Let's unite for a life unlimited
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Jamie Fox, who has CF and is a fundraiser for the Trust

Cystic Fibrosis Trust | Annual report and financial statements | March 2023
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 3880215) 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 last year has been one of wide-ranging activity and innovation as we continue to focus on achieving our vision of a Life Unlimited.

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

Against this everchanging backdrop, we had left the worst challenges of the COVID-19 pandemic behind us. The year started with optimism that ‘Life Unlimited’ by cystic fibrosis (CF).

As I have said we won’t stop until that vision of a life unlimited is a true reality for everyone with CF.

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 true for everyone with CF.

As the needs of people with CF have changed, 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 for people in our community who urgently need help.

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.

As this report demonstrates, the last year has been one of wide-ranging activity and innovation as we continue to focus on achieving our vision of a Life Unlimited.
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 condition. This information could be used to manage their condition from day to day and also to find out the effectiveness of new treatments being trialed in CF clinical trials.

People with CF on CFTR modulator 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 new ways to monitor function due to these medicines as soon as possible.

A new Strategic Research Centre (SRC) approved by 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.

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 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).

I have taken part in over 20 trials throughout my life. Put 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

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 it’s also used for cleaning things around the house. However, the administration of sodium bicarbonate in a bowl or mug will fail, and it’s the ‘bicarbonate’ part of the chemical that causes this.

Bicarbonate is an important chemical in the body. 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 of 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 rare 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. The SRC will begin a programme of research to investigate how and whether these new MRI methods can be incorporated into CF clinical practice. In particular, 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. The SRC will begin a programme of research to investigate how and whether these new MRI methods can be incorporated into CF clinical practice.

Without the Trust, the CF community would not have seen the incredible, life-changing advancements in medicine, education 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 making medical and treatment miracles happen.
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 expertise and skills in CF care and running clinical trials. Collectively the network covers ~90% of the UK CF community.

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.

Rachel (right) and daughter Anna
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 therapies are likely to 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

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

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 of the work undertaken in a review article from December 2021.

In 2022, in partnership with the University of Nottingham, the JLA and 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 75 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 modulator) in CF?
7. What are the effects of modulators on systems outside the lungs, such as pancreatic function, lung 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 option 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

Nicole, Martyn and Arlo, who has CF
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.

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.

Campaigning hard

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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

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

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Jamie*, who has CF

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

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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.

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.
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.

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 NICC 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.

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.

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.

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

Cystic Fibrosis Trust | Annual report and financial statements | March 2023
Coming together for the CF community
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 whilst also signposting to practical help and advice.

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 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

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

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 63 Joseph Levy Education Fund grants, helping people with CF with the costs of higher or further education.

We also provided 50 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.

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Benefits advice
Our welfare team supported 377 people this year and secured benefits income of over £900,000 for people affected by cystic fibrosis. 380 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.

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 via social media, making sure our support is as accessible as possible.

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

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 belligerence 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.

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.

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I joined YAG to not only help other people with CF, but also to get to know other young people with CF. This included a careers-focused project, ‘When I grow up’, which shared positive stories about CF and empowerment to encourage young people with CF to develop their own career aspirations.

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

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 empowerment 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

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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.

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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 56 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.

#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.

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

“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.
Lizzie, podcast listener
you’re my friend.”

in the room with you and
understood. I feel like I’m
and I felt you and the Trust
understands me. But then
but sometimes I feel no one
anyone being a teenager,
different. It is a hard time for
CF and sometimes feel a bit
I’m in high school with
own authentic voices.

of the way to ensure we’re telling their stories in their
and relevant to them, keeping them involved every step
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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

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 can understand and relate
to something.*

Lucy Baxter, CForYourself podcast host

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 stages, ranging from those who already have
a connection to CF, 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
many 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 our
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
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.

Sharing stories from our community
We strive to share diverse and new stories from our community
through our blogs and video content, which
covers a range of topics such as CF research,
manpower, mental health, breastfeeding, and what it
is really like living with an invisible condition. We listen to our
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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.

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.

Supporter experience

The Trust received 20 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 the supporters and community are telling us.

We are continuously improving our website through regular iterative developments to improve the supporter 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 includes 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 national Helpline and our social media as well as proactively requesting stories from the CF community to develop relevant and engaging content. Feedback from 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.
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.

Community and event fundraising

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• 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.

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

"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
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 tribute to those who have passed away. We are incredibly grateful to those who have thought of us in this special way and are considering doing so, and we continue to raise people’s awareness of legacy giving.

Regular gifts

We like to express our gratitude to our loyal regular donors who provide invaluable ongoing support that enables us to plan effectively for the future. In 2022/23, just over £834,000 in regular giving contributed over £834,000 in 2022/23, as well as gifts in wills, which included a gift to the Trust in their Will. In 2022/23, 48 supporters who generously included a gift to the Trust in their Will, as well as 48 supporters who told us they had pledged a gift. It is 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.

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 had pledged a gift. It is 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.

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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 like to express our gratitude to our loyal regular donors who provide invaluable ongoing support that enables us to plan effectively for the future. In 2022/23, just over £834,000 in regular giving contributed over £834,000 in 2022/23, as well as gifts in wills, which included a gift to the Trust in their Will. In 2022/23, 48 supporters who generously included a gift to the Trust in their Will, as well as 48 supporters who told us they had pledged a gift. It is incredibly grateful to those who have thought of us in this special way and are considering doing so, and we continue to raise people’s awareness of legacy giving.

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 had pledged a gift. It is 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. — James Dunmore

“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

Cystic Fibrosis a lifelong challenge

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 long-standing 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, making over £700,000 over the last decade in support of our mission to ensure that nobody with CF are turned away from treatments in the time since my sisters passed away.

We are grateful for the continued 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 Rosettes 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 grateful for the continued support of our Sixty Five Roses Club, for the continued support of our Sixty Five Roses Club, as well as our Sixty Five Roses Giving Club.

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 Langbouixon’s Charity of the Year 2022 through a nomination from an employee who has cystic fibrosis. For Wear Yellow Day, a team from Langbouixon walked 32 miles from their office in Bishamond in London. They completed it in 12 hours and walked 75,000 steps! In addition, the Langbouixon Awards raised nearly £8,000 on the right from a silent auction and donations.

We value the ongoing support of 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 Bp, 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.

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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 our 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 fundraising activities continues to provide a diverse range of 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 benefit from 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 more 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 ViP programme launched 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 the final 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. 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.
Results for the year

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.

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 £2.5m (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 balanced approach generating an investment income to support the ongoing activities of the Charity, while maintaining the real capital value of the investments over the long-term.

The majority of the general fund portfolio is held 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 investments in companies that 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 capital gains, protecting the original inflation-adjusted endowment values. We also hold cash reserves to maintain working liquidity and provide for current year’s commitments. 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 during the year due to both equities and bonds. No change was made to the allocation between amounts held as stocks and shares and that held as cash. Income generated on investments totalled £0.3m which is £0.2m more than in 2022 and reflects increasing business outlook as they materialise.

Relevant Risks

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 and uncertainties that management and Trustees have identified and the key actions to mitigate these are:

- Strategic risk
- Strategic risk
- Strategic risk
- Strategic risk
- Strategic risk

Reserves

The Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, in the range above six months’ core running costs and below 12 months’ core running costs to support the ongoing activities of the Charity, while maintaining the real capital value of the investments over the long-term.

At 31 March 2023, after adjusting for the designated reserves explained below, the Trust’s 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, 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 £8.5m at 31 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 asset cannot be readily realised as cash.
- Proposed capital investments. Income from the investment can be used by the Trust as
- Operating reserves will be maintained within policy.
- 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.
- In the strategic financial framework, we will build upon successes of the previous year.
- The trust also holds Endowment and restricted funds:
- Fixed asset reserve of £0.16m (2022: £0.02m). The reserve is maintained as
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- Endowment funds – The Trust maintains a number of endowment funds where the donor requires the Trustees to hold the funds as capital investments. Income from the investment can be used by the Trust as
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- The Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, in the range above six months’ core running costs and below 12 months’ core running costs to support the ongoing activities of the Charity, while maintaining the real capital value of the investments over the long-term.

Total reserves at 31 March 2023 were £11.4m (2022: £9.7m). This level of reserves has allowed the Trustees to approve a business plan and deficit budget for the next financial year, 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 £8.5m at 31 March 2024 meaning that the Trust will be operating only marginally above its reserves policy.

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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.

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 grants 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.

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 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 that 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

Sophie Pierce, Trustee

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 they are represented honestly and fairly.”

Sophie Pierce, Trustee

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 2003, 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 applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2023 and the Transfer 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:

• 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’ regimes and take advantage of the small companies’ exemptions in preparing the trustees’ report and from the requirement to prepare a strategic report.

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 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 under 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 the date of our audit opinion.

In our opinion, the financial statements do not contain any material misstatement of this other information, we are not required to report that fact.

In connection with our audit of the financial statements, our responsibilities include to:

• obtain and consider the other information;
• 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;
• identify such material inconsistencies or apparent material misstatements, and make inquiries of the group’s personnel and others, as appropriate, to determine the extent thereof;
• based on the work we have performed, conclude whether there is a material misstatement in the financial statements or a material misstatement of the other information.

In our opinion, the financial statements:

• 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.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our 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 and the parent charitable company’s net movement in funds, including the income and expenditure, for the year then ended, and the accompanying notes, are presented in accordance with applicable legal requirements.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Trustees’ Annual Report and the Transfer Annual Report (which incorporates the strategic report and the directors’ report).

In our opinion, the other information does not contain any material misstatement or any items that are inconsistent with the information included in the financial statements.

In connection with our audit of the financial statements, our responsibilities include to:

• obtain and consider the other information;
• 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;
• identify such material inconsistencies or apparent material misstatements, and make inquiries of the group’s personnel and others, as appropriate, to determine the extent thereof;
• based on the work we have performed, conclude whether there is a material misstatement of this other information, we are not required to report that fact.

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

• the printed matter 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 in the Trustees’ Annual Report and the parent charitable company’s net movement in funds, including the income and expenditure, for the year then ended, and the accompanying notes, are presented 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 parent charitable company and its environment obtained in the course of the audit, we have not identified any matters on which we are required to report by exception.

In our opinion, based on the work undertaken in the course of our 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 and the parent charitable company’s net movement in funds, including the income and expenditure, for the year then ended, and the accompanying notes, are presented in accordance with applicable legal requirements.

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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, including the ability to meet the costs of operating the charity and to continue to raise funds. They are also responsible for providing a true and fair view of the group’s and the parent charitable company’s financial position, financial performance, and changes in financial position for the period ended on the reporting date.

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.

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 if it exists. Material 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 concluded that the principal risks of non-compliance with laws and regulations related to fundraising regulation, charity and company law applicable in England, Wales and Scotland, and we considered the extent to which compliance may have a material effect on the financial statements.

We also considered those laws and regulations that might have a material effect on the financial statements. We also considered those laws and regulations that might have a material effect on the financial statements.

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-of of voluntary income, legacy income, 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 recognition of grants 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 a law or 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.

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-of of voluntary income, legacy income, 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 recognition of grants income and the recognition of grant expenditure

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 Act 2011 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 | Annual report and financial statements | March 2023

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Cystic Fibrosis Trust
Consolidated statement of financial activities
For the year ended 31 March 2023

<table>
<thead>
<tr>
<th>Note</th>
<th>Unrestricted Funds 2023 £'000</th>
<th>Restricted Funds 2023 £'000</th>
<th>Endowment Funds 2023 £'000</th>
<th>Total Funds 2023 £'000</th>
<th>Total Funds 2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income and endowments from:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donations and legacies</td>
<td>2</td>
<td>6,577</td>
<td>3,046</td>
<td>-</td>
<td>10,623</td>
</tr>
<tr>
<td>Charitable activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other trading activities</td>
<td>5</td>
<td>3,073</td>
<td>-</td>
<td>2,879</td>
<td>5,952</td>
</tr>
<tr>
<td>Investments</td>
<td>5</td>
<td>279</td>
<td>-</td>
<td>279</td>
<td>558</td>
</tr>
<tr>
<td>Other income</td>
<td></td>
<td>1,007</td>
<td>-</td>
<td>1,007</td>
<td>2,014</td>
</tr>
<tr>
<td>Total income</td>
<td>10,666</td>
<td>3,046</td>
<td>-</td>
<td>14,666</td>
<td>16,666</td>
</tr>
<tr>
<td>Expenditure:</td>
<td>4</td>
<td>5,301</td>
<td>21</td>
<td>-</td>
<td>5,322</td>
</tr>
<tr>
<td>Raising funds</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>4</td>
<td>1,122</td>
<td>646</td>
<td>-</td>
<td>1,768</td>
</tr>
<tr>
<td>Other charitable activities</td>
<td>4</td>
<td>694</td>
<td>1,281</td>
<td>-</td>
<td>1,975</td>
</tr>
<tr>
<td>Information, advice &amp; support</td>
<td>4</td>
<td>3,263</td>
<td>377</td>
<td>-</td>
<td>3,640</td>
</tr>
<tr>
<td>Total charitable activities</td>
<td>11,778</td>
<td>2,272</td>
<td>-</td>
<td>14,050</td>
<td>16,984</td>
</tr>
<tr>
<td>Total resource expended</td>
<td>16,756</td>
<td>2,293</td>
<td>-</td>
<td>19,049</td>
<td>21,008</td>
</tr>
<tr>
<td>Income/(expenditure) before investment gains/(losses)</td>
<td>3,347</td>
<td>1,597</td>
<td>-</td>
<td>1,894</td>
<td>1,871</td>
</tr>
<tr>
<td>Realised investment losses/(gains)</td>
<td>(13)</td>
<td>-</td>
<td>-</td>
<td>(13)</td>
<td>76</td>
</tr>
<tr>
<td>Unrealised investment gains/(losses)</td>
<td>(100)</td>
<td>-</td>
<td>74</td>
<td>(274)</td>
<td>568</td>
</tr>
<tr>
<td>Net investment losses/(gains)</td>
<td>(114)</td>
<td>-</td>
<td>74</td>
<td>(348)</td>
<td>542</td>
</tr>
<tr>
<td>Net income/(expenditure)</td>
<td>313</td>
<td>1,597</td>
<td>74</td>
<td>1,696</td>
<td>155</td>
</tr>
<tr>
<td>Transfers between funds:</td>
<td>15</td>
<td>1,144</td>
<td>1,046</td>
<td>-</td>
<td>2,190</td>
</tr>
<tr>
<td>Net movement in funds</td>
<td>1,557</td>
<td>403</td>
<td>74</td>
<td>1,650</td>
<td>155</td>
</tr>
<tr>
<td>Reconciliation of funds:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total funds brought forward</td>
<td>8,154</td>
<td>271</td>
<td>1,046</td>
<td>9,471</td>
<td>9,516</td>
</tr>
<tr>
<td>Total funds carried forward</td>
<td>15</td>
<td>9,711</td>
<td>674</td>
<td>972</td>
<td>10,357</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>2023 £'000</th>
<th>2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td>14,532</td>
<td>16,060</td>
</tr>
<tr>
<td>Gains/(losses) on investments (excludes endowments)</td>
<td>(134)</td>
<td>79</td>
</tr>
<tr>
<td>Investment income</td>
<td>279</td>
<td>274</td>
</tr>
<tr>
<td>Gross income in the reporting period</td>
<td>14,332</td>
<td>16,080</td>
</tr>
<tr>
<td>Expenditure</td>
<td>12,770</td>
<td>15,968</td>
</tr>
<tr>
<td>Interest payable</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Depreciation and charges for impairment of fixed assets</td>
<td>29</td>
<td>18</td>
</tr>
<tr>
<td>Total expenditure in the reporting period</td>
<td>12,799</td>
<td>16,086</td>
</tr>
<tr>
<td>Net income before tax for the reporting period</td>
<td>1,760</td>
<td>32</td>
</tr>
<tr>
<td>Tax payable</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Net income for the financial year</td>
<td>1,760</td>
<td>32</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Notes</th>
<th>Consolidated</th>
<th>Charity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total 2023 £'000</td>
<td>Total 2022 £'000</td>
</tr>
<tr>
<td>Fixed assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>7</td>
<td>156</td>
</tr>
<tr>
<td>Investments</td>
<td>8</td>
<td>5,388</td>
</tr>
<tr>
<td></td>
<td>5,543</td>
<td>5,637</td>
</tr>
<tr>
<td>Current assets</td>
<td>9</td>
<td>6,589</td>
</tr>
<tr>
<td>Creditors</td>
<td>11,485</td>
<td>11,265</td>
</tr>
<tr>
<td>Cash and at bank and in hand</td>
<td>5,438</td>
<td>5,197</td>
</tr>
<tr>
<td>20,984</td>
<td>18,462</td>
<td>18,462</td>
</tr>
<tr>
<td>Liabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creditors: amounts falling due within one year</td>
<td>10</td>
<td>6,268</td>
</tr>
<tr>
<td>Creditors and accrued charges</td>
<td>11</td>
<td>3,287</td>
</tr>
<tr>
<td>13,555</td>
<td>12,388</td>
<td>12,388</td>
</tr>
<tr>
<td>Net current assets</td>
<td>16,448</td>
<td>11,473</td>
</tr>
<tr>
<td>Creditors: amounts falling due after one year</td>
<td>10</td>
<td>6,268</td>
</tr>
<tr>
<td>Provisions: amounts falling due after one year</td>
<td>15</td>
<td>3,287</td>
</tr>
<tr>
<td>Total net assets</td>
<td>11,357</td>
<td>9,671</td>
</tr>
</tbody>
</table>

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

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

Richard Hunt, Chairman
Company number 3880213

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

<table>
<thead>
<tr>
<th>Notes</th>
<th>Consolidated</th>
<th>Charity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total 2023 £'000</td>
<td>Total 2022 £'000</td>
</tr>
<tr>
<td>The funds of the charity:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endowment funds</td>
<td>20</td>
<td>972</td>
</tr>
<tr>
<td>Restricted income funds</td>
<td>21</td>
<td>674</td>
</tr>
<tr>
<td>Unrestricted funds</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Total designated funds</td>
<td>1,155</td>
<td>1,155</td>
</tr>
<tr>
<td>Operating reserves</td>
<td>-</td>
<td>3,461</td>
</tr>
<tr>
<td>Retained reserves</td>
<td>8,546</td>
<td>6,029</td>
</tr>
<tr>
<td>Total unrestricted funds</td>
<td>9,701</td>
<td>7,054</td>
</tr>
<tr>
<td>Total charity funds</td>
<td>19</td>
<td>11,357</td>
</tr>
</tbody>
</table>

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

Approved and authorised for issue by the Trustees on 28 September 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

<table>
<thead>
<tr>
<th>2023</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>£'000</td>
<td>£'000</td>
</tr>
</tbody>
</table>

**Cash flows from operating activities:**

<table>
<thead>
<tr>
<th></th>
<th>2023</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net cash provided by operating activities (Note A)</td>
<td>(1,669)</td>
<td>1,728</td>
</tr>
</tbody>
</table>

**Cash flows from investing activities:**

<table>
<thead>
<tr>
<th></th>
<th>2023</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dividends and interest</td>
<td>279</td>
<td>78</td>
</tr>
<tr>
<td>Purchase of property, plant and equipment</td>
<td>(161)</td>
<td>-</td>
</tr>
<tr>
<td>Proceeds of sales of investments</td>
<td>437</td>
<td>1,128</td>
</tr>
<tr>
<td>Increase in cash held as short term investments</td>
<td>(220)</td>
<td>(9)</td>
</tr>
<tr>
<td>Increase/(decrease) in cash (Note B)</td>
<td>(1,767)</td>
<td>1,831</td>
</tr>
</tbody>
</table>

**Notes to cash flow statement**

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

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

Continued on the next page

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

<table>
<thead>
<tr>
<th></th>
<th>2023</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents at the beginning of the reporting period</td>
<td>16,462</td>
<td>14,462</td>
</tr>
<tr>
<td>Change in cash and cash equivalents in the reporting period</td>
<td>16,765</td>
<td>1,411</td>
</tr>
<tr>
<td>Net cash (used in)/provided by operating activities</td>
<td>(1,669)</td>
<td>1,728</td>
</tr>
<tr>
<td>Cash and cash equivalents at the end of the reporting period (being cash at bank and in hand and cash fields as short term investments)</td>
<td>14,895</td>
<td>16,462</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>2023</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents at the beginning of the reporting period</td>
<td>16,462</td>
<td>14,462</td>
</tr>
<tr>
<td>Cash on hand</td>
<td>3,438</td>
<td>5,197</td>
</tr>
<tr>
<td>Total cash and cash equivalents</td>
<td>14,895</td>
<td>16,462</td>
</tr>
</tbody>
</table>
Expenditure

Lobbies 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 it 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. Grants are paid to charitable companies 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 retranslated 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 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 expenditures 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.

Leases are accounted for as an asset when the right to use the property is received and the amount can be measured reliably. The leasing arrangements are classified as finance leases. When the leasing arrangement is such that settlement will be required and the amount of obligation can be measured reliably.

Leases 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.

Lease payments are included in the statement of financial activities when received and the amount can be measured reliably. The lease arrangement is classified as a finance lease when the Charity has a legal obligation to purchase, or has leased, the property at the end of the lease term.

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. Grants are paid to charitable companies and the development of the CF Registry.

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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 expenditures 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.

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. Grants are paid to charitable companies 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 retranslated 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 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.

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Leases

The trust recognises expenditures 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.
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 from the donor.

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

Unrestricted funds are those which the 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 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.

Going concern
The Trustees have reviewed the financial statements and supplementary financial information and conclude that the Trust is a valid going concern.

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 probable future 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 are not been reflected in these accounts. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an account and relates 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

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted Funds 2023 £’000</th>
<th>Restricted Funds 2023 £’000</th>
<th>Total 2023 £’000</th>
<th>Unrestricted Funds 2022 £’000</th>
<th>Restricted Funds 2022 £’000</th>
<th>Total 2022 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Branches, Groups &amp; Community</td>
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<td>44</td>
<td>2,191</td>
<td>2,371</td>
<td>29</td>
<td>2,400</td>
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<tr>
<td>Legacies</td>
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<td>3</td>
<td>1,483</td>
<td>1,503</td>
<td>321</td>
<td>1,824</td>
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<tr>
<td>Individual donations</td>
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<td>74</td>
<td>455</td>
<td>364</td>
<td>90</td>
<td>467</td>
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<tr>
<td>Corporate</td>
<td>146</td>
<td>32</td>
<td>178</td>
<td>160</td>
<td>4</td>
<td>164</td>
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<tr>
<td>Regular giving and appeals</td>
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<td>2</td>
<td>1,334</td>
<td>1,401</td>
<td>23</td>
<td>1,424</td>
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<td>3,056</td>
<td>3,069</td>
<td>94</td>
<td>2,521</td>
<td>2,615</td>
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<td>610</td>
<td>610</td>
<td>-</td>
<td>626</td>
<td>658</td>
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<td>1,450</td>
<td>-</td>
<td>1,450</td>
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<tr>
<td>Government grant income</td>
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<td>129</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>National Services England</td>
<td>176</td>
<td>-</td>
<td>176</td>
<td>145</td>
<td>-</td>
<td>145</td>
</tr>
<tr>
<td>and Scotland</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total income from donations and legacies</strong></td>
<td><strong>6,577</strong></td>
<td><strong>3,840</strong></td>
<td><strong>10,417</strong></td>
<td><strong>8,161</strong></td>
<td><strong>3,627</strong></td>
<td><strong>11,788</strong></td>
</tr>
</tbody>
</table>

*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 2023 relates to the recovery of partial salary costs through the Job Retention Scheme during the COVID-19 pandemic.

### 3. Investment Income

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted Funds 2023 £’000</th>
<th>Restricted Funds 2023 £’000</th>
<th>Total 2023 £’000</th>
<th>Unrestricted Funds 2022 £’000</th>
<th>Restricted Funds 2022 £’000</th>
<th>Total 2022 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income from listed investments</td>
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<td>-</td>
<td>279</td>
<td>279</td>
<td>-</td>
<td>279</td>
</tr>
<tr>
<td>Bank interest</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total investment income</strong></td>
<td><strong>279</strong></td>
<td><strong>-</strong></td>
<td><strong>279</strong></td>
<td><strong>279</strong></td>
<td><strong>-</strong></td>
<td><strong>279</strong></td>
</tr>
</tbody>
</table>

### 4. Expenditure

<table>
<thead>
<tr>
<th></th>
<th>Grants Restricted £’000</th>
<th>Grants Unrestricted £’000</th>
<th>Direct costs £’000</th>
<th>Support costs £’000</th>
<th>Total 2022 £’000</th>
<th>Total 2023 £’000</th>
<th>Total raising funds £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Raising funds</strong></td>
<td>2,218</td>
<td>-</td>
<td>2,218</td>
<td>431</td>
<td>2,649</td>
<td>2,649</td>
<td>2,243</td>
</tr>
<tr>
<td><strong>Trading and merchandising</strong></td>
<td>609</td>
<td>64</td>
<td>673</td>
<td>1,691</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Total raising funds</strong></td>
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<td>64</td>
<td>3,461</td>
<td>2,649</td>
<td>2,827</td>
<td>2,827</td>
<td>3,461</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Grants Restricted £’000</th>
<th>Grants Unrestricted £’000</th>
<th>Direct costs £’000</th>
<th>Support costs £’000</th>
<th>Total 2022 £’000</th>
<th>Total 2023 £’000</th>
<th>Total charitable activities £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Charitable activities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>11,788</td>
</tr>
<tr>
<td>Research</td>
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<td>1,954</td>
<td>638</td>
<td>2,744</td>
<td>2,744</td>
<td>1,345</td>
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<tr>
<td>Clinical care</td>
<td>599</td>
<td>572</td>
<td>310</td>
<td>1,067</td>
<td>1,372</td>
<td>1,372</td>
<td>1,345</td>
</tr>
<tr>
<td>Information, advice and support</td>
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<td>2,861</td>
<td>606</td>
<td>3,757</td>
<td>3,963</td>
<td>3,963</td>
<td>1,345</td>
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<tr>
<td><strong>Total charitable activities</strong></td>
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<td><strong>3,158</strong></td>
<td><strong>4,923</strong></td>
<td><strong>10,983</strong></td>
<td><strong>11,788</strong></td>
<td></td>
<td><strong>11,788</strong></td>
</tr>
<tr>
<td><strong>Total resources expended</strong></td>
<td><strong>1,764</strong></td>
<td><strong>3,158</strong></td>
<td><strong>4,923</strong></td>
<td><strong>10,983</strong></td>
<td><strong>11,788</strong></td>
<td></td>
<td><strong>11,788</strong></td>
</tr>
</tbody>
</table>
### Support Costs – prior year

**Analysis of allocated Support Costs – current year**

<table>
<thead>
<tr>
<th>Governance</th>
<th>Finance</th>
<th>IT Support</th>
<th>People &amp; OD</th>
<th>HQ &amp; Facilities</th>
<th>Total</th>
<th>2022 £’000</th>
<th>Total 2023 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grants</td>
<td>Restricted</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
</tr>
<tr>
<td>Raising funds</td>
<td>-</td>
<td>2,152</td>
<td>341</td>
<td>2,493</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Trading and merchandising</td>
<td>1,640</td>
<td>51</td>
<td>1,691</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total raising funds</td>
<td>-</td>
<td>2,152</td>
<td>341</td>
<td>2,493</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total costs</td>
<td>3,805</td>
<td>1,090</td>
<td>4,895</td>
<td>1,345</td>
<td>609</td>
<td>6,094</td>
<td>6,094</td>
</tr>
</tbody>
</table>

**Analysis of allocated Support Costs – prior year**

<table>
<thead>
<tr>
<th>Governance</th>
<th>Finance</th>
<th>IT Support</th>
<th>People &amp; OD</th>
<th>HQ &amp; Facilities</th>
<th>Total</th>
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<th>Total 2023 £’000</th>
</tr>
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<td>£’000</td>
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<td>341</td>
<td>2,493</td>
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<td>-</td>
<td>-</td>
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<td>1,691</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total raising funds</td>
<td>-</td>
<td>2,152</td>
<td>341</td>
<td>2,493</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
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<td>4,895</td>
<td>1,345</td>
<td>609</td>
<td>6,094</td>
<td>6,094</td>
</tr>
</tbody>
</table>

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

**Analysis of allocated support costs – prior year**

<table>
<thead>
<tr>
<th>Governance</th>
<th>Finance</th>
<th>IT Support</th>
<th>People &amp; OD</th>
<th>HQ &amp; Facilities</th>
<th>Total</th>
<th>2022 £’000</th>
<th>Total 2023 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grants</td>
<td>Restricted</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
</tr>
<tr>
<td>Raising funds</td>
<td>-</td>
<td>79</td>
<td>25</td>
<td>104</td>
<td>47</td>
<td>67</td>
<td>341</td>
</tr>
<tr>
<td>Trading and merchandising</td>
<td>203</td>
<td>67</td>
<td>269</td>
<td>121</td>
<td>350</td>
<td>486</td>
<td></td>
</tr>
<tr>
<td>Total raising funds</td>
<td>-</td>
<td>203</td>
<td>67</td>
<td>269</td>
<td>121</td>
<td>350</td>
<td>486</td>
</tr>
<tr>
<td>Total costs</td>
<td>448</td>
<td>146</td>
<td>595</td>
<td>268</td>
<td>546</td>
<td>1,107</td>
<td>1,107</td>
</tr>
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</table>

**Net income for the year is stated after charging**

<table>
<thead>
<tr>
<th>Governance</th>
<th>Finance</th>
<th>IT Support</th>
<th>People &amp; OD</th>
<th>HQ &amp; Facilities</th>
<th>Total</th>
<th>2022 £’000</th>
<th>Total 2023 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grants</td>
<td>Restricted</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
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<tr>
<td>Raising funds</td>
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<td>67</td>
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<td>Trading and merchandising</td>
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<td>486</td>
<td></td>
</tr>
<tr>
<td>Total raising funds</td>
<td>-</td>
<td>203</td>
<td>67</td>
<td>269</td>
<td>121</td>
<td>350</td>
<td>486</td>
</tr>
<tr>
<td>Total costs</td>
<td>448</td>
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<td>595</td>
<td>268</td>
<td>546</td>
<td>1,107</td>
<td>1,107</td>
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</table>

**Auditors remuneration excluding VAT**

<table>
<thead>
<tr>
<th></th>
<th>2022 £’000</th>
<th>2023 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance</td>
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</tr>
<tr>
<td>Depreciation</td>
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<td>Operating leases – building</td>
<td>271</td>
<td>272</td>
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<tr>
<td>Operating leases – other</td>
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<tr>
<td>Travel expenses</td>
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### Support Costs – current year

<table>
<thead>
<tr>
<th>Governance</th>
<th>Finance</th>
<th>IT Support</th>
<th>People &amp; OD</th>
<th>HQ &amp; Facilities</th>
<th>Total</th>
<th>2022 £’000</th>
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<tr>
<td>Grants</td>
<td>Restricted</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
</tr>
<tr>
<td>Raising funds</td>
<td>-</td>
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<td>431</td>
</tr>
<tr>
<td>Trading and merchandising</td>
<td>61</td>
<td>87</td>
<td>207</td>
<td>69</td>
<td>194</td>
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<tr>
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<td>61</td>
<td>87</td>
<td>207</td>
<td>69</td>
<td>194</td>
<td>428</td>
</tr>
<tr>
<td>Total costs</td>
<td>190</td>
<td>276</td>
<td>647</td>
<td>278</td>
<td>637</td>
<td>1,956</td>
<td>1,956</td>
</tr>
</tbody>
</table>

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

**Analysis of allocated support costs – current year**

<table>
<thead>
<tr>
<th>Governance</th>
<th>Finance</th>
<th>IT Support</th>
<th>People &amp; OD</th>
<th>HQ &amp; Facilities</th>
<th>Total</th>
<th>2022 £’000</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Grants</td>
<td>Restricted</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
</tr>
<tr>
<td>Raising funds</td>
<td>-</td>
<td>41</td>
<td>59</td>
<td>140</td>
<td>60</td>
<td>131</td>
<td>431</td>
</tr>
<tr>
<td>Trading and merchandising</td>
<td>61</td>
<td>87</td>
<td>207</td>
<td>69</td>
<td>194</td>
<td>428</td>
<td>886</td>
</tr>
<tr>
<td>Total raising funds</td>
<td>-</td>
<td>61</td>
<td>87</td>
<td>207</td>
<td>69</td>
<td>194</td>
<td>428</td>
</tr>
<tr>
<td>Total costs</td>
<td>190</td>
<td>276</td>
<td>647</td>
<td>278</td>
<td>637</td>
<td>1,956</td>
<td>1,956</td>
</tr>
</tbody>
</table>

**Support costs are apportioned based on the direct costs in each activity category**
Grants awarded during the year as follows:

<table>
<thead>
<tr>
<th>Institution Name</th>
<th>2023 £'000</th>
<th>2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Innovation Hub Cambridge</td>
<td>241</td>
<td>1,500</td>
</tr>
<tr>
<td>University of Nottingham</td>
<td>115</td>
<td>880</td>
</tr>
<tr>
<td>University of Liverpool</td>
<td>17</td>
<td>-</td>
</tr>
<tr>
<td>University of Sheffield</td>
<td>175</td>
<td>-</td>
</tr>
<tr>
<td>University of Cambridge</td>
<td>121</td>
<td>365</td>
</tr>
<tr>
<td>Medical Research Council</td>
<td>50</td>
<td>267</td>
</tr>
<tr>
<td>Cystic Fibrosis Canada (Fibrose Kystique) CFC</td>
<td>116</td>
<td>141</td>
</tr>
<tr>
<td>RNID</td>
<td>-</td>
<td>105</td>
</tr>
<tr>
<td>Diabetes UK</td>
<td>-</td>
<td>45</td>
</tr>
<tr>
<td>Royal College of Surgeons in Ireland</td>
<td>20</td>
<td>37</td>
</tr>
<tr>
<td>NIDCR (NIDCR Syndicate)</td>
<td>50</td>
<td>22</td>
</tr>
<tr>
<td>Medicine Discovery Consortium Limited</td>
<td>116</td>
<td>141</td>
</tr>
<tr>
<td>Imperial College London/Royal Brompton Hospital</td>
<td>100</td>
<td>70</td>
</tr>
<tr>
<td>Belfast City Hospital</td>
<td>-</td>
<td>50</td>
</tr>
<tr>
<td>Medicus Pharmaceuticals</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>Ockham Biotech Limited</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>University Hospital Llandough</td>
<td>-</td>
<td>45</td>
</tr>
<tr>
<td>Newcastle University</td>
<td>20</td>
<td>37</td>
</tr>
<tr>
<td>Aston University</td>
<td>-</td>
<td>25</td>
</tr>
<tr>
<td>The University of Manchester</td>
<td>-</td>
<td>23</td>
</tr>
<tr>
<td>Queen’s University Belfast</td>
<td>26</td>
<td>-</td>
</tr>
<tr>
<td>Medical Research Council</td>
<td>81</td>
<td>-</td>
</tr>
<tr>
<td>Western General Hospital</td>
<td>20</td>
<td>95</td>
</tr>
<tr>
<td>University of Edinburgh</td>
<td>-</td>
<td>70</td>
</tr>
<tr>
<td>Imperial College London/Royal Brompton Hospital</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>Medicus Pharmaceuticals</td>
<td>10</td>
<td>-</td>
</tr>
</tbody>
</table>

Grants awarded to the following institutions:

<table>
<thead>
<tr>
<th>Institution Name</th>
<th>2023 £'000</th>
<th>2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ockham Biotech Limited</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>University Hospital Llandough</td>
<td>-</td>
<td>45</td>
</tr>
<tr>
<td>Newcastle University</td>
<td>20</td>
<td>37</td>
</tr>
<tr>
<td>Aston University</td>
<td>-</td>
<td>25</td>
</tr>
<tr>
<td>Queen’s University Belfast</td>
<td>26</td>
<td>-</td>
</tr>
<tr>
<td>Medical Research Council</td>
<td>81</td>
<td>-</td>
</tr>
<tr>
<td>Imperial College London/Royal Brompton Hospital</td>
<td>100</td>
<td>70</td>
</tr>
<tr>
<td>Belfast City Hospital</td>
<td>-</td>
<td>50</td>
</tr>
<tr>
<td>Medicus Pharmaceuticals</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>Ockham Biotech Limited</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>University Hospital Llandough</td>
<td>-</td>
<td>45</td>
</tr>
<tr>
<td>Newcastle University</td>
<td>20</td>
<td>37</td>
</tr>
<tr>
<td>Aston University</td>
<td>-</td>
<td>25</td>
</tr>
<tr>
<td>Queen’s University Belfast</td>
<td>26</td>
<td>-</td>
</tr>
<tr>
<td>Medical Research Council</td>
<td>81</td>
<td>-</td>
</tr>
<tr>
<td>Western General Hospital</td>
<td>20</td>
<td>95</td>
</tr>
<tr>
<td>University of Edinburgh</td>
<td>-</td>
<td>70</td>
</tr>
<tr>
<td>Imperial College London/Royal Brompton Hospital</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>Medicus Pharmaceuticals</td>
<td>10</td>
<td>-</td>
</tr>
</tbody>
</table>

Analysis of total average monthly headcount by category:

<table>
<thead>
<tr>
<th>Category</th>
<th>2023 No.</th>
<th>2022 No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>17</td>
<td>8</td>
</tr>
<tr>
<td>Clinical care</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>Information, advice and support</td>
<td>36</td>
<td>32</td>
</tr>
<tr>
<td>Fundraising</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Management</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Finance</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>IT and project management support</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Facilities</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Total average monthly headcount</td>
<td>125</td>
<td>135</td>
</tr>
</tbody>
</table>

Analysis of total average monthly headcount by salary range:

<table>
<thead>
<tr>
<th>Salary Range</th>
<th>2023 No.</th>
<th>2022 No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>£60,001 – £70,000</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>£70,001 – £80,000</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>£80,001 – £90,000</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>£90,001 – £100,000</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>£110,001 – £120,000</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>£140,001 – £150,000</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

Pension contributions to defined contribution pension schemes for those employees totalled £33,475 (2022: £35,692).

The total remuneration paid to key management personnel, including pension and social security contributions, was £237,752 which relates to 7 individuals who served on the Senior Leadership Team during the year (2022: £248,529 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.

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

<table>
<thead>
<tr>
<th>Category</th>
<th>2023 £'000</th>
<th>2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salaries</td>
<td>4,481</td>
<td>3,898</td>
</tr>
<tr>
<td>Redundancy and other termination payments</td>
<td>-</td>
<td>34</td>
</tr>
<tr>
<td>Temporary Staff</td>
<td>-</td>
<td>34</td>
</tr>
<tr>
<td>Social security costs</td>
<td>80</td>
<td>412</td>
</tr>
<tr>
<td>Other pension costs</td>
<td>70</td>
<td>277</td>
</tr>
<tr>
<td>Total staff costs</td>
<td>4,591</td>
<td>4,587</td>
</tr>
</tbody>
</table>

Analysis of total average monthly headcount by salary category:

<table>
<thead>
<tr>
<th>Salary Range</th>
<th>2023 No.</th>
<th>2022 No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>£60,001 – £70,000</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>£70,001 – £80,000</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>£80,001 – £90,000</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>£90,001 – £100,000</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>£110,001 – £120,000</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>£140,001 – £150,000</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

Pension contributions to defined contribution pension schemes for those employees totalled £33,475 (2022: £35,692).

The total remuneration paid to key management personnel, including pension and social security contributions, was £237,752 which relates to 7 individuals who served on the Senior Leadership Team during the year (2022: £248,529 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.
### Fixed Assets

<table>
<thead>
<tr>
<th>Group and charity</th>
<th>Furniture &amp; fittings £'000</th>
<th>Computer hardware £'000</th>
<th>Computer software £'000</th>
<th>Website development £'000</th>
<th>Platform development £'000</th>
<th>Total £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost At 31 March 2022</td>
<td>630</td>
<td>870</td>
<td>243</td>
<td>403</td>
<td>183</td>
<td>2,329</td>
</tr>
<tr>
<td>Additions</td>
<td>-</td>
<td>59</td>
<td>41</td>
<td>59</td>
<td>-</td>
<td>161</td>
</tr>
<tr>
<td>Disposals</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>At 31 March 2023</td>
<td>630</td>
<td>929</td>
<td>284</td>
<td>462</td>
<td>183</td>
<td>2,490</td>
</tr>
</tbody>
</table>

**Depreciation**

<table>
<thead>
<tr>
<th>Group and charity</th>
<th>Furnitures &amp; fittings £'000</th>
<th>Computer hardware £'000</th>
<th>Computer software £'000</th>
<th>Website development £'000</th>
<th>Platform development £'000</th>
<th>Total £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost At 31 March 2022</td>
<td>630</td>
<td>851</td>
<td>243</td>
<td>403</td>
<td>183</td>
<td>2,310</td>
</tr>
<tr>
<td>Additions</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Disposals</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Charge for the year</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20</td>
</tr>
<tr>
<td>At 31 March 2023</td>
<td>630</td>
<td>871</td>
<td>243</td>
<td>418</td>
<td>183</td>
<td>2,335</td>
</tr>
</tbody>
</table>

**Net book value**

<table>
<thead>
<tr>
<th>Group and charity</th>
<th>Furnitures &amp; fittings £'000</th>
<th>Computer hardware £'000</th>
<th>Computer software £'000</th>
<th>Website development £'000</th>
<th>Platform development £'000</th>
<th>Total £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>At 31 March 2023</td>
<td>-</td>
<td>58</td>
<td>43</td>
<td>54</td>
<td>-</td>
<td>155</td>
</tr>
<tr>
<td>At 31 March 2022</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>19</td>
</tr>
</tbody>
</table>

---

**Investments**

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

<table>
<thead>
<tr>
<th></th>
<th>Total 2023 £'000</th>
<th>Total 2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Market value as at 31 March 2022</td>
<td>£, 2,024</td>
<td>£, 1,157</td>
</tr>
<tr>
<td>Market value as at 31 March 2023</td>
<td>£, 2,490</td>
<td>£, 1,504</td>
</tr>
</tbody>
</table>

**8. Investments**

- **Group and Charity**

  - **Total 2023 £'000**
    - £1,230
    - £1,194
    - £58
    - £35
    - £22
    - £0
  - **Total 2022 £'000**
    - £0
    - £0
    - £0
    - £0
    - £0
    - £0

- **Adjustment to brought forward balance**
  - £12
  - £(14)

- **Additions at cost**
  - £407
  - £1,063

- **Disposals at opening book value**
  - £(469)
  - £(1,018)

- **Net gains/(losses) on investments**
  - £(192)
  - £366

- **Market value at 31 March 2023**
  - £1,304
  - £1,504

**9. Debtors**

<table>
<thead>
<tr>
<th>Group</th>
<th>2023 £'000</th>
<th>2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trade debtors</td>
<td>£1,125</td>
<td>£1,124</td>
</tr>
<tr>
<td>Amount due from subsidiary undertaking</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Prepayments and accrued income</td>
<td>£5,293</td>
<td>£2,784</td>
</tr>
<tr>
<td>Other debtors</td>
<td>£71</td>
<td>£40</td>
</tr>
</tbody>
</table>

Total debtors: £6,589 | £5,396

**Net book value**: £2,490 | £1,504

---

**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).
10. Grants Payable

<table>
<thead>
<tr>
<th></th>
<th>2023</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grant creditor at 31 March 2022</td>
<td>£13,654</td>
<td>£12,230</td>
</tr>
<tr>
<td>Prior year adjustment</td>
<td>-</td>
<td>(17)</td>
</tr>
<tr>
<td>Grants paid during the year</td>
<td>£8,978</td>
<td>£3,379</td>
</tr>
<tr>
<td>Grants approved before 31 March 2023 and payable within one year</td>
<td>£1,088</td>
<td>£2,384</td>
</tr>
<tr>
<td>Grants approved before 31 March 2023 and payable after one year</td>
<td>£2,792</td>
<td>£3,379</td>
</tr>
<tr>
<td>Grant creditor at 31 March 2023</td>
<td>£13,263</td>
<td>£13,654</td>
</tr>
</tbody>
</table>

11. Creditors

<table>
<thead>
<tr>
<th></th>
<th>Group 2023</th>
<th>Charity 2023</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trade creditors</td>
<td>£610</td>
<td>£600</td>
</tr>
<tr>
<td>Other creditors</td>
<td>90</td>
<td>-</td>
</tr>
<tr>
<td>Other taxation and social security</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Accruals and deferred income</td>
<td>£1,474</td>
<td>£1,470</td>
</tr>
<tr>
<td>Total</td>
<td>£2,257</td>
<td>£2,500</td>
</tr>
</tbody>
</table>

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.

12. 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.

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:

<table>
<thead>
<tr>
<th></th>
<th>Total 2023</th>
<th>Total 2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sales and service income</td>
<td>£2,873</td>
<td>£2,700</td>
</tr>
<tr>
<td>Cost of sales and administration</td>
<td>(679)</td>
<td>(690)</td>
</tr>
<tr>
<td>Intercompany charges</td>
<td>(46)</td>
<td>(40)</td>
</tr>
<tr>
<td>Net contribution to parent charity</td>
<td>£2,154</td>
<td>£1,924</td>
</tr>
</tbody>
</table>
14. Lease commitments
At 31 March, the Trust's future minimum operating lease payments relating to buildings were:

<table>
<thead>
<tr>
<th>Property</th>
<th>Equipment</th>
</tr>
</thead>
<tbody>
<tr>
<td>2023</td>
<td>£'000</td>
</tr>
<tr>
<td>Within one year</td>
<td>271</td>
</tr>
<tr>
<td>Between two and five years</td>
<td>271</td>
</tr>
</tbody>
</table>

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

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.

18. Analysis of net assets between funds

<table>
<thead>
<tr>
<th>Unrestricted</th>
<th>£'000</th>
<th>Endowment funds</th>
<th>£'000</th>
<th>Other restricted</th>
<th>£'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior year</td>
<td>2023</td>
<td>2022</td>
<td>2023</td>
<td>2022</td>
<td>2023</td>
</tr>
<tr>
<td>Tangible fixed assets</td>
<td>122</td>
<td>525</td>
<td>-</td>
<td>-</td>
<td>122</td>
</tr>
<tr>
<td>Investments</td>
<td>4,464</td>
<td>-</td>
<td>972</td>
<td>-</td>
<td>5,436</td>
</tr>
<tr>
<td>Current assets</td>
<td>20,030</td>
<td>-</td>
<td>674</td>
<td>21,504</td>
<td>-</td>
</tr>
<tr>
<td>Current liabilities</td>
<td>12,441</td>
<td>-</td>
<td>5,954</td>
<td>-</td>
<td>15,504</td>
</tr>
<tr>
<td>Liabilities due in more than one year</td>
<td>10,564</td>
<td>-</td>
<td>10,564</td>
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<td>Provisions due in more than one year</td>
<td>170</td>
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<td>170</td>
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<tr>
<td>Total</td>
<td>9,711</td>
<td>972</td>
<td>674</td>
<td>11,357</td>
<td>-</td>
</tr>
</tbody>
</table>
Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

19. Current year fund movements summary

<table>
<thead>
<tr>
<th></th>
<th>Balance 31 March 2022 £’000</th>
<th>Investment Gains/(Losses) £’000</th>
<th>Income £’000</th>
<th>Expenditure £’000</th>
<th>Transfers £’000</th>
<th>Balance 31 March 2023 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>The funds of the charity</td>
<td></td>
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</tr>
<tr>
<td>Endowment funds (Note 20)</td>
<td>1,046</td>
<td>(74)</td>
<td></td>
<td></td>
<td></td>
<td>972</td>
</tr>
<tr>
<td>Restricted funds (Note 21)</td>
<td>275</td>
<td></td>
<td>3,040</td>
<td>(2,205)</td>
<td>(1,144)</td>
<td>674</td>
</tr>
<tr>
<td>Unrestricted funds</td>
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<tr>
<td>Appeal deficit</td>
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<td>(1,265)</td>
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<td>Total designated funds</td>
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<td>Total unrestricted funds</td>
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<tr>
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<td>11,357</td>
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</table>

20. Endowment funds

Ena Bennie Endowment

<table>
<thead>
<tr>
<th>Balance 31 March 2022 £’000</th>
<th>Investment Gains/(Losses) £’000</th>
<th>Income £’000</th>
<th>Expenditure £’000</th>
<th>Transfers £’000</th>
<th>Balance 31 March 2023 £’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ena Bennie Endowment</td>
<td>530</td>
<td>(39)</td>
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<td>EW Joseph Endowment</td>
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<tr>
<td>Joseph Levy Endowment</td>
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<td>(22)</td>
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<td>Sally Wrigley Memorial Fund</td>
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<td>Total endowment funds</td>
<td>1,046</td>
<td>(74)</td>
<td></td>
<td></td>
<td>972</td>
</tr>
</tbody>
</table>

 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 1989. 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.

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 to fund the commitment in full from new donations, and therefore there was £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 balanced plan and deficit budget for the next financial year which maintain services and grant awards at a level similar to previous years but which anticipate lower levels of income. Assumptions about future income are based on an income mix in line with 2022/23. Retained reserves are forecast to be £3.6m 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 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 Restricted Reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently beenbackfilled by restricted donations.
### Cystic Fibrosis Trust

#### Notes to the Financial Statements (continued)

For the year ended 31 March 2023

#### 21 Restricted funds

<table>
<thead>
<tr>
<th>Balance</th>
<th>31 March 2022 £'000</th>
<th>Investment Gains/(Losses) £'000</th>
<th>Income £'000</th>
<th>Expenditure £'000</th>
<th>Transfers £'000</th>
<th>Balance</th>
<th>31 March 2023 £'000</th>
</tr>
</thead>
</table>

**Restricted Income Funds**

- Against Innovation Hub at Cambridge
  - £ 1,272 (348) [1,924]

**Restricted funds related to research**

- General therapies
  - £ 3 (3) [-]
- General medical research
  - £ 213 (225) [-]
- Sport England - lending the active step active
  - £ 7 (5) [2]
- Imperial BSC: Pulmonary anaesthesia
  - £ 10 (10) [-]
- University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis
  - £ 20 (30) [-]
- University College London: Therapeutic gene editing
  - £ 14 (14) [-]
- University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis
  - £ 14 (14) [-]
- UK CF infection biopreservation
  - £ 32 (32) [-]
- CF Active programme
  - £ 5 (5) [0]
- Transition intervention resources
  - £ 35 (35) [-]
- Quality Improvement project
  - £ 35 (35) [-]
- Other research related restricted funds
  - £ 4 [4]

- Total funds related to research
  - £ 1,284 (545) [1,045] 437

**Restricted funds related to Information and Support**

- K Joseph home care fund
  - £ 1,085 (20) [1,065]
- Joseph Levy education grants
  - £ 4 (3) [1]
- Building Brighter Futures
  - £ 29 (26) [3]
- Support services (ex: welfare grants)
  - £ 68 (45) [23]
- Work Forwards (England)
  - £ 30 (29) [-]
- Work Forwards (Scotland)
  - £ 12 (3) [9]
- Helen Barrett Bright Ideas Awards
  - £ 22 (9) [13]
- Forum
  - £ 15 [15]
- Corporate/Children in Need
  - £ 173 (16) [157]

- Total funds related to Information and Support
  - £ 1,065 (510) [555] 142

**Other funds**

- Work Forwards (England) - funding to support people with cystic fibrosis so that they can take advantage of opportunities, to be safe and comfortable at home during challenging times, to build new futures and strengthen their families, including the welfare grants to support people with cystic fibrosis and their families. These include:
  - £ 97 [97]

**Restricted funds related to Information and Support**

- £ 1,496 (1,437) [59]

**Total restricted funds**

- £ 3,840 (2,260) [1,584] 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 building programme. The funds are used to fund any additional commitments to the Innovation Hub building programme. Any surplus is transferred to the designated appeal deficit fund (see note 19).

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

- £ 1,085 home care fund – to support people with cystic fibrosis to live safe and comfortable at home through challenging times.
- £ 4 Joseph Levy education grants – funding people with cystic fibrosis in their education and studies.
- £ 29 Building Brighter Futures – funding young people’s programmes supporting young people with cystic fibrosis. The fund is supported by BBC Children in Need.
- £ 68 Support Services – various activities for supporting people with cystic fibrosis and their families. These include: £ 30 Work Forwards (England), £ 12 Work Forwards (Scotland), £ 15 Helen Barrett Bright Ideas Awards.

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

- £ 1,085 home care fund – to support people with cystic fibrosis to live safe and comfortable at home through challenging times.
- £ 4 Joseph Levy education grants – funding people with cystic fibrosis in their education and studies.
- £ 29 Building Brighter Futures – funding young people’s programmes supporting young people with cystic fibrosis. The fund is supported by BBC Children in Need.
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- £ 4 Joseph Levy education grants – funding people with cystic fibrosis in their education and studies.
- £ 29 Building Brighter Futures – funding young people’s programmes supporting young people with cystic fibrosis. The fund is supported by BBC Children in Need.
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- £ 1,085 home care fund – to support people with cystic fibrosis to live safe and comfortable at home through challenging times.
- £ 4 Joseph Levy education grants – funding people with cystic fibrosis in their education and studies.
- £ 29 Building Brighter Futures – funding young people’s programmes supporting young people with cystic fibrosis. The fund is supported by BBC Children in Need.
- £ 68 Support Services – various activities for supporting people with cystic fibrosis and their families. These include: £ 30 Work Forwards (England), £ 12 Work Forwards (Scotland), £ 15 Helen Barrett Bright Ideas Awards.
### Cystic Fibrosis Trust
### Notes to the Financial Statements (continued)

#### For the year ended 31 March 2023

### Prior year consolidated statement of financial activities

<table>
<thead>
<tr>
<th>Note</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Endowment Funds</th>
<th>Total Funds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
</tr>
<tr>
<td>Income and endowments from:</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donations and legacies</td>
<td>2</td>
<td>8,161</td>
<td>3,627</td>
<td>3,627</td>
</tr>
<tr>
<td>Charitable activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other trading activities</td>
<td>3</td>
<td>7,761</td>
<td>3</td>
<td>7,763</td>
</tr>
<tr>
<td>Investments</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other income</td>
<td>159</td>
<td>13</td>
<td>152</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1,203</td>
<td>1,045</td>
<td></td>
<td>2,248</td>
</tr>
<tr>
<td>Expenditure on:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Raising funds</td>
<td>4</td>
<td>1,063</td>
<td></td>
<td>1,064</td>
</tr>
<tr>
<td>Charitable activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>4</td>
<td>2,219</td>
<td>1,213</td>
<td>1,006</td>
</tr>
<tr>
<td>Clinical care</td>
<td>4</td>
<td>431</td>
<td>314</td>
<td>117</td>
</tr>
<tr>
<td>Information, advice and support</td>
<td>4</td>
<td>3,074</td>
<td>162</td>
<td>2,912</td>
</tr>
<tr>
<td>Total charitable activities</td>
<td>7,544</td>
<td>3,235</td>
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<td>10,779</td>
</tr>
<tr>
<td>Total resources expended</td>
<td>10,757</td>
<td>4,355</td>
<td>6</td>
<td>15,968</td>
</tr>
<tr>
<td>Net income/(expenditure) before investment gains/(losses)</td>
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<td></td>
</tr>
<tr>
<td>Total funds brought forward</td>
<td>9,516</td>
<td>379</td>
<td>12,035</td>
<td>(11,727)</td>
</tr>
</tbody>
</table>

#### Endowment funds

- **Endowment funds**
  - **Unrestricted funds**: £989, £63, £3,646, £3,646
  - **Restricted funds**: £20, £3,646, £4,235, £412

#### Total endowment funds

- **Total endowment funds**: £1,046

---

### Cystic Fibrosis Trust
### Notes to the Financial Statements (continued)

#### For the year ended 31 March 2022

### Prior year movements in funds Summary

#### The funds of the charity:

- **Endowment funds**
  - **Unrestricted funds**: £989, £63, £3,646, £3,646
  - **Restricted funds**: £20, £3,646, £4,235, £412

#### Other endowment funds

- **Unrestricted funds**: £28
- **Restricted funds**: £-28

#### Total endowment funds

- **Total endowment funds**: £1,046

---

### Notes to the Financial Statements (continued)

#### For the year ended 31 March 2023

### Prior year consolidated statement of financial activities

<table>
<thead>
<tr>
<th>Note</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Endowment Funds</th>
<th>Total Funds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
<td>£’000</td>
</tr>
<tr>
<td>Income and endowments from:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donations and legacies</td>
<td>2</td>
<td>8,161</td>
<td>3,627</td>
<td>3,627</td>
</tr>
<tr>
<td>Charitable activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other trading activities</td>
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<td>7,761</td>
<td>3</td>
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#### Total endowment funds

- **Total endowment funds**: £1,046

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### Notes to the Financial Statements (continued)

#### For the year ended 31 March 2022

### Prior year movements in funds Summary

#### The funds of the charity:

- **Endowment funds**
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  - **Restricted funds**: £20, £3,646, £4,235, £412

#### Other endowment funds

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- **Restricted funds**: £-28

#### Total endowment funds

- **Total endowment funds**: £1,046

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### Notes to the Financial Statements (continued)

#### For the year ended 31 March 2023

### Prior year consolidated statement of financial activities

<table>
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<tr>
<th>Note</th>
<th>Unrestricted Funds</th>
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<tbody>
<tr>
<td></td>
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<tr>
<td>Net income/(expenditure) before investment gains/(losses)</td>
<td></td>
<td></td>
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<tr>
<td>Total funds brought forward</td>
<td>9,516</td>
<td>379</td>
<td>12,035</td>
<td>(11,727)</td>
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</tbody>
</table>

#### Endowment funds

- **Endowment funds**
  - **Unrestricted funds**: £989, £63, £3,646, £3,646
  - **Restricted funds**: £20, £3,646, £4,235, £412

#### Total endowment funds

- **Total endowment funds**: £1,046

---

### Notes to the Financial Statements (continued)

#### For the year ended 31 March 2022

### Prior year movements in funds Summary

#### The funds of the charity:

- **Endowment funds**
  - **Unrestricted funds**: £989, £63, £3,646, £3,646
  - **Restricted funds**: £20, £3,646, £4,235, £412

#### Other endowment funds

- **Unrestricted funds**: £28
- **Restricted funds**: £-28

#### Total endowment funds

- **Total endowment funds**: £1,046
Restricted income funds  

<table>
<thead>
<tr>
<th></th>
<th>Balance 31 March 2021 £'000</th>
<th>Investment gains/(losses) £'000</th>
<th>Income £'000</th>
<th>Expenditure £'000</th>
<th>Transfers £'000</th>
<th>Balance 31 March 2022 £'000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Against Innovation Hub at Cambridge</td>
<td>-</td>
<td>-</td>
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</tbody>
</table>
| Restricted funds related to research  

<table>
<thead>
<tr>
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<th>Balance 31 March 2021 £'000</th>
<th>Investment gains/(losses) £'000</th>
<th>Income £'000</th>
<th>Expenditure £'000</th>
<th>Transfers £'000</th>
<th>Balance 31 March 2022 £'000</th>
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<tbody>
<tr>
<td>Genetic therapies (104)</td>
<td>15</td>
<td>-</td>
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<tr>
<td>General medical research (6)</td>
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<tr>
<td>Sport England (helping the active step action)</td>
<td>7</td>
<td>-</td>
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<tr>
<td>Imperial SRC: Pneumonialiasis</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Imperial SRC: Targeting Immune therapy for fungal infections</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Sheffield SRC: Gastrointestinal cancer</td>
<td>-</td>
<td>-</td>
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<tr>
<td>UCL/Leiden SRC: Therapeutic gene editing</td>
<td>4</td>
<td>-</td>
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<tr>
<td>Bristol SRC: CTRF training and function</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>University College London (Pharmacological repair of bicarbonate transport in cystic fibrosis)</td>
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<tr>
<td>Life-expectancy project (3)</td>
<td>2</td>
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<tr>
<td>Transition information resources</td>
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<tr>
<td>Quality improvement project (5)</td>
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<td>Other research related restricted funds (4)</td>
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<tr>
<td>Total funds related to research</td>
<td>43</td>
<td>-</td>
<td>1,151</td>
<td>5,000</td>
<td>162</td>
<td>61</td>
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Restricted funds related to Information and Support  

<table>
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<th>Investment gains/(losses) £'000</th>
<th>Income £'000</th>
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<th>Transfers £'000</th>
<th>Balance 31 March 2022 £'000</th>
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</thead>
<tbody>
<tr>
<td>E W Joseph/Homecare grants</td>
<td>18</td>
<td>-</td>
<td>7</td>
<td>22</td>
<td>-</td>
<td>3</td>
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<tr>
<td>Joseph Levy/Education Grants</td>
<td>(15)</td>
<td>-</td>
<td>37</td>
<td>(48)</td>
<td>30</td>
<td>4</td>
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<td>Building Brighter Futures (28)</td>
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<td>28</td>
<td>29</td>
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<td>Support services (inc. welfare grants)</td>
<td>(60)</td>
<td>-</td>
<td>(469)</td>
<td>(2)</td>
<td>(154)</td>
<td>112</td>
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<tr>
<td>Forum (24)</td>
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<td>-</td>
<td>22</td>
<td>22</td>
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<tr>
<td>CF Connect (youth and parents)</td>
<td>34</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Inner Barrel Bright Ideas Awards</td>
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<tr>
<td>Total funds related to Information and Support</td>
<td>137</td>
<td>-</td>
<td>316</td>
<td>564</td>
<td>166</td>
<td>179</td>
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</table>

Other funds – various categories:  

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<th>Income £'000</th>
<th>Expenditure £'000</th>
<th>Transfers £'000</th>
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<tbody>
<tr>
<td>Coombe Hill (8)</td>
<td>-</td>
<td>-</td>
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<td>SmartCare CF (16)</td>
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<tr>
<td>Clinical Trials Accelerator Platform (CTAP) (17)</td>
<td>-</td>
<td>-</td>
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<td>-</td>
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<tr>
<td>Digital Health Research Programme (Project Breathe)</td>
<td>-</td>
<td>-</td>
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<td>-</td>
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<tr>
<td>CTRF digital conference (10)</td>
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<td>-</td>
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</tr>
<tr>
<td>CF Registry (12)</td>
<td>-</td>
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<tr>
<td>Continuous documents (23)</td>
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<tr>
<td>HDRUK grant award (25)</td>
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<tr>
<td>Other older funds (36)</td>
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<tr>
<td>Total other funds (38)</td>
<td>-</td>
<td>-</td>
<td>1,163</td>
<td>6,082</td>
<td>162</td>
<td>37</td>
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<tr>
<td>Total Restricted Reserves (248)</td>
<td>-</td>
<td>-</td>
<td>3,666</td>
<td>14,255</td>
<td>612</td>
<td>275</td>
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</table>
Legal structure

Cystic Fibrosis Trust (‘the Trust’) is a registered charity in England and Wales (charity number 1070945) and is also a company incorporated in 1964 and limited by guarantee (SC040499). 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 specialist area.

Senior Leadership Team

The Trustees have delegated day-to-day responsibility 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.

Structure, governance and management

Chair

• The former Prince of Wales, KG, KT, GCB, OM

Honorary President

• Dr James Littlewood OBE

Honorary President

• The former Prince of Wales, Patron and management

• Professor Martin Walshaw MD FRCP

• Sonya Trivedy

• Sophie Pierce

• Joanna Barrett

• Michelle Shore (resigned June 2022)

• Richard Hoey

• Anne Byrne

• Sean Collins

• Professor Rosalind Smyth CBE FMedSci

Richard Hunt CBE

• Joanna Barrett

People Committee

Chair

• Michelle Shore

• Sonya Trivedy

• Joanna Barrett

Senior Leadership Team

• Richard Hoey – Chief Executive

• Dr Keith Browne – Director of Medical Affairs

• Dr Anne Shrinkin – Director of Research and Healthcare data

• Rebecca Cosgriff – Director of Data and Quality Improvement (resigned June 2022)

• Clare Corbett – Director of External Affairs

• Dr Lucy Allen – Director of Research

• David Ramsden – Chief Executive

• David Sawer – Independent member

• Joanne Hilditch (resigned June 2022)

• David Titmus (resigned June 2022)

• Ed Rushton – Independent member

• Michelle Shore

• Sarah Clarke - Associate Director, Data and Quality Improvement (appointed September 2022)

• Alex Fowles - Director of Finance

• Simon Hawkins – Director of Healthcare-data

• Lucy Allen – Director of Research

• Clare Corbett – Director of External Affairs

• Joanne Hilditch – Director of Research and Healthcare data

• David Sawer – Independent member

• Michelle Shore

• Ed Rushton – Independent member, Investments Committee

• Nick Wood – Independent member, Investments Committee

Company Secretary

• Alex Fowles

Principal and Registered Office

One Aldgate

London

EC3N 1RE

enquiries@cysticfibrosis.org.uk

020 3795 1555

cysticfibrosis.org.uk

Company Limited by Guarantee

Company registration number: 3880213

Charity registration number: England & Wales —1070945

Scotland —SC040199

Haysmacintyre LLP

12 Queen Street Place,

Edinburgh, EH2 2EJ

Principal and Registered Office

Scotland —SC040196

Company registration number: Company Limited by Guarantee

Charity registration number: England and Wales —1070949

England & Wales —1079049

Scotland —SC040199

Auditors

Haymacintyre LLP

12 Queen Street Place,

London EC4R 1JG

Bankers

National Plc

15 Bishopsgate London EC2N 3NW

Investment Managers

Cazeneuve Capital Management

12 Moorgate London EC2R 6DA

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Cystic Fibrosis Trust | Annual report and financial statements | March 2023

2
<table>
<thead>
<tr>
<th>VIA Award Number</th>
<th>Lead Applicant(s)</th>
<th>Host Institution</th>
<th>Title</th>
<th>CF Trust Commitment</th>
<th>Source of External Funds</th>
<th>External Leveraged Funds</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>VIA208</td>
<td>Prof David Denning</td>
<td>University of Manchester</td>
<td>Developing polygenic scores for aspergillosis in CF</td>
<td>£22,986</td>
<td>HRC Partnership grant</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA209</td>
<td>Dr James Duloff</td>
<td>Medusa Pharma</td>
<td>Developing combination therapeutics that overcome intrinsic resistance to Pseudomonas aeruginosa infections and reduce treatment associated side effects</td>
<td>£50,000</td>
<td>N/A Application unsuccessful in MRC peer review</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA210</td>
<td>Prof Petro Ciccia</td>
<td>University of Cambridge</td>
<td>Technologies for an in-vitro ‘carbon copy’ of lung disease</td>
<td>£80,000</td>
<td>EPSRC Biomedical Catalyst Feasibility grant</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA211</td>
<td>Professor Lucrèce Martin</td>
<td>Queen’s University Belfast</td>
<td>Developing a novel regenerative gene therapy platform technology for induced CF therapy</td>
<td>£20,000</td>
<td>EPSRC Lipidomics grant</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA212</td>
<td>Dr Martin Welch</td>
<td>University of Cambridge</td>
<td>Investigating the impact of patho-adaptive mutations on the fitness of Pseudomonas aeruginosa in a polychromatid airway environment</td>
<td>£47,100</td>
<td>MiCFS</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA213</td>
<td>Dr Christine Jones</td>
<td>University of Surrey</td>
<td>Mindfulness-based well being intervention for parents who have a child with cystic fibrosis (CF)</td>
<td>£44,184</td>
<td>N/A Application unsuccessful in MI-CF peer review</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA214</td>
<td>Dr Gay Mills</td>
<td>University College London</td>
<td>Exploring the therapeutic potential of 84 channels</td>
<td>£44,631</td>
<td>N/A Application unsuccessful in MI-CF peer review</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA215</td>
<td>Dr Freddie Frost</td>
<td>Liverpool Heart and Chest Hospital</td>
<td>Paediatric Sparse Tissue engineering (PST-E)</td>
<td>£17,774</td>
<td>N/A Application unsuccessful in MI-CF peer review</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>VIA216</td>
<td>Prof Jane Sasse</td>
<td>Imperial College London</td>
<td>Repurposing the multiple antibiotic drug Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections</td>
<td>£39,999</td>
<td>LifeArc CDP call</td>
<td>£3,148,000</td>
<td></td>
</tr>
<tr>
<td>VIA217</td>
<td>Prof Jane Sasse</td>
<td>Glisham Biotech</td>
<td>Investigating anti-pseudomonal effects of repurposed, non-anticoagulant derivative of heparin with multiple anti-microbial properties</td>
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<td>LifeArc CDP call</td>
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<tr>
<td>VIA218</td>
<td>Prof Paul McNally</td>
<td>Royal College of Surgeons (Glasgow) (RCSG)</td>
<td>ENHANCE – Establishing Natural History in an Advanced New CF care era</td>
<td>£46,604</td>
<td>CFF</td>
<td>£4,471,000 (£5,100,000 VAD)</td>
<td></td>
</tr>
</tbody>
</table>

Total CF Trust Committed: £431,338 (excluding unsuccessful awards)
Total Potential Leverage: £10,537,619 (excluding unsuccessful awards)

Committed VIA Awards 2022/23

<table>
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<th>VIA Award Number</th>
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Summer Studentships 2022/23

<table>
<thead>
<tr>
<th>Supervisor</th>
<th>Student &amp; Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Gap Moss</td>
<td>UCL</td>
</tr>
<tr>
<td>Dr Bettina Scheck</td>
<td>Queen’s University Belfast</td>
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</table>

Dr Sean Lenox – Effect of anticoagulants on anti-inflammatory A20 expression and investigating the synergy of a combination therapy
<table>
<thead>
<tr>
<th>SRC Award Number</th>
<th>Lead Applicant(s)</th>
<th>Institution</th>
<th>Title</th>
<th>CF Trust Commitment</th>
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</thead>
<tbody>
<tr>
<td>SRC 011*</td>
<td>Professor Soraya Shirazi-Beechey</td>
<td>University of Liverpool</td>
<td>Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)</td>
<td>£746,094</td>
</tr>
<tr>
<td>SRC 012*</td>
<td>Dr Daniel Peckham</td>
<td>St James’ University Hospital</td>
<td>The Impact of Dysbiosis on Lung Inflammation in CF</td>
<td>£750,000</td>
</tr>
<tr>
<td>SRC 013*</td>
<td>Dr Mike Gray</td>
<td>Newcastle University</td>
<td>Personalised Therapies for airway Restoring Goblet Function in CF using Alternative Chloride Channels</td>
<td>£750,000</td>
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<tr>
<td>SRC 014*</td>
<td>Dr Jane Davies</td>
<td>Imperial College London</td>
<td>Personalised Approach to Pseudomonas aeruginosa (PAPA)</td>
<td>£750,000</td>
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<tr>
<td>SRC 015*</td>
<td>Dr Darius Armstrong-Jones</td>
<td>Imperial College London</td>
<td>TrIFIC: Targeting Immunotherapy for Fungal Infections in Cystic Fibrosis</td>
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<tr>
<td>SRC 016*</td>
<td>Prof Pietro Cicuta</td>
<td>University of Cambridge</td>
<td>Mucociliary clearance – from fundamentals to personalised treatment</td>
<td>£743,852</td>
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<tr>
<td>SRC 017*</td>
<td>Dr Martin Welch</td>
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<td>Gas, food and lodging: understanding the physiological and metabolic requirements of Pseudomonas aeruginosa in the cystic fibrosis airways</td>
<td>£748,538</td>
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<tr>
<td>SRC 018</td>
<td>Professor Steven Renshaw</td>
<td>University of Sheffield</td>
<td>Preventing Gastrointestinal Cancer in cystic fibrosis</td>
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<tr>
<td>SRC 019</td>
<td>Professor James Shaw</td>
<td>University of New South Wales</td>
<td>Personalised Medicine for the Pathway Through Which Cystic Fibrosis Patients Develop Infection</td>
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<tr>
<td>SRC 020</td>
<td>Prof Stephen Hart</td>
<td>University of Cambridge</td>
<td>Therapeutic gene editing of CFTR</td>
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<tr>
<td>SRC 021</td>
<td>Dr David Sheppard</td>
<td>University of Cambridge</td>
<td>The CFTR Folding and Function SRC</td>
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<tr>
<td>SRC 022</td>
<td>Dr Jo Efstathiou</td>
<td>University of Liverpool</td>
<td>An evidence-based practical framework for the development of physiological therapeutics in Cystic Fibrosis (CFPT): Co-funded with CFF</td>
<td>£740,373</td>
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<tr>
<td>SRC 023</td>
<td>Prof Abi Smyth</td>
<td>University of Nottingham</td>
<td>Gut-Brain Axis: a pharmacological insight into the physiology and impact of gut dysbiosis in Cystic Fibrosis</td>
<td>£740,182</td>
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<tr>
<td>SRC 024</td>
<td>Dr Paula Vergani</td>
<td>University of Manchester</td>
<td>Restoring the Goblet Cell Transport in Cystic Fibrosis</td>
<td>£740,073</td>
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*Grant issued extension due to COVID-19 related delays.

Open VIA Awards (March 2023)

<table>
<thead>
<tr>
<th>VIA Award Number</th>
<th>Lead Applicant(s)</th>
<th>Institution</th>
<th>Title</th>
<th>CF Trust Commitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>VIA035</td>
<td>Dr Fred Peri</td>
<td>Imperial College London</td>
<td>PhD Studentship 1 – Air pollution and environmental factors on infection – linking with Registry data</td>
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<tr>
<td>VIA036</td>
<td>Dr Fred Peri</td>
<td>Imperial College London</td>
<td>PhD Studentship 2 – Air pollution and environmental factors on infection – linking with Registry data</td>
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<tr>
<td>VIA039</td>
<td>Ms Laura Birch</td>
<td>Bristol University</td>
<td>Detection of CF lung pathogens using engineered bacteriophages</td>
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<td>VIA045</td>
<td>Professor Chris van der Gat</td>
<td>Manchester Metropolitan University</td>
<td>Elucidating the structural role of filamentous bacteriophage in Pseudomonas aeruginosa biofilms for disrupting infection in Cystic Fibrosis airways</td>
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<tr>
<td>VIA046</td>
<td>Professor Sara Di Giorgio</td>
<td>Imperial College London</td>
<td>Exploring the utility of novel antimicrobial resistance breakers on strains of Pseudomonas aeruginosa obtained from patients with cystic fibrosis</td>
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<tr>
<td>VIA047</td>
<td>Dr Joseph Jacobs</td>
<td>UCL</td>
<td>Investigating the impact of Horton amiloride resistance breakers on the causation of Pseudomonas aeruginosa infections</td>
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<tr>
<td>VIA051</td>
<td>Professor Abi Smyth</td>
<td>University of Nottingham</td>
<td>Gut-mapping for function and transit in CF – The CFIT Study</td>
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<td>VIA052</td>
<td>Professor Miguel Carreras</td>
<td>University of Sheffield</td>
<td>Scholarship for the National Biofilms Innovation Centre (NBIC)</td>
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<td>VIA053</td>
<td>Professor Stephen Hart</td>
<td>University of Manchester</td>
<td>Development of gut microbiota therapeutic for cystic fibrosis</td>
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<tr>
<td>VIA054</td>
<td>Dr Andrew Jones</td>
<td>University of Manchester</td>
<td>Antiporters in Adults with cystic fibrosis</td>
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VIA Award Number | Lead Applicant(s) | Host Institution | Title | CF Trust Commitment
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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 | Dr Laura Nolan | Imperial College London | Understanding interbacterial competition in the CF airway to identify opportunities for intervention | £30,000
VIA 069 | Dr Elise Lannertyn | ECFS | The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in CF | £36,000
VIA 070 | Dr Charles Maurice | Papworth Hospital | In the thick of it: Competitive Microbial Interactions in Biofilms | £20,000
VIA 071 | Dr Viek Dua | University College London | Modelling and machine learning to aid the design of CF therapy | £50,000
VIA 072 | Prof Chris van der Gast | Manchester Metropolitan University | Exploring the utility of quorum sensing inhibitors and biofilm disruptors on growth and virulence behaviours of P. aeruginosa obtained from patients with CF | £50,000
VIA 073 | Dr Christabella Ng | University of Nottingham | Gut Imaging for Function & Transit in CF: Study 3 | £65,000
VIA 074 | Prof Kevin Southern | University of Liverpool | A randomised registry-based open label study to assess change in respiratory function for people with CF with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of mucoactive aerosolised therapies (the CF STORM study) | £18,931.70
VIA 075 | Prof Michael Givskov | University of Copenhagen | Co-therapy of a novel P. aeruginosa biofilm disruptor with standard of care antibiotics | £26,500
VIA 076 | Dr James Reihill | Queen’s University Belfast | The ubiquitylation system as a therapeutic target in CF | £15,000
VIA 077 | 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 078 | Prof Pietro Cicuta | University of Cambridge | Technologies for an in-vitro carbon copy of lung disease | £40,000
VIA 079 | Dr Beverley Isherwood | Medicines Discovery Catapult | CF AMR Biorepository | £49,500
VIA 080 | Prof Jane Davies | Imperial College London | Exploring the utility of quantum sensing inhibitors and biodegradable polymers on growth and survival of P. aeruginosa and potential impact on chronic inflammatory disease | £50,000
VIA 081 | Dr Elise Lannertyn | ECFS | The idealised LCI (i-LCI): tuning in on the ‘silent years’ of paediatric CF | £98,594.93
VIA 082 | 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
VIA 083 | Dr Paul McNally | Our Lady’s Children’s Hospital | RCPCH BiS World Clinical Outcomes with Novel Respiratory Therapy Combinations in People with CF | £357,297
VIA 084 | Dr Charles Maurice | Papworth Hospital | Organ and function of the gut microbiota in CF | £47,000
VIA 085 | Prof Pietro Cicuta | University of Cambridge | Technologies for an in-vitro carbon copy of lung disease | £40,000
VIA 086 | Prof Kevin Southern | University of Liverpool | A randomised registry-based open label study to assess change in respiratory function for people with CF with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of mucoactive aerosolised therapies (the CF STORM study) | £18,931.70
VIA 087 | Prof Jane Davies | Imperial College London | The Pseudomonas aeruginosa c-di-GMP signalling network: adaptation and impact in clinical strains | £47,692
VIA 088 | Dr Christabella Ng | University of Nottingham | Gut Imaging for Function & Transit in CF: Study 3 | £65,000
VIA 089 | Dr Beverley Isherwood | Medicines Discovery Catapult | CF AMR Biorepository | £49,500
VIA 090 | Prof Jane Davies | Imperial College London | Exploring the utility of quantum sensing inhibitors and biodegradable polymers on growth and survival of P. aeruginosa and potential impact on chronic inflammatory disease | £50,000
VIA 091 | Dr Elise Lannertyn | ECFS | The idealised LCI (i-LCI): tuning in on the ‘silent years’ of paediatric CF | £98,594.93
VIA 092 | Dr Charles Maurice | Papworth Hospital | In the thick of it: Competitive Microbial Interactions in Biofilms | £20,000
VIA 093 | Dr Paul McNally | Our Lady’s Children’s Hospital | RCPCH BiS World Clinical Outcomes with Novel Respiratory Therapy Combinations in People with CF | £357,297
VIA 094 | Prof Pietro Cicuta | University of Cambridge | Technologies for an in-vitro carbon copy of lung disease | £40,000
VIA 095 | Prof Kevin Southern | University of Liverpool | A randomised registry-based open label study to assess change in respiratory function for people with CF with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of mucoactive aerosolised therapies (the CF STORM study) | £18,931.70
VIA 096 | Dr Beverley Isherwood | Medicines Discovery Catapult | CF AMR Biorepository | £49,500
VIA 097 | Prof Jane Davies | Imperial College London | Exploring the utility of quantum sensing inhibitors and biodegradable polymers on growth and survival of P. aeruginosa and potential impact on chronic inflammatory disease | £50,000
VIA 098 | Dr Elise Lannertyn | ECFS | The idealised LCI (i-LCI): tuning in on the ‘silent years’ of paediatric CF | £98,594.93
VIA 099 | Dr Paul McNally | Our Lady’s Children’s Hospital | RCPCH BiS World Clinical Outcomes with Novel Respiratory Therapy Combinations in People with CF | £357,297
VIA 100 | Prof Jane Davies | Imperial College London | Exploring the utility of quantum sensing inhibitors and biodegradable polymers on growth and survival of P. aeruginosa and potential impact on chronic inflammatory disease | £50,000
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<thead>
<tr>
<th>VIA Award Number</th>
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<tr>
<td>VIA 098</td>
<td>Dr Jonathan Cox</td>
<td>Aston University</td>
<td>Discovery of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>VIA 099</td>
<td>Dr Jonathan Cox</td>
<td>Aston University</td>
<td>An implementation study investigating the feasibility of using patient-oriented outcome measures in people with cystic fibrosis</td>
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<td>VIA 100</td>
<td>Dr Jonathan Cox</td>
<td>Aston University</td>
<td>Bacteriophage based screening for the detection of SARS-CoV-2 nAbs in people with cystic fibrosis</td>
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<td>VIA 101</td>
<td>Dr Jonathan Cox</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>VIA 103</td>
<td>Dr Jonathan Cox</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>VIA 104</td>
<td>Dr Jonathan Cox</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>VIA 105</td>
<td>Dr Jonathan Cox</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>VIA 106</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>VIA 107</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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<td>VIA 110</td>
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<td>Development of new and repurposed β-lactamase inhibitors for improving <em>Mycobacterium abscessus</em> treatment</td>
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Open VIA Awards (March 2023)
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.