrying out a content audit to ensure our content is as relevant and accessible as it can be.

Volunteering

Over the last year, we've been really grateful that the hard work of our volunteers, supporters, branches and groups has continued despite the cost of living crisis. Our volunteers come from a wide range of backgrounds and are at different life stages, ranging from those who already have a connection to CF, to university students, people working directly for companies partnering with the Trust, or those who have more time to give in their careers and want to use the skills they have developed to help us do more for people with CF. Since the pandemic, we've opened up more volunteering activities from home, which has allowed some volunteers to continue to support us that otherwise couldn't.

Being an effective organisation

The Trust's ability to achieve our vision depends on our effectiveness as an organisation, which is supported by our employees' and volunteers' skills, passion and energy. For employees, we nurture this by providing a positive working environment and employee benefits that we know from their feedback that our staff value, such as flexible working; holiday and parental leave allowances which exceed statutory requirements; learning and development opportunities; and good communication, such as regular briefings led by our CEO.

The Executive Team shares information with the People Committee on key human resources measures, which show how we are doing in areas such as staff turnover, sickness absence and participation in learning and development activities and update the Trustees on projects designed to enhance the engagement of our people and to make the Trust a welcoming and inclusive place to work. The People Committee also reviews the outcomes reported from the annual staff survey, which again this year had a high response rate of 78% and saw improved scores for most areas. We are extremely grateful for the efforts of our staff and volunteers during a challenging year.

The pressures on people with CF have been magnified by the cost of living crisis over the last year, which has resulted in a high volume of work for all teams at the Trust. As we move into 2023/24, we are in the process of introducing a newly refreshed set of values; planning activities to make our workplace even more inclusive; implementing a more streamlined recruitment process; and further improving learning and development.

Uniting in fundraising

We would like to thank all the fantastic 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 know everyone is feeling the financial pressure much more this year, and that makes your support so incredibly special to us. We greatly appreciate everything you do for the CF community – we couldn't do it without you.

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

Voluntary income at the Trust has been significantly impacted by the cost of living crisis this year, which has been challenging as we continue to build back after the reduction in income due to COVID-19. In 2022/23, £6.45 million gross income was raised compared to £7.4 million in 2021/22 and £4.29 million net income. The difference was due to a decrease in income from community, events and individuals as a result of the cost of living crisis, alongside a significant reduction in gifts in wills income of over £680,000 due to house sales falling through and the delays at the probate office and HMRC. Overall, this represents a 42% reduction in net income compared to pre-pandemic income in 2019-20.

We continue to innovate and adapt our fundraising plans. Examples of new innovations include a new look for Wear Yellow Day, our continued focus on engaging schools with fundraising and a new gaming proposition which will be launched in autumn 2023. We are now able to use Whatsapp to improve communication with event participants.

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.

Some of our fantastic Wear Yellow Day fundraisers

Supporter experience

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

We are continuously improving our website through custom iterative developments to improve the user experience so that our supporters can access the content they need as quickly and easily as possible. We continue to review the content across all of our platforms based on feedback we receive and the data we analyse so that our content is relevant, useful and accessible. This has included a full analytical content audit of our website, identifying what is most useful and any gaps in our content. We also take into account feedback from a number of different surveys across the year, including the Your Life and CF survey, feedback from our Helpline and social media as well as proactively requesting stories from the CF community to develop relevant and timely content on topics our community are telling us are important to them. Our key campaigns, including CF Week and our awareness campaign, went through various involvement testing with our community to ensure it reflected their experiences. This allowed for the co-creation of content and stories throughout, and both campaigns received positive feedback and engagement.

Amelia and David

> "I want to run for David, for every CF warrior and every person who's sadly lost their life to it. You are all so incredible and if running 26.2 miles is even a tiny show of admiration, I would do it a thousand times over."

Amelia, Team CF runner whose partner, David, has CF

Community and event fundraising

This year our focus has been to continue to offer a portfolio of activity and campaigns to grow our income back to pre-pandemic levels. This growth has continued to be slowed by the impact of the cost-of-living crisis.

Our portfolio of activities aims to capture the imaginations of all our wonderful supporters who continue to support us, despite all the external challenges they face. We are extremely grateful to everyone who walks, runs, bakes, dresses in yellow and every other fundraising activity they undertake for us.

- Our Team CF runners took on an array of races across the country, including, Belfast City Marathon, Cardiff Half Marathon, Edinburgh Running Festival, London Landmarks, Royal Parks and London Marathon. The amazing runners who took part in these events raised a combined total of £480,000.
- Our loyal branches and groups across the country raised a fantastic £124,000.
- Our annual Wear Yellow Day continues to go from strength to strength and raised £110,000 with growing numbers of our incredible CF Mamas and schools.
- The 20th Anniversary of the Carols by Candlelight event raised £60,000.

Robyn

> "The Trust is such an amazing charity for the diverse work that they do to support people with CF and their families. Any amount of money raised for them will make a huge difference to the lives of thousands of people."

Robyn, Team CF runner who has CF

Gifts in Wills

In 2022/23, we received 93 legacies from supporters who generously included a gift to the Trust in their Will, as well as 48 supporters who told us they have pledged a gift. We are incredibly grateful to those who have thought of us in this special way or are considering doing so, and we continue to raise people's awareness of legacy giving.

In Memory

We continue to remember with respect and affection those who have lost their lives because of cystic fibrosis, and we thank all our supporters who fundraise in memory of their loved ones. In 2022/23, more than £259,000 was donated in memory of those who are no longer with us, and many will continue to be remembered through our Book of Remembrance, tribute funds, and in the hearts of all who were close to them.

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 £834,000 in 2022/23, including Gift Aid. This year, we carried out 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 and a direct debit recruitment campaign) resulted in an additional annual income of £15,000.

> **"Continuing to raise awareness of CF is really important to me. 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

Philanthropy

The support we receive from charitable trusts, foundations and individual supporters has been more important this year than ever.

Many in the CF community are feeling the pressure of the cost of living crisis. To respond to this need, we launched our Cost of Living Support Package in October 2022, which was made possible by the support of generous donors. Thanks to those who contributed to our Cost of Living appeal, we were able to provide grants to 341 of the most vulnerable households this winter.

We have been supported by generous individuals who are longstanding supporters of our work. We are so grateful for the continued support of our Sixty Five Roses Club, which celebrated its 10th anniversary in 2022. The past decade has seen incredible advancements in CF care and treatments, changing what it means to live with the condition today.

Members of our Sixty Five Roses Giving Club have been on this journey every step of the way; raising over £700,000 over the last decade in support of our mission to ensure everybody with CF can live a life unlimited.

We are able to continue our critical work and plan effectively thanks to the support of trusts and foundations who provide multi-year donations and grants, particularly committed partners such as the Joseph Levy Foundation, BBC Children in Need and Rosetrees Trust. We are grateful for our new partnership with the National Lottery Community Fund, enabling us to set up our employment programme, Work Forwards.

Support has grown for our Innovation Hub, which has raised £3.4m to date with income received and pledges. We are particularly grateful to AJN Steelstock, Robert Luff Foundation and Garfield Weston Foundation for their continued support, among many others.

Corporate Partnerships

Over the last year, the corporate partnerships team have continued to strengthen relationships with existing partners and build new partnerships to raise funds and awareness for Cystic Fibrosis Trust.

We were delighted to be chosen as LaingBuisson's Charity of the Year 2022 through a nomination from an employee who has cystic fibrosis. For Wear Yellow Day, a team from LaingBuisson walked 32 miles from their office in Berkhamsted to London. They completed it in 12 hours and walked 75,000 steps! In addition, the LaingBuisson Awards raised nearly £8,000 on the night from a silent auction and donations.

We value the ongoing support from our advertising partners, such as Clear Channel, promoting our awareness campaigns, through gift-in-kind outdoor advertising and campaign advice. We would also like to thank Bip, who we have been working with since 2019 (as Chaucer), and have donated advice as well as joining the assessment panel for the Helen Barrett Bright Ideas Awards and running workshops for our 60th Anniversary.

We are grateful for fundraising through AmazonSmile, which has raised over £45,000 for the Trust in the five years before its closure in February 2023.

Thank you again to our sponsors for UK CF Clinical Trials Conference, the CF Registry Annual Meeting, and UKCFC, who we look forward to working with again this year.

Looking to the future and building effective partnerships

Uniting in research for a life unlimited

While a long-term aim of the Trust is to tackle the underlying cause of CF, leading to the development of potentially novel and innovative future treatments and care, we also need to continue to pursue research that will improve the health and wellbeing of people living with CF today.

With the recent breakthrough in access to highly effective modulators for a significant proportion of the CF community comes new health and research challenges for all people with CF. The research we fund, support and prioritise through the Trust must continue to be informed by and address the changing needs and priorities in CF.

The results of the James Lind Alliance CF Research Priority Refresh project conducted as a partnership between the Trust, the James Lind Alliance, and the University of Nottingham will guide the direction of future research funding and support.

Delivering our strategy

Our response during the pandemic and cost of living crisis highlighted how important it is that we demonstrate our relevance to our community by stepping up and addressing emerging issues during periods of crisis and change. As such, we have invested additional time, effort and resources into addressing the new and emerging challenges facing the cystic fibrosis community across the three following goals:

- physical wellbeing: together, we can live without the physical challenges of cystic fibrosis.
- mental wellbeing: 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 developing a new equality, diversity and inclusion strategy.

Being great fundraisers

Raising funds and growing our income back from the impacts of COVID-19 and the cost of living crisis is vital to enable us to continue our work to support people with CF to live a life unlimited. We understand the financial pressures everyone is experiencing, and it makes the continued support of the CF community so incredibly special to us. We will continue to work closely with our incredible supporters, branches and groups at a local level 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 processes. We also want to strengthen our insight and analysis to ensure we understand the needs of our supporters and we are making the best decisions.

Innovation remains a key pillar of our fundraising strategy to diversify our income and engage new supporters. We will ensure our portfolio of activity includes new products and fundraising activities to test and learn from. Maximising the potential of our key campaigns continues including Wear Yellow Day, engagement with schools and gifts in wills, in addition to our challenge events, community activities and ways to donate. We are looking forward to launching our updated gaming proposition, #Game4CysticFibrosis in the Autumn of 2023 and marking our 60th anniversary in 2024.

Campaigning hard

Through our Cost of CF campaign, we will continue to highlight the additional financial burdens faced by the cystic fibrosis community – and expect to publish new data on this in mid-2023. Alongside this campaign, our core mission of ensuring as many people as possible can benefit from access to innovative new treatments continues, with the NICE appraisal of modulator therapies hopefully concluding in the autumn of 2023, and coinciding with a renewed focus from the government on research investment, particularly around antimicrobial resistance.

Day-to-day support

We want to make sure our support reaches as many people affected by CF as possible. This year, a significant development was the launch of a WhatsApp service, providing a new route for people to access our Helpline support.

As the landscape of cystic fibrosis changes, we've continued to evolve our support to meet the needs of everyone with CF. We launched our new Work Forwards employment programme, supported by the National Lottery Community Fund, which provides dedicated employment and careers advice to people with CF and those who care for them. This personalised support involves one-to-one and group sessions, exploring everything from CV writing to reasonable adjustments at work. The programme will support people affected by CF move towards secure, fulfilling work – whatever that means for them – and a sustainable financial future.

The past few years have been challenging and continue to leave a legacy on the mental health of many in the CF community. We've continued to support people with the impact of new treatments, both for those who have seen dramatic improvements in health, and for those who haven't. We re-launched our online forum this year, providing a safe-space for people to come together and share their experiences. We've also worked with people affected by CF and CF professionals to update our grants programme, with a focus on supporting the overall health and wellbeing of those who most need support to live well with CF.

UK CF Registry

The UK CF Registry Annual Report 2022 will be published later in 2023, followed by the Annual Registry meeting in Autumn allowing colleagues across the UK to meet in person and share best practice. The Data Validation Visit programme relaunched earlier this year, with a new hybrid meeting format of in person and online.

The initial wave of the programme will conclude in 23/24, and our data validation report will be published. Following submission to NICE of the final analysis report of the CFTR modulators in 2023, the Registry team will work with our collaborators on a publication of the final results and continue to provide input into the ongoing appraisal process.

After the merger of the Data and QI Directorate with the Research Directorate, the team continue to find collaborative opportunities and projects across the health data and research landscape, supported by the Senior Health Studies Development Manager, a new role in the team.

Quality improvement

In 2023/24, the QI team will report on findings from the second cycle of our patient experience survey in children's services and will provide bespoke feedback to all CF centres that took part. The team is also developing a follow-up offer for CF centres to support them to explore their findings and plan targeted quality improvement activities once they have received their bespoke data summaries.

In the autumn, new data will be collected on staffing levels in CF services, and the team will launch the second cycle of our patient-reported experience survey in adult CF centres.

Financial review

Results for the year

The final result for the year, including movements on investments, was a surplus of £1.7m (2022: surplus of £0.1 million). This increase in surplus is driven by a small number of one off items including £1.0m (2022: £nil) income from a revenue share agreement with the Gene Therapy Consortium/Boehringer Ingelheim and a further grant of £0.6m from the Medical Research Council as part of their UK Government Covid Medical Research Charity Support Fund.

Due to the cost of living crisis, the underlying financial trend is that generating voluntary income is challenging whilst costs are increasing.

Income

The Trust's income from normal activities for the year to March 2023 was £14.7m, a reduction of £1.0m (6%) compared to the previous year.

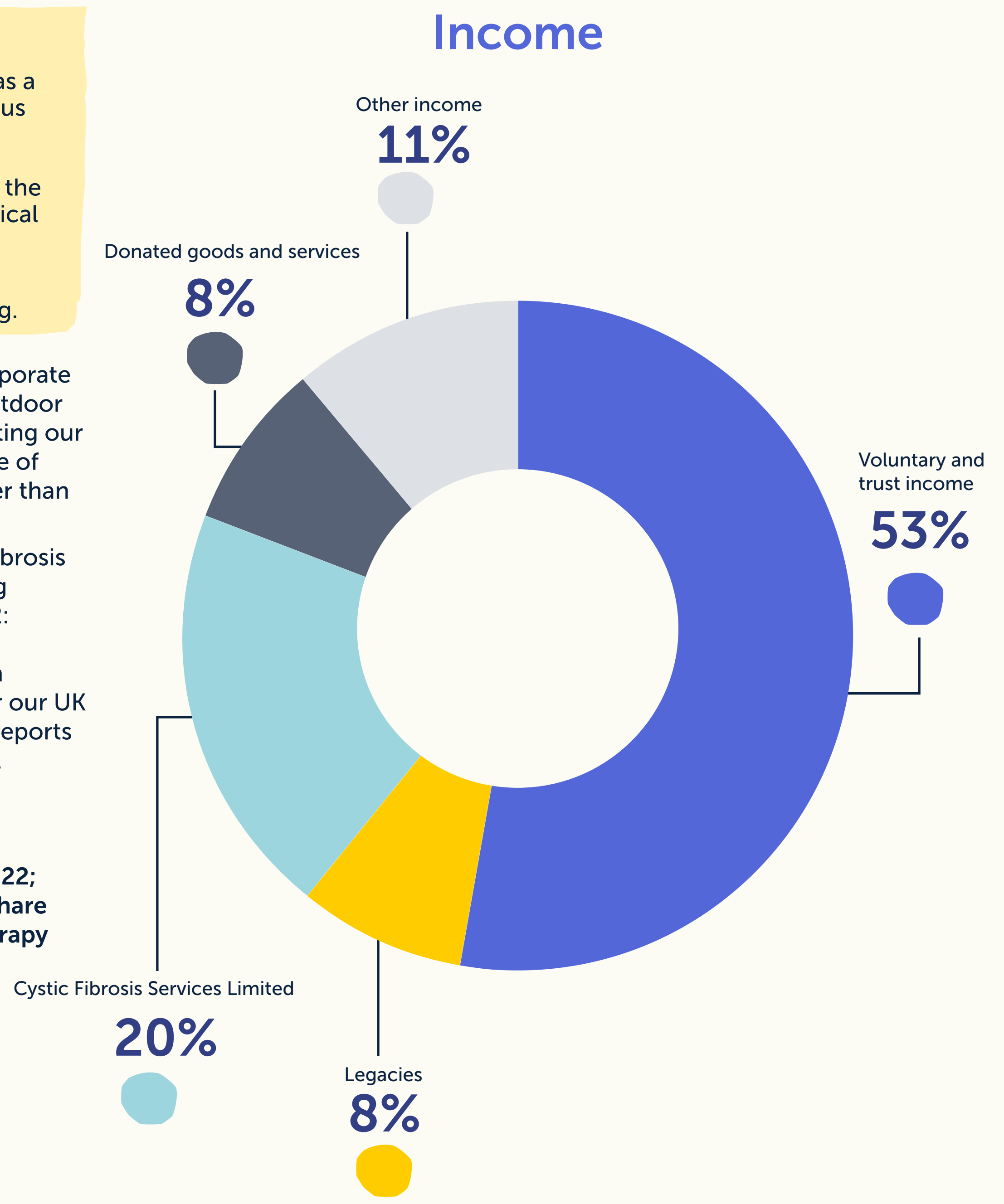
Voluntary and trust income of £7.8m (2022: £7.8m) includes regular giving programmes and appeals, from branches, groups and communities, corporate partnerships and trusts. In common with many charities, the on-going cost of living crisis means that generating income remains challenging. Income in 2023 is significantly below that generated in 2019 (£9.2m).

Legacy income of £1.2m (2022: £1.9m) has been impacted by pressures in the housing market meaning property left in estates can be difficult to sell or sells at lower values than in recent years. Processing delays at the probate office also contribute to the £0.7m reduction in legacy income compared to last year.

We benefit from generous corporate donations in kind including outdoor advertising and advice supporting our campaigns. However, the value of these services was £0.7m lower than in 2022.

Income generated by Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £2.9m (2022: £3.7m). 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.

Other income of £1.1m (2022: £0.1m) includes the £1.0m (2022: £nil) income from a revenue share agreement with the Gene Therapy Consortium.



Expenditure

The Trust's total expenditure for the year was £12.8m, a £3.2m (20%) reduction compared to the previous year.

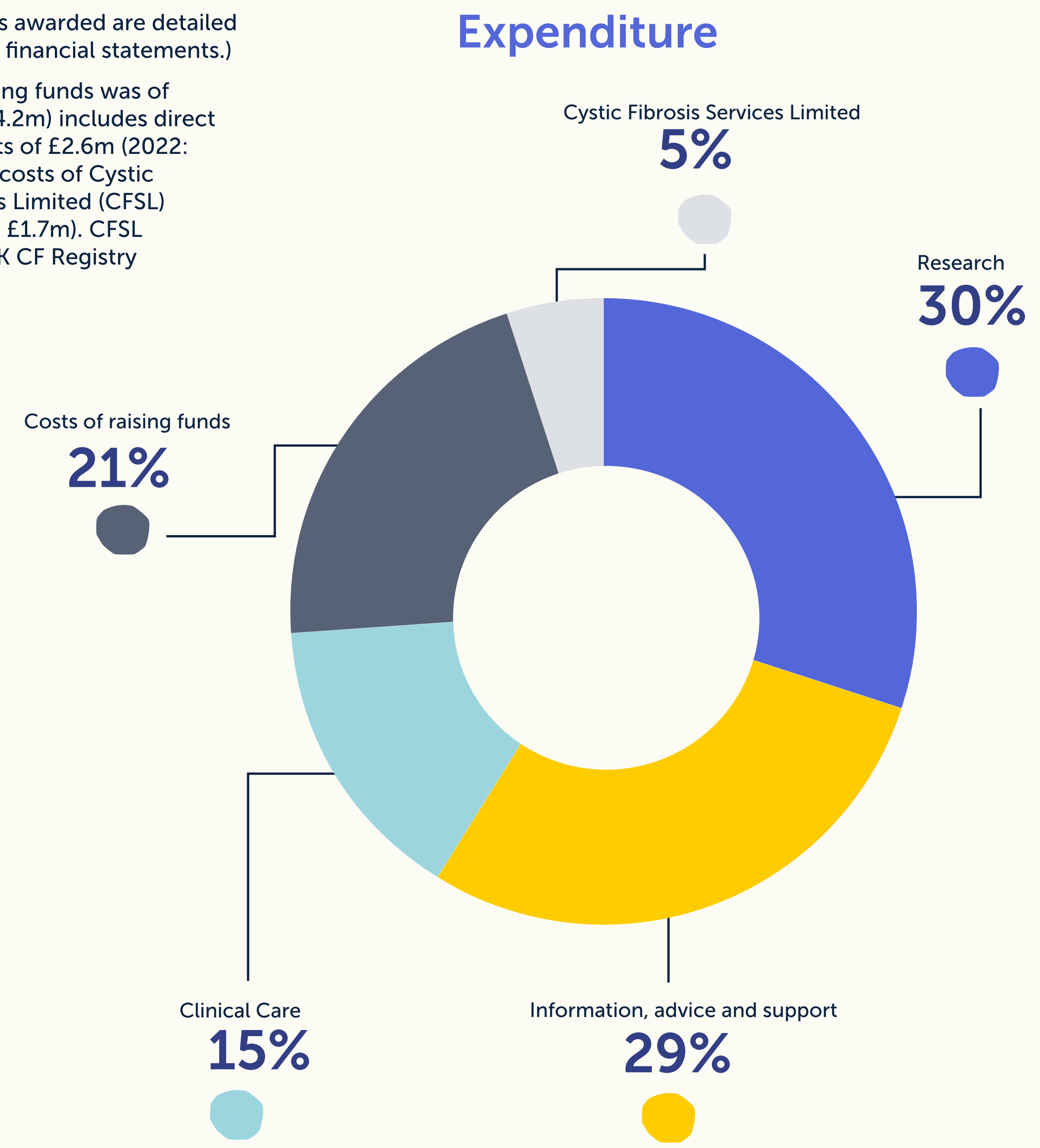
Expenditure on charitable activities in the year was £9.4m (2022: £11.8m). This includes funding research, providing information and advice and support and supporting clinical care. The reduction in expenditure is mainly as a result of focusing on research projects most likely to address our priorities; £3.3m of grants were awarded in 2023, compared to £5.5m in the year to March 2022.

Grants to support charitable activities include:

- £2m (2022: £4.5m) grants to a range of medical 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.
- £1m (2022: £0.7m) to fund the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme
- £0.3m (2022: £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 of £3.3m (2022: £4.2m) includes direct fundraising costs of £2.6m (2022: £2.5m) and the costs of Cystic Fibrosis Services Limited (CFSL) of £0.7m (2022: £1.7m). CFSL costs include UK CF Registry Support grants.



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 Charity, 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 77% 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 £5.4m at 31 March 2023 (2022: £5.6m). This is a reduction of £0.2m due to mainly unrealised investment losses due to the challenging year for both equities and bonds. No change was made tothe allocation between amounts held as stocks and shares and that held as cash. Income generated on investments totalled £0.3m which is £0.2m more than in 2022 and reflects increasing interest rates.

Reserves

The Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, in the range above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £3.6m and £5.8m.

At 31 March 2023, after adjusting for the designated reserves explained below, the Trusts' Unrestricted Reserves were £8.6m. This level of reserves has allowed the Trustees to approve a business plan and deficit budget for the next financial year which maintain services and grant awards at a level similar to previous years despite the continued challenge of returning income to pre Covid pandemic levels. Unrestricted reserves are forecast to be c£6.0m at March 2024 meaning that the Trust will be operating only marginally above its reserves policy.

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

- Organisational reserve: £1m (2022: £nil) has been established for investment in process improvement and our digital/data strategy, including implementation of a new Customer Relationship Management (CRM) system.
- Fixed asset reserve of £0.16m (2022: £0.02m). 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 2023 the endowment funds totalled £972,000 (2022: £1,046,000). See note 20 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 2023 restricted funds totalled £674,000 (2022: £271,000). Note 21 lists the individual restricted funds and their movement in the year.

Total reserves at 31 March 2023 were £11.4m (2022: £9.7m).

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 charity 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.

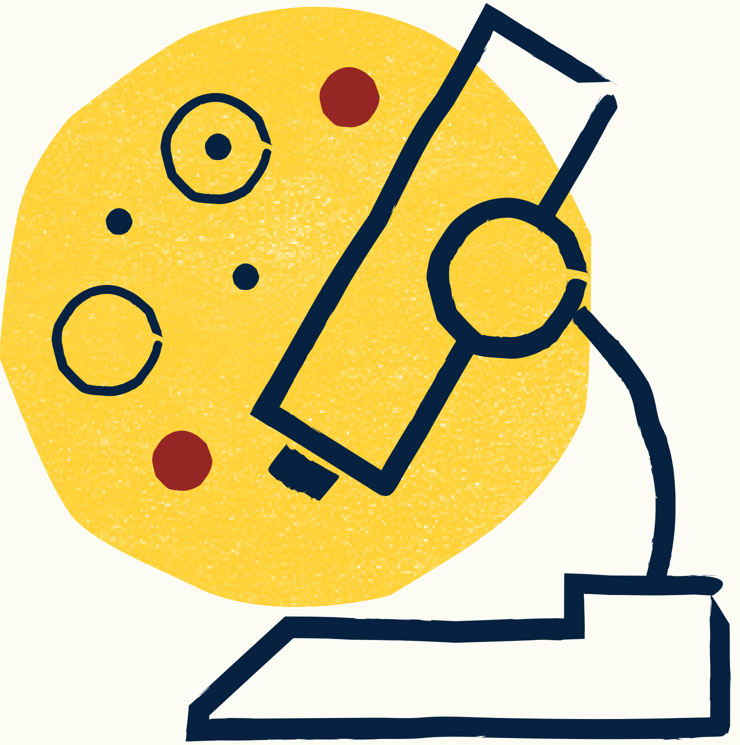
The main strategic risks and uncertainties that management and Trustees have identified and the key actions to mitigate these risks are:

Strategic risk	Strategies/plans for managing risks
Relevance • Failing to address the changing needs and expectations of people with cystic fibrosis • Failing to effectively get our message across to our community, key stakeholders and decision makers	• Our strategies and work programmes reflect the views and priorities expressed by people with CF through consultation, involvement and co-design. • We explore innovative new content and channels including podcasts, awareness campaigns and audience insight work. • We will build upon successes of access to medicines campaigns to pivot to new and emerging priorities including air quality, housing, poverty, CF care resourcing and benefits & welfare reform.
Financial • Failing to manage the impact of the cost of living crisis and other economic factors.	• Strategic financial framework and budget for 2023/24 includes measures to closely track income and expenditure including scrutiny from the Finance Committee. • Some cost savings already achieved, with further savings targets set over the next year. • Operating reserves will be maintained within policy.
Data • Failing to adequately protect the data we hold (especially the UKCF Registry)	• GDPR compliance framework; Data Protection Policies and DPO; ongoing staff training & oversight from Data Governance Group. • Regular penetration testing of website and Registry.

Strategic risk	Strategies/plans for managing risks
People • Failing to attract, retain and support a high quality and diverse group of staff. • Failing to safeguard young people & vulnerable adults.	• Comprehensive range of policies in place covering welfare, safeguarding, recruitment & retention, learning and development and employee benefits. • Development of EDI Strategy • Values refreshed and launched • Board safeguarding lead appointed
Reputation • Failing to proactively consider and prevent reputational issues in advance. • Failing to respond to damaging events in a timely and appropriate manner.	• Comms policies & processes in place to ensure quality control, including 'red flag' processes on potentially sensitive communications. •Clear and tested communications plans and processes in place to highlight and escalate contentious issues or complaints, agree public response and internally reflect on lessons learned.

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

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

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

Venture & Innovation Awards (VIAs)

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

The UK 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 2022/23 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £2.9m (2022: £3.7m) 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 pharmaceutical companies to ensure we have the funds to run the events that we know are so important for healthcare professionals and people affected by cystic fibrosis. These events enable us to keep these audiences informed on all aspects of clinical care and research.

We would like to thank Gilead, Vertex and Chiesi who provided sponsorship for the UK Cystic Fibrosis Conference (UKCFC). We also received sponsorship from Vertex for the Annual Registry Meeting held in November 2022.

The Trust organised the UK CF Clinical Trials Conference in March 2023 at the ICC, South Wales. We again received an Independent Medical Education (IME) grant from Vertex towards the cost of the event and they were the sole sponsors.

> **"I'm proud of being part of the conversation and shaping how the Trust supports the CF community. With my social work background, I know how important it is to respond to the community's needs. I was involved in shaping the new advertising campaign, and I really appreciate getting to input on projects like that to ensure CF is represented honestly and fairly."**
>
> Sophie Pierce, Trustee

Sophie Pierce

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 **28 September 2023** 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 for the year ended 31 March 2023 which comprise the Consolidated Statement of Financial Activities, Consolidated Income and Expenditure Account, the Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows, and notes to the financial statements, including a summary of significant accounting policies. 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 parent charitable company's affairs as at 31 March 2023 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 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'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 Trustees' Annual Report and the Chairman's statement. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

- the information given in the Trustees' Annual Report (which includes the strategic report and the directors' report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements
- the strategic report and the directors' report included within the Trustees' Annual Report have 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 parent charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report (which incorporates the strategic report and the directors' report).

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

- adequate accounting records have not been kept by the parent charitable company or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable 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; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement (set out on page 67), 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 parent charitable 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 parent charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion.

Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of noncompliance 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.

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to fundraising regulations, charity and company law applicable in England, Wales and Scotland, and we considered the extent to which non-compliance might have a material effect on the financial statements.

We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Act 2011 and payroll taxes.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the completeness and cut-off of voluntary income, legacies, grant income and investment income. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud
- Evaluating management's controls designed to prevent and detect irregularities
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions
- Challenging assumptions and judgements made by management in their critical accounting estimates, in particular donation and legacy recognition, the recognition of grant income and the recognition of grant expenditure.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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, section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006.

Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Vikram Sandhu (Senior Statutory Auditor)
For and on behalf of Haysmacintyre LLP, Statutory Auditor

10 Queen Street Place,
London
EC4R 1AG

Date 10 October 2023

Cystic Fibrosis Trust

Consolidated statement of financial activities

For the year ended 31 March 2023

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2023 £'000**	Total Funds 2022 £'000
Income and endowments from:						
Donations and legacies	2	6,577	3,840	-	**10,417**	11,788
Charitable activities						
Other trading activities		2,873	-	-	**2,873**	3,703
Investments	3	279	-	-	**279**	78
Other income		1,097	-	-	**1,097**	112
Total income		10,826	3,840	-	**14,666**	15,681
Expenditure on:						
Raising funds	4	3,301	21	-	**3,322**	4,184
Charitable activities						
Research	4	3,122	644	-	**3,766**	6,457
Clinical care	4	696	1,251	-	**1,947**	1,345
Information, advice & support	4	3,360	377	-	**3,737**	3,982
Total charitable activities		7,178	2,272	-	**9,450**	11,784
Total resources expended	4	10,479	2,293	-	**12,772**	15,968
Net income/(expenditure) before investment gains/(losses)		**347**	**1,547**	**-**	**1,894**	(287)
Realised investment (losses)/gains		(32)	-	-	**(32)**	76
Unrealised investment (losses)/gains		(102)	-	(74)	**(176)**	366
Net investment (losses)/gains		**(134)**	**-**	**(74)**	**(208)**	442
Net income/(expenditure)		**213**	**1,547**	**(74)**	**1,686**	**155**
Transfers between funds	19	1,144	(1,144)	-	**-**	-
Net movement in funds		1,357	403	(74)	**1,686**	155
Reconciliation of funds:						
Total funds brought forward		8,354	271	1,046	**9,671**	9,516
Total funds carried forward	19	**9,711**	**674**	**972**	**11,357**	9,671

All of the operations are continuing.

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

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

The notes on pages 78 to 101 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated income and expenditure account

For the year ended 31 March 2023

	2023 £'000	2022 £'000
Income	**14,387**	15,603
Gains/(losses) on investments (excludes endowments)	**(134)**	379
Investment income	**279**	78
Gross income in the reporting period	**14,532**	16,060
Expenditure	**12,747**	15,950
Interest payable	**-**	-
Depreciation and charges for impairment of fixed assets	**25**	18
Total expenditure in the reporting period	**12,772**	15,968
Net income before tax for the reporting period	**1,760**	92
Tax payable	**-**	-
Net Income for the financial year	**1,760**	92

The consolidated summary income and expenditure account is derived from the statement of financial activities on page 72 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 78 to 101 form part of these financial statements.

Cystic Fibrosis Trust
Consolidated and charity balance sheets
For the year ended 31 March 2023

		Consolidated		Charity	
	Notes	**Total 2023 £'000**	Total 2022 £'000	**Total 2023 £'000**	Total 2022 £'000
Fixed assets					
Tangible assets	7	**155**	19	**155**	19
Investments	8	**5,388**	5,604	**5,388**	5,604
		5,543	5,623	**5,543**	5,623
Current assets					
Debtors	9	**6,589**	3,948	**5,396**	2,824
Cash held as short term investment		**11,485**	11,265	**11,485**	11,265
Cash at bank and in hand		**3,430**	5,197	**2,734**	4,777
		21,504	20,410	**19,615**	18,866
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	10	**(2,799)**	(6,229)	(2,799)	(6,229)
Creditors and accrued charges	11	**(2,257)**	(2,708)	(2,500)	(3,107)
		(5,056)	(8,937)	**(5,299)**	(9,336)
Net current assets		**16,448**	11,473	**14,315**	9,350
Creditors: amounts falling due after one year					
Grants payable	10	**(10,464)**	(7,425)	(10,464)	(7,425)
Provisions: amounts falling due after one year	15	**(170)**	-	**(170)**	-
Total net assets		**11,357**	9,671	**9,224**	7,728

Continued on the next page

Cystic Fibrosis Trust
Consolidated and charity balance sheets (continued)
For the year ended 31 March 2023

		Consolidated		Charity	
	Notes	**Total 2023 £'000**	Total 2022 £'000	**Total 2023 £'000**	Total 2022 £'000
The funds of the charity:					
Endowment funds	20	**972**	1,046	**972**	1,046
Restricted income funds	21	**674**	271	**674**	271
Unrestricted funds	19				
Total designated funds		**1,155**	(1,266)	1,155	(1,266)
Operating reserves		**-**	3,411	-	3,411
Retained reserves		**8,566**	6,209	6,423	4,266
Total unrestricted funds		**9,711**	8,354	7,578	6,411
Total charity funds	19	**11,357**	9,671	**9,224**	7,728

The notes on pages 78 to 101 form part of these financial statements.

Approved and authorised for issue by the Trustees on 28 Septmber 2023 and signed on their behalf by:

Richard Hunt, Chairman
Company number 3880213

Cystic Fibrosis Trust
Consolidated Statement of cash flows
For the year ended 31 March 2023

	2023 £'000	2022 £'000
Net cash provided by operating activities (Note A)	**(1,669)**	1,728
Cash flows from investing activities:		
Dividends and interest	**279**	78
Purchase of property, plant and equipment	**(161)**	-
Purchase of investments	**(417)**	(1,082)
Movement in cash awaiting investment	**(16)**	8
Proceeds of sales of investments	**437**	1,108
	122	112
Increase in cash held as short term investments	**(220)**	(9)
Increase/(decrease) in cash (Note B)	**(1,767)**	1,831

Notes to cash flow statement

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

	2023 £'000	2022 £'000
Net income for the reporting period (as per the statement of financial activities)	**1,686**	155
Adjustment for:		
Depreciation charges	**25**	18
Dividends and interest from investments	**(279)**	(78)
Losses/(gains) on investments	**208**	(442)
Increase in debtors	**(2,641)**	(647)
(Decrease)/increase in creditors	**(838)**	2,722
Increase in provisions	**170**	-
Net cash (used in)/provided by operating activities	**(1,669)**	1,728

Continued on the next page

Cystic Fibrosis Trust
Consolidated Statement of cash flows (continued)
For the year ended 31 March 2023

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

	2023 £'000	2022 £'000
Cash and cash equivalents at the beginning of the reporting period	**16,462**	14,622
Change in cash and cash equivalents in the reporting period	**(1,767)**	1,831
Increase in short-term investments	**220**	9
Cash and cash equivalents at the end of the reporting period (being cash at bank and in hand and cash held as short-term investments)	**14,915**	16,462

	2023 £'000	2022 £'000
Analysis of cash and cash equivalents:		
Notice deposits (less than 3 months)	**11,485**	11,265
Cash on hand	**3,430**	5,197
Total cash and cash equivalents	**14,915**	16,462

Cystic Fibrosis Trust
Notes to the Financial Statements
For the year ended 31 March 2023

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 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 102. 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 charity 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 £1,496,000 (2022- deficit of £710,000).

Cystic Fibrosis Services Limited 's results for the year ended 31 March 2023 are summarised in note 13. The net surplus for the year of £2,134,000 (2022; £1,943,000) will be donated in full to the parent charity after the year end.

Income
All income is recognised once the charity 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.

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 Charity. 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.

Expenditure
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the charity 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 charity, 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 Charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Charity pays fixed contributions into a separate entity. Once the contributions have been paid the Charity 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 Charity 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.

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2023

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

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

Unrestricted funds are those which the Trustees 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 charity. 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.

Profits 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.

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 charity 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 Trustees 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 Charity 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 accounts. 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 and conclude that the Trust is a valid going concern.

2. Income from donations and legacies

	Unrestricted Funds 2023 £'000	**Restricted Funds 2023 £'000**	**Total 2023 £'000**	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	Total 2022 £'000
Branches, Groups & Community	2,147	44	**2,191**	2,371	29	2,400
Legacies	1,240	3	**1,243**	1,593	321	1,914
Individual donations	383	74	**457**	364	93	457
Corporate	149	51	**200**	192	4	196
Regular giving and appeals	1,232	2	**1,234**	1,411	23	1,434
Trusts	13	3,056	**3,069**	94	2,521	2,615
Appeal for Innovation Hub	-	610	**610**	-	636	636
Donations in kind	1,234	-	**1,234**	1,892	-	1,892
Government grant income	-	-	**-**	129	-	129
NHS National Services England and Scotland	179	-	**179**	115	-	115
Total income from donations and legacies	6,577	3,840	**10,417**	8,161	3,627	11,788

Total income from donations and legacies includes gift aid of £411,000 (2022: £567,000).

Donations In Kind refer to non-monetary donations received from partner organisations. In 2023 £1,234,000 (2022: £1,892,000) 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 Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, Advice and Support.

Government grant income in 2022 related to the recovery of partial salary costs through the Job Retention Scheme during the COVID-19 pandemic.

3. Investment Income

	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	**Total 2023 £'000**	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	**Total 2022 £'000**
Income from listed investments	279	-	**279**	59	19	78
Bank interest	-	-	**-**	-	-	-
Total investment income	279	-	**279**	59	19	78

4. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2023 £'000**	**Total 2022 £'000**
Raising funds						
Fundraising	-	-	2,218	431	**2,649**	2,493
Trading and merchandising	-	609	64	-	**673**	1,691
Total raising funds	-	609	2,282	431	**3,322**	4,184
Charitable activities						
Research	601	1,345	1,182	638	**3,766**	6,457
Clinical care	999	58	572	318	**1,947**	1,345
Information, advice and support	164	103	2,861	609	**3,737**	3,982
Total charitable activities	1,764	1,506	4,615	1,565	**9,450**	11,784
Total resources expended	**1,764**	**2,115**	**6,897**	**1,996**	**12,772**	15,968

4. Expenditure (continued)

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

Analysis of allocated Support Costs – current year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2023 £'000**	**Total 2022 £'000**
Fundraising	41	59	140	60	131	**431**	**341**
Research	61	87	207	89	194	**638**	**886**
Clinical care	30	44	103	44	97	**318**	**184**
Information, advice and support	58	84	197	85	185	**609**	**546**
Governance	-	-	-	-	-	**-**	**-**
Total costs	**190**	**274**	**647**	**278**	**607**	**1,996**	**1,957**

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2022 £'000**
Raising funds					
Fundraising	-	-	2,152	341	**2,493**
Trading and merchandising	-	1,640	51	-	**1,691**
Total raising funds	-	1,640	2,203	341	**4,184**
Charitable activities					
Research	3,072	1,435	1,064	886	**6,457**
Clinical care	716	(61)	506	184	**1,345**
Information, advice and support	17	286	3,133	546	**3,982**
Total charitable activities	3,805	1,660	4,703	1,616	**11,784**
Total resources expended	**3,805**	**3,300**	**6,906**	**1,957**	**15,968**

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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 2022 £'000**
Fundraising	78	25	104	47	87	**341**
Research	203	67	269	121	226	**886**
Clinical care	42	14	56	25	47	**184**
Information, advice and support	125	40	166	75	140	**546**
Total costs	448	146	595	268	500	**1,957**

Net income for the year is stated after charging

	2023 £'000	2022 £'000
Auditors remuneration excluding VAT	**28**	20
Depreciation	**25**	18
Operating leases – building	**271**	272
Operating leases – other	**7**	5
Trustees' travel expenses	**2**	-

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

5. Grants

Grants were awarded during the year as follows:

	2023 £'000	2022 £'000
Grants to institutions	**3,565**	6,744
Grants to individuals	**314**	361
	3,879	7,105

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 Charity's network of regions and branches.

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

	2023 £'000	2022 £'000
Innovation Hub Cambridge	241	1,500
University of Nottingham	115	880
University of Liverpool	17	-
UCL Great Ormond Street	46	750
University of Sheffield	753	-
University of Cambridge	121	365
Medical Research Council	50	267
Cystic Fibrosis Canada (Fibrose Kystique) CFC	116	141
RNID	-	105
Diabetes UK	-	105
Royal College of Surgeons in Ireland	96	-
MDC (CF AMR Syndicate)	20	95
Medicines Discovery Catapult Limited	81	-
Western General Hospital	78	-
University of Edinburgh	-	70
Imperial College London/Royal Brompton Hospital	100	70
Belfast City Hospital	-	50
Medusa Pharmaceuticals	50	-
Ockham Biotech Limited	50	-
University Hospital Llandough	-	45
Newcastle University	20	37
Aston University	-	25
The University of Manchester	-	23
Queen's University Belfast	26	-
Other Institutions (less than £20k)	28	39
	2,008	4,567
Trial Coordinator commitments made to CTAP centres (see note)	953	685
Registry support grants made to various CF centres	609	1,571
Release of grants made in previous years (see note below)	(5)	(79)
Total grants made to institutions	**3,565**	6,744

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 £5,000 (2022: £79,000) 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.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

6. Staff costs

	2023 £'000	2022 £'000
Salaries	**4,481**	3,898
Redundancy and other termination payments	-	34
Temporary Staff	**80**	16
Social security costs	**493**	412
Other pension costs	**270**	227
	5,324	4,587

No redundancy and other termination payments were paid in the financial year (2022: termination payment totalling £34,000 were paid to three members of staff).

Analysis of total average monthly headcount by category:

	2023 No.	2022 No.
Research	**17**	14
Clinical care	**8**	6
Information, advice and support	**38**	33
Fundraising	**36**	36
Management	**2**	2
Finance	**6**	5
IT and project management support	**8**	8
HR & OD	**5**	5
Facilities	**1**	1
Total average monthly headcount	**121**	110

The number of employees whose total remuneration exceeded £60,000 in the year was:

	2022 No.	2021 No.
£60,001 – £70,000	**9**	6
£70,001 – £80,000	-	2
£80,001 – £90,000	**2**	1
£90,001 – £100,000	**3**	2
£110,001 – £120,000	-	1
£140,001 – £150,000	**1**	-

(Remuneration includes employer National Insurance contributions and pension contributions.)

Pension contributions to defined contribution pension schemes for these employees totalled £66,370 (2022: £51,049).

The total remuneration paid to key management personnel, including pension and social security contributions, was £573,722 which relates to 7 individuals who served on the Senior Leadership Team during the year (2022: £584,529 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. £4,684 of expenses were settled on behalf of 5 Trustees (2021/22 – £154 was paid to 2 Trustees) as meetings were held equally in person and remotely during the period.

7. Fixed Assets

Group and charity	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 31 March 2022	**630**	**870**	**243**	**403**	**183**	**2,329**
Additions	-	59	43	59	-	161
Disposals	-	-	-	-	-	-
At 31 March 2023	**630**	**929**	**286**	**462**	**183**	**2,490**
Depreciation						
At 31 March 2022	**630**	**851**	**243**	**403**	**183**	**2,310**
Disposals	-	-	-	-	-	-
Charge for the year	-	20	-	5	-	25
At 31 March 2023	**630**	**871**	**243**	**408**	**183**	**2,335**
Net book value **At 31 March 2023**	**-**	**58**	**43**	**54**	**-**	**155**
At 31 March 2022	-	19	-	-	-	19

8. Investments

Group and Charity	**Total 2023 £'000**	Total 2022 £'000
Market value as at 31 March 2022	**5,604**	5,196
Adjustment to brought forward balance	**12**	(14)
Additions at cost	**417**	1,082
Disposals at opening book value	**(469)**	(1,018)
Net gains/(losses) on investments	**(192)**	366
	5,372	5,612
Change in cash	**16**	(8)
Market value as at 31 March 2023	**5,388**	5,604

Represented by:	**Total 2023 £'000**	Total 2022 £'000
Equities	**589**	343
Fixed Interest and multi-asset funds	**4,513**	4,767
Property	**162**	292
Cash	**124**	202
	5,388	5,604

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 Charity's holding at 31 March 2023 was £4,417,000 (2022: £4,566,000).

9. Debtors

	Group 2023 £'000	Group 2022 £'000	**Charity 2023 £'000**	Charity 2022 £'000
Trade debtors	**1,125**	1,124	**32**	-
Amount due from subsidiary undertaking	**-**	-	**-**	-
Prepayments and accrued income	**5,293**	2,784	**5,293**	2,784
Other debtors	**71**	40	**71**	40
	6,589	3,948	**5,396**	2,824

10. Grants Payable

Group and charity	**2023 £'000**	2022 £'000
Grant creditor at 31 March 2022	13,654	12,230
Prior year adjustment	-	(17)
Grants paid during the year	**(4,271)**	(4,019)
Grants approved before 31 March 2023 and payable within one year	**2,792**	3,379
Grants approved before 31 March 2023 and payable after one year	**1,088**	2,081
Grant creditor at 31 March 2023	**13,263**	13,654
Represented by		
Grants due within one year at 31 March 2023	**2,799**	6,229
Grants due after one year at 31 March 2023	**10,464**	7,425
	13,263	13,654

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 2023 £'000	Group 2022 £'000	**Charity 2023 £'000**	Charity 2022 £'000
Trade creditors	**610**	668	**600**	655
Other creditors	**36**	-	**36**	-
Other taxation and social security	**137**	108	**137**	108
Amounts owed to subsidiary undertaking	**-**	-	**257**	412
Accruals and deferred income	**1,474**	1,932	**1,470**	1,929
	2,257	2,708	**2,500**	3,104

12. Financial Instruments

	Group 2023 £'000	Group 2022 £'000	**Charity 2023 £'000**	Charity 2022 £'000
Financial assets measured at amortised cost	**16,145**	17,593	**14,224**	16,048
Financial assets measured at fair value	**5,388**	5,604	**5,388**	5,604
Financial liabilities measured at amortised cost	**(15,338)**	(16,255)	**(15,325)**	(16,238)
Net financial assets measured at amortised cost	**6,195**	**6,942**	**4,287**	**5,414**

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

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

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

13. Interest in subsidiary undertaking

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

The subsidiary's activities include 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 2023:	**Total 2023 £'000**	Total 2022 £'000
Sales and sundry income	**2,873**	3,703
Cost of sales and administration	**(673)**	(1,691)
Intercompany recharges	**(66)**	(69)
Net contribution to parent charity	**2,134**	1,943

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2023

13. Interest in subsidary undertaking (continued)

Summary balance sheet at 31 March 2023	**Total 2023 £**	Total 2022 £
Current assets		
Debtors	**1,450**	1,539
Cash at bank	**696**	420
	2,146	1,959
Creditors: amounts falling due within one year	**(12)**	(16)
Net assets	**2,134**	1,943
Capital and reserves		
Called up share capital (£2)	**-**	-
Profit and loss account	**2,134**	1,943
Shareholder's funds	**2,134**	1,943

The Charity 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**	
	2023 £'000	2022 £'000	**2023 £'000**	2022 £'000
Within one year	**271**	271	**5**	9
Between two and five years	**271**	543	**18**	14

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

15. Provisions

The Charity's office at One Aldgate, London is under a lease that expires on 31 March 2025. Under the terms of the lease the Charity must restore the property to the condition prior to the Charity taking possession of the office. After seeking advice from surveyors, the Charity has made a provision of £170,000 (2022: £nil) for this work.

16. Related party transactions

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

Total donation income from the Trustees in the period was £11,911 (2022: £14,428). In addition, 7 of the trustees (2022: 7) were involved in fundraising activities carried out by regional fundraising branches.

Four trustees claimed travel expenses totalling £2,000 in the year (2022: no trustees claimed expenses).

17. Related party transactions

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

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2023

18. Analysis of net assets between funds

	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**
Current liabilities	(5,056)	-	-	**(5,056)**
Liabilities due in more than one year	(10,464)	-	-	**(10,464)**
Provisions due in more than one year	(170)	-	-	**(170)**
	9,711	972	674	**11,357**

Prior year	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2022 £'000**
Tangible fixed assets	19	-		19
Investments	4,558	1,046	-	5,604
Current assets	20,139	-	271	20,410
Current liabilities	(8,937)	-	-	(8,937)
Liabilities due in more than one year	(7,425	-	-	(7,425)
	8,354	1,046	271	9,671

19. Current year fund movements 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 20)	1,046	(74)	-	-	-	**972**
Restricted funds (Note 21)	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 charity funds	**9,671**	**(208)**	**14,666**	**(12,772)**	**-**	**11,357**

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

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.

- The designated fixed assets reserve matches the net book value of the charity's tangible fixed assets. These assets support the Trust's ongoing work and are not readily convertible to cash.

- Appeal Deficit. At the end of March 2022 the Trust had committed £3.8m in the form of a research grant to Cambridge University as part of the Innovation Hub flagship programme. At that date it had received £2.5m from donors in funding for this grant (shown in the separate restricted fund line, see note 21). The Trust has committed the to fund the commitment in full from new donations, and therefore there was a £1.3m funding deficit. Appeal income in the year to March 2023 of £1.3m means this deficit has been eliminated.

As explained on page **62**, retained reserves are held in the range above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £3.6m and £5.8m. The Trustees have approved a business plan and deficit budget for the next financial year which maintain services and grant awards at a level similar to previous years despite the continued challenge of building income to pre Covid pandemic levels. Unrestricted reserves are forecast to be c£6.0m at March 2024 meaning that the Trust will be operating only marginally above its reserves policy.

Transfers between funds

The following transfers were made between funds:

- A transfer was made to establish the organisational reserve.
- A transfer was made to from the restricted income fund for the Innovation Hub at Cambridge to remove the appeal deficit fund as the deficit has now been eliminated.
- 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.

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20. 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**

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

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

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

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

21 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	-	-	200	(200)	-	-
Sport England – Helping the active stay active	7	-	25	-	-	**32**
Imperial SRC: *Pseudomonas aeruginosa*	-	-	10	-	(10)	-
University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis	-	-	77	(20)	(57)	-
University College London: Therapeutic gene editing	-	-	16	-	(16)	-
University of Sheffield: Pulmonary magnetic resonance imaging for cystic fibrosis	-	-	366	-	-	**366**
UK CF infection biorepository	-	-	32	(32)	-	-
CF Active programme	-	-	5	(50)	45	-
Transition information resources	15	-	-	-	(15)	-
Quality Improvement project	35	-	-	-	-	**35**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**61**	**-**	**2,004**	**(543)**	**(1,085)**	**437**

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

21 Restricted 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						
EW Joseph/Homecare grants	3	-	-	(3)	-	-
Joseph Levy/Education grants	4	-	53	(46)	-	**11**
Building Brighter Futures	29	-	26	(39)	-	**16**
Support services (inc. welfare grants)	112	-	186	(160)	(45)	**93**
Work Forwards (England)	-	-	42	(29)	-	**13**
Work Forwards (Scotland)	-	-	12	(3)	-	**9**
Helpline	-	-	5	(5)	-	-
Forum	22	-	-	(9)	(13)	-
Helen Barrett Bright Ideas Awards	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)	-	**14**
Gut symptoms	-	-	39	-	-	**39**
Carols by Candlelight	-	-	12	(6)	-	**6**
Other older funds	36	-	1	-	(1)	**36**
Total other funds	**37**	**-**	**1,496**	**(1,437)**	**(1)**	**95**
Total restricted funds	**271**	**-**	**3,840**	**(2,293)**	**(1,144)**	**674**

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

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. Any surplus is the set against the designated appeal deficit fund (see note 19).

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:

- **EW Joseph home care fund** – grants to support adults and children with cystic fibrosis to be safe and comfortable at home through challenging times.
- **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 (RC England Wide).

22. Prior year consolidated statement of financial activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2022 £'000**
Income and endowments from:					
Donations and legacies	2	8,161	3,627	-	**11,788**
Charitable activities					
Other trading activities		3,703	-	-	**3,703**
Investments	3	59	19	-	**78**
Other income:		112	-	-	**112**
Total		12,035	3,646	-	**15,681**
Expenditure on:					
Raising funds	4	4,183	-	1	**4,184**
Charitable activities					
Research	4	3,239	3,215	3	**6,457**
Clinical care	4	431	914	-	**1,345**
Information, advice and support	4	3,874	106	2	**3,982**
Total charitable activities		7,544	4,235	5	**11,784**
Total resources expended	4	11,727	4,235	6	**15,968**
Net income/(expenditure) before investment gains/(losses)		**308**	**(589)**	**(6)**	**(287)**
Realised investment gains/(losses)		5	-	71	**76**
Unrealised investment gains/(losses)		374	-	(8)	**366**
Net investment gains/(losses)		**379**	**-**	**63**	**442**
Net (expenditure)/income		**687**	**(589)**	**57**	**155**
Transfers between funds	23	(612)	612	-	**-**
Net movement in funds		75	23	57	**155**
Reconciliation of funds:					
Total funds brought forward		8,279	248	989	**9,516**
Total funds carried forward	**23**	**8,354**	**271**	**1,046**	**9,671**

23 Prior year movements in funds Summary

	Balance 31 March 2021 £'000	Investment gains/(losses)	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
The funds of the charity:						
Endowment funds	989	63	-	(6)	-	1,046
Restricted funds	248	-	3,646	(4,235)	612	271
Unrestricted funds:						
Designated reserves						
Fixed asset reserve	37	-	-	-	(18)	19
Appeal deficit	(421)	-	-	-	(864)	(1,285)
Strategic reserve	200	-	-	-	(200)	-
Total designated funds	(184)	-	-	-	(1,082)	(1,266)
Operating reserves	3,448	-	-	-	(37)	3,411
Retained reserves	5,015	379	12,035	(11,727)	507	6,209
Total unrestricted funds	**8,279**	**379**	**12,035**	**(11,727)**	**(612)**	**8,354**
Total chairty funds	**9,516**	**442**	**15,681**	**(15,968)**	**-**	**9,671**

Endowment funds	Balance 31 March 2021 £'000	Investment gains/(losses) £0'00	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Ena Bennie Endowment	491	42	-	(3)	-	530
EW Joseph Endowment	165	11	-	(1)	-	175
Joseph Levy Endowment	285	10	-	(2)	-	293
Sally Wrigley Memorial fund	20	-	-	-	-	20
Other endowment funds	28	-	-	-	-	28
Total endowment funds	**989**	**63**	**-**	**(6)**	**-**	**1,046**

23 Prior year movements in funds Summary (continued)

	Balance 31 March 2021 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Restricted income funds						
Appeal: Innovation Hub at Cambridge	-	-	636	(1,500)	864	-
Restricted funds related to research:						
Genetic therapies	87	-	28	-	(115)	-
General medical research	-	-	438	(438)	-	-
Sport England - Helping the active stay active	7	-	-	-	-	7
Imperial SRC: *Pseudomonas aeruginosa*	-	-	15	-	(15)	-
Imperial SRC: Targeting immuno theraphy for fungal infections	-	-	4	-	(4)	-
Sheffield SRC: Gastrointestinal cancer	-	-	2	-	(2)	-
UCL/GOSH SRC: Therapeutic gene editing	4	-	41	-	(45)	-
Bristol SRC: CFTR folding and function	-	-	208	(208)	-	-
University College London: Pharmacological repair of bicarbonate transport in cystic fibrosis	-	-	375	(375)	-	-
Life expectancy project	(23)	-	-	-	23	-
Transition information resources	15	-	-	-	-	15
Quality Improvement project	-	-	35	-	-	35
Other research related restricted funds	(7)	-	5	-	6	4
Total funds related to research	**83**	**-**	**1,151**	**(1,021)**	**(152)**	**61**

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23 Prior year movements in funds Summary (continued)

	Balance 31 March 2021 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Restricted funds related to Information and Support						
E W Joseph/Homecare grants	18	-	7	(22)	-	3
Joseph Levy/Education Grants	(15)	-	37	(48)	30	4
Building Brighter Futures	28	-	50	(21)	(28)	29
Support services (inc. welfare grants)	80	-	148	(2)	(114)	112
Forum	-	-	-	-	22	22
CF Connect (youth and parents)	26	-	-	-	(26)	-
Helen Barrett Bright Ideas Awards	-	-	16	(13)	-	3
Total funds related to Information and Support	**137**	**-**	**258**	**(106)**	**(116)**	**173**

Other funds – various categories:						
Coombe Hill	8	-	-	-	-	8
SmartCare CF	(10)	-	-	-	10	-
Clinical Trials Accelerator Platform (CTAP)	(10)	-	914	(914)	10	-
Digital Health Research Programme (Project Breathe)	-	-	684	(684)	-	-
CTAP digital conference	-	-	3	(10)	-	(7)
CF Registry	(12)	-	-	-	12	-
Consensus documents	21	-	-	-	(21)	-
HDRUK grant award	(5)	-	-	-	5	-
Other older funds	36	-	-	-	-	36
Total other funds	**28**	**-**	**1,601**	**(1,608)**	**16**	**37**
Total Restricted Reserves	**248**	**-**	**3,646**	**(4,235)**	**612**	**271**

Structure, governance and management

Patron
- The former Prince of Wales, KG, KT, GCB, OM

Honorary President
- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees
Chair
- Richard Hunt CBE

- Professor Rosalind Smyth CBE FMedSci
- Sean Collins
- Anne Byrne
- Richard Hoey
- David Titmuss (resigned June 2022)
- Michelle Shore
- Joanna Barrett
- Sophie Pierce
- Sonya Trivedy
- Professor Martin Walshaw MD FRCP

Engagement Committee
(Previously Marketing, Communications & Income Generation Committee)

Chair
- Richard Hoey

- Sean Collins
- Joanna Barrett
- Sophie Pierce (appointed February 2023)
- David Titmuss (resigned June 2022)
- Joanne Hilditch – Independent member (resigned May 2022)

Finance Committee
Chair
- Sean Collins

- Anne Byrne
- David Sawer – Independent member
- Michelle Shore
- Ed Rushton – Independent member, Investments Committee
- Nick Wood – Independent member, Investments Committee

People Committee
Chair
- Michelle Shore

- Sonya Trivedy
- Joanna Barrett

Senior Leadership Team
- David Ramsden – Chief Executive
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising
- Rebecca Cosgriff – Director of Data and Quality Improvement (resigned June 2022)
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research and Healthcare data
- Simon Hawkins – Director of Finance and Resources (appointed February 2022, resigned June 2023)
- Alex Fowles - Director of Finance and Resources (appointed June 2023)
- Sarah Clarke - Associate Director, Data and Quality Improvement (appointed September 2022)

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
Haysmacintyre LLP
10 Queen Street Place,
London EC4R 1AG

Bankers
Natwest 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 1964 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 10 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.

Committed VIAs 2022/23

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment	Source of External Funds	External Leveraged Funds
VIA108	Prof David Denning	University of Manchester	Developing polygenic scores for aspergillosis in CF	£22,986	MRC Partnership grant	N/A Application unsuccessful in MRC peer review
VIA109	Dr James Duboff	Medusa Pharma	Developing combination therapeutics that overcome antimicrobial resistance in *Pseudomonas aeruginosa* infections and reduce treatment-associated side effects	£50,000	Innovate UK Biomedical Catalyst feasibility grant	£50,000
VIA110	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro 'carbon copy' of lung disease	£80,000	EPSRC	N/A application unsuccessful in EPSRC peer review
VIA111	Professor Lorraine Martin	Queens University Belfast	Developing a novel regenerative gene therapy platform technology for inhaled CF therapy	£26,000	Emily's Entourage	£220,000
VIA112	Prof Martin Welch	University of Cambridge	Investigating the impact of pathoadaptive mutations on the fitness of *Pseudomonas aeruginosa* in a polymicrobial airway environment	£47,100	NC3Rs	£181,820
VIA113	Dr Chrissie Jones	University of Surrey	Mindfulness-based well-being intervention for parents who have a child with cystic fibrosis (CF)	£64,084	NIHR RfPB	N/A application unsuccessful in NIHR peer review
VIA114	Dr Guy Moss	University College London	Exploring the therapeutic potential of BK channels	£44,601	CFF	£217,229
VIA115	Dr Freddy Frost	Liverpool Heart and Chest Hospital	Postal Sputum Testing for Early Detection of *Pseudomonas aeruginosa* in CF: POSTED-CF	£17,214	Asthma and Lung UK	£97,570
VIA 116	Prof Jane Davies	Imperial College London	Repurposing the multiple sclerosis drug, Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections	£99,999	LifeArc CDP call	£2,500,000
VIA 117	Prof Janis Shute	Ockham Biotech	Investigating anti-pseudomonal effects of roneparstat, a non-anticoagulant derivative of heparin with multiple anti-microbial, anti-inflammatory and mucolytic activities.	£50,000	LifeArc CDP call	£2,500,000
VIA 118	Prof Paul McNally	Royal College of Surgeons in Ireland (RCSI)	ENHANCE – Establishing Natural History in an Advanced New CF care era	£96,424	CFF	£4,771,000 (6,100,000 USD)
			Total CF Trust Committed	£431,338 (excluding unsuccessful awards)	**Total Potential Leverage**	£10,537,619(excluding unsuccessful awards)

Summer Studentships 2022/23

Supervisor	Host Institution	Student & Project
Dr Guy Moss	UCL	Miss Saidi Li – Understanding the rheology of mucociliary clearance
Dr Bettina Schock	Queen's University Belfast	Mr Sean Sexton – Effect of corticosteroids on anti-inflammatory A20 expression and investigating the synergy of a combination therapy

Open SRC Awards (March 2023)

SRC Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
SRC 011*	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)	£749,694
SRC 012*	Dr Daniel Peckham	St James' University Hospital	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC 013*	Dr Mike Gray	Newcastle University	Personalised Therapies for all: Restoring airway function in CF using Alternative Chloride Channels	£750,000
SRC 014*	Prof Jane Davies	Imperial College London	Personalised Approach to *Pseudomonas aeruginosa* (PAPA)	£750,000
SRC 015*	Dr Darius Armstrong-James	Imperial College London	TrIFIC: Targeting Immunotherapy for Fungal Infections in Cystic Fibrosis	£750,000
SRC 016*	Prof Pietro Cicuta	University of Cambridge	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC 017*	Dr Martin Welch	University of Cambridge	Gas, food and lodging; understanding the physiological and metabolic requirements of *Pseudomonas aeruginosa* in the cystic fibrosis airways	£748,538
SRC 018	Professor Steven Renshaw	University of Sheffield	Preventing Gastrointestinal Cancer in cystic fibrosis	£749,214
SRC 019	Professor James Shaw	University of Newcastle	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes	£750,000
SRC 020	Prof Stephen Hart	University College London	Therapeutic gene editing of CFTR	£740,142
SRC 021	Prof David Sheppard	University of Bristol	The CFTR Folding and Function SRC	£747,972
SRC 022	Dr Jo Fothergill	University of Liverpool	An evidence-based preclinical framework for the development of antimicrobial therapeutics in cystic fibrosis (PIPE-CF) **Co-funded with CFF**	£749,373
SRC 023	Prof Alan Smyth	University of Nottingham	Gut Research Advancing a Mechanistic & Personalised Understanding of Symptoms in Cystic Fibrosis: A Strategic Research Centre: The GRAMPUS-CF SRC	£749,592
SRC 024	Dr Paola Vergani	University College London	Restoring the Fizz: Pharmacological Repair of Bicarbonate Transport in Cystic Fibrosis **Co-funded with CFF**	£749,973

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

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA035	Dr Fred Piehl	Imperial College London	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA036	Dr Fred Piehl	Imperial College London	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA039	Ms Laura Birch	Bristol University	Dietary manipulation to improve glycaemic control in young people with cystic fibrosis and altered glucose handling: a feasibility study	£25,000
VIA045	Professor Chris van der Gast	Manchester Metropolitan University	Detection of CF lung pathogens using engineered bacteriophages	£45,950.50
VIA051	Dr Tanmay Bharat	Action Medical Research	Elucidating the structural role of filamentous bacteriophage in *Pseudomonas aeruginosa* biofilms for disrupting infection in cystic fibrosis airways	£89,917.50
VIA052	Professor Jane Davies	Imperial College London	Exploring the utility of novel 'antimicrobial resistance breakers' on strains of *Pseudomonas aeruginosa* obtained from patients with cystic fibrosis	£50,000
VIA059	Dr Joseph Jacob	UCL	Quantifying bronchiectasis severity in cystic fibrosis	£50,000
VIA061	Prof Alan Smyth	University of Nottingham	Gut Imaging for Function and Transit in CF – The GIFT Study	£35,369
VIA062	Prof Miguel Camara	University of Nottingham	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000
VIA063	Prof Stephen Hart	University College London	Development of in vitro Transcribed mRNA Therapeutics for cystic fibrosis	£51,545
VIA064	Dr Andrew Jones	University of Manchester	Arthropathy in Adults with cystic fibrosis	£34,000

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 067	Dr Martin Welch	University of Cambridge	Tackling CF Lung Infection in vitro: Assessing the Global Impact of Antibiotics on the CF Airway Microflora in a Laboratory Bioreactor	£33,000
VIA 068	Professor Jane Davies	Imperial College London	The idealised LCI (i-LCI): tuning in on the 'silent years' of paediatric CF	£98,594.93
VIA 070	Dr Laura Nolan	Imperial College London	Understanding interbacterial competition in the Cystic Fibrosis lung to identify opportunities for intervention	£30,000
VIA 071	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA 072	Dr Charles Haworth	Papworth Hospital	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis	£36,000
VIA 073	Dr Viek Dua	University College London	Modelling and machine learning to aid the design of CF therapy	£50,000
VIA 076	Dr Luke Allsopp	Imperial College London	In the thick of it: Competitive Microbial Interactions in Biofilms	£20,000
VIA 077	Prof Chris van der Gast	Manchester Metropolitan University	Organisation and function of the gut microbiota in cystic fibrosis	£47,000
VIA 078	Prof Chris van der Gast	Manchester Metropolitan University	Non-tuberculosis mycobacteria infection and the wider lung microbiota in cystic fibrosis	£48,000
VIA 079	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)	£32,600
VIA 081	Dr Anand Shah	Imperial College London	FREAL – Fungal Resistance Evolution and Acquisition in chronic Lung disease	£38,000
VIA 082	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£21,304
VIA 083	Dr Paul McNally	Our Lady's Children's Hospital	RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in People with CF)	£97,297

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 085	Professor Jane Davies	Imperial College London	Exploring the utility of quorum sensing inhibitors and biofilm disruptors on growth and virulence behaviours of *Pseudomonas aeruginosa* obtained from patients with cystic fibrosis	£50,000
VIA 086	Dr Christabella Ng	Univeristy of Nottingham	Gut Imaging for Function & Transit in cystic fibrosis Study 3	£65,000
VIA 088	Prof Kevin Southern	University of Liverpool	A randomised registry-based open label study to assess change in respiratory function for people with cystic fibrosis (pwCF) with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of muco-active aerosolised therapies (the CF STORM study)	£18,931.70
VIA 090	Prof Michael Givskov	University of Copenhagen	Co-therapy of a novel Pseudomonas aeruginosa biofilm disruptor with standard of care antibiotics	£26,500
VIA 091	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA 092	Dr James Reihill	Queen's University Belfast	The ubiquitylation system as a therapeutic target in CF	£15,000
VIA 093	Dr Anand Shah	Imperial College London	Development and validation of the use of videogames and virtual reality to enable autonomous remote monitoring of ototoxicity in high-risk population groups	£15,000
VIA 094	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro carbon copy of lung disease	£40,000
VIA 095	Dr Beverley Isherwood	Medicines Discovery Catapult	CF AMR Biorepository	£49,500
VIA 096	Prof Jane Davies	Imperial College London	The Pseudomonas aeruginosa c-di-GMP signalling network: adaptation and impact in clinical strains	£47,692
VIA 097	Prof David Denning	University of Manchester	Developing polygenic scores for aspergillosis in CF	£22,510

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 098	Dr Jonathan Cox	Aston University	Discovery of new and repurposed ß-lactamase inhibitors for improving *Mycobacterium abscessus* treatment	£25,000
VIA 099	Professor Chris Ward	Newcastle University	An implementation study investigating the feasibility of using gastrointestinal patient related outcome measures in people with cystic fibrosis	£37,000
VIA 101	Gerry McCauley	OmniSpirant Limited	Electrophysiology assessment of OS001 CFTR exosomes	£4,200
VIA 102	Dr Michelle Willicombe	Kidney Research UK	Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people (MELODY Study)	£50,000
VIA 103	Mr Andy Short	Ockham Biotech Ltd	Development of a non-anticoagulant heparin derivative as a therapy in CF	£50,000
VIA 104	Dr Beverley Isherwood	Medicines Discovery Catapult	Support for the UK CF Infection Biorepository	£95,000
VIA 105	Professor Alan Smyth	University of Nottingham	Core Outcome Set Taskforce for Cystic Fibrosis (COST-CF): a patient-initiated core outcome set for CF	£93,089
VIA 106	Dr Robert Gray	University of Edinburgh	A live airway model that incorporates a network of optical sensors for drug discovery and regenerative therapy development	£70,000
VIA 107	Dr Rian Griffiths	University of Nottingham	Development of a rapid and highly sensitive analytical method for the detection of biomarkers of infection in samples from people with CF	£37,726
VIA 108	Prof David Denning	University of Manchester	Developing polygenic scores for aspergillosis in CF	£22,986
VIA 109	Dr James Duboff	Medusa Pharmaceuticals	Developing combination therapeutics that overcome antimicrobial resistance in *Pseudomonas aeruginosa* infections and reduce treatment-associated side effects	£350,000
VIA 110	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro 'carbon copy' of lung disease (Phase 2)	£80,000

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 111	Prof Lorraine Martin	Queen's University Belfast	Developing a novel regenerative gene therapy platform technology for inhaled CF therapy	£26,000
VIA 112	Dr Martin Welch	University of Cambridge	Investigating the impact of pathoadaptive mutationson the fitness of *Pseudomonas aeruginosa* in a polymicrobial airway environment	£47,100
VIA 113	Dr Christina Jones	University of Surrey	Mindfulness-based well-being intervention for parents who have a child with cystic fibrosis	£64,084
VIA 114	Dr Guy Moss	UCL	Exploring the therapeutic potential of BK channels	£44,601
VIA 115	Dr Freddy Frost	University of Liverpool	Postal Sputum Testing for Early Detection of *Pseudomonas aeruginosa* in CF: POSTED-CF	£17,215
VIA 116	Prof Jane Davies	Imperial College London	Repurposing the multiple sclerosis drug, Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections	£99,999
VIA 117	Prof Janis Shute	Ockham Biotech	Investigating anti-pseudomonal effects of roneparstat, a non-anticoagulant derivative of heparin with multiple anti-microbial, anti-inflammatory and mucolytic activities.	£50,000
VIA 118	Prof Paul McNally	Royal College of Surgeons in Ireland (RCSI)	ENHANCE – Establishing Natural History in an Advanced New CF care era	£96,424

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*