

**Cystic
Fibrosis Trust**

Let's write for a life unlimited

Annual Report and Financial Statements
for the year ended 31 March 2022

A man with glasses and a dark blue polo shirt is seated in a brown armchair, painting on a canvas mounted on a wooden easel. He is holding a paintbrush in his right hand and a palette in his left. The easel is positioned on a white table. To the left of the easel, there is a clear glass jar filled with paintbrushes and a small container of paint. A flexible gooseneck lamp is positioned above the man, providing light for his work. The background is a plain, light-colored wall.

Uniting for a life unlimited

Contents

Thanks to you, in 2021/22...	4
Introduction from our Chair	6
Uniting for life unlimited	
Objectives and activities	10
About CF	10
About us	10
Our goals	11
Measuring success	11
Uniting in research	
Understanding and treating lung infections	14
Tackling the underlying cause of CF	14
Understanding and treating the symptoms of CF	15
Digital health research	16
Refreshing the research priorities for CF	17
Uniting to ensure everybody with CF can access the care and support they need	
Collaborating with and supporting the clinical community to promote the highest quality of care	20
The impact of Kafrio on the CF community	22
The impact of COVID-19 on the CF community	23
Keeping the community informed	23
Campaigning hard	24
The UK CF Registry	26
Annual data report	27
Quality improvement	27

On the cover: Dom



Supporting access to medicines at every step from laboratory to medicine cabinet	
Clinical Trials Accelerator Programme	30
Network of CTAP centres	30
Early phase coordinator pilot	30
CTAP's new five-year strategy	31
Community involvement	32
Aligning the UK's Clinical Research Programme	33
Delivering the UK CF Clinical Trials Conference	33
CF Clinical Trials Hub	33
Providing day-to-day support; and reaching people with cystic fibrosis when they need us most	
Day-to-day support	36
Grants	36
Benefits advice	37
Helpline	37
Information	38
Youth programme	39

Reaching all people with CF	
CF Week 2021	42
#CFTruths	43
CF Live	43
Our brand	43
Website	43
Volunteering	44
Being an effective organisation	44
Uniting in fundraising	
Supporter experience	49
Regular gifts	49
Community fundraising	49
Corporate partnerships	50
Gifts in Wills	50
In memory	51
Philanthropy	51
Looking to the future	
Uniting in research for a life unlimited	54
Delivering our strategy	54
Being great fundraisers	55
Campaigning hard	55
Day-to-day support	56
UK CF Registry	57
Quality improvement	57
Financial review	
Independent auditor's report to the Members and Trustees of the Cystic Fibrosis Trust	68
Consolidated statement of financial activities	72
Consolidated and charity balance sheets	74
Consolidated statement of cash flows	76
Notes to the Financial Statements	78
Structure, governance and management	102
Committed VIAs	104
Currently active SRCs	107
Summer Studentships	109



Thanks to you, in 2021/22...



321 people with cystic fibrosis enrolled on to a CTAP clinical trial, helping to develop new medicines for everyone with CF.



We co-funded a new Strategic Research Centre (SRC) on CFTR folding and function, with the aim to design new and innovative medicines to act on the CFTR protein that will make a bigger difference for more people with cystic fibrosis.



We helped people with CF to access at least £1.025 million in benefits through our Welfare and Benefits Advice service.



Our Helpline responded to over 4,200 enquiries from people affected by CF and continued to provide support to the community through the COVID-19 pandemic.



Through our new Winter Hardship Support Fund, we supported 250 people on low incomes with a grant to fund household essentials such as food and energy, protecting their health through the coldest winter months.



We launched our public awareness campaign #CFTruths, resulting in a 120% increase in cystic fibrosis-related searches online.

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2022. 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 72 to 103 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 21/22 Annual Report.

This past year was another influenced by the challenges of the COVID-19 pandemic. It certainly had its lows, but also some significant highs.

January saw Kaftrio being made available to 6–11-year-olds across the UK, which marked another critical step forward after the years of campaigning by the Trust and the CF community.

It has also been a year when we have continued to focus on the fact that Kaftrio is not a cure and alongside those who can't benefit from it, we know that many challenges remain. It is vital that we are fully committed to a diverse and innovative research portfolio to help us achieve our goal of a life unlimited for everyone with CF.

The changing CF landscape also led to new information and support needs. We've reflected this in the information resources we provide, updating our Kaftrio factsheet to recognise the complex and individual responses across the CF Community. We have also been working to understand and respond to emerging needs, developing programmes of support to ensure health improvements can translate into life opportunities.

The pandemic has also created new challenges for many, both socially and economically. In many ways it has highlighted, or perhaps accelerated, new challenges that we must face head on. As reflected in our current Strategy, we are increasingly aware of the need to support not just physical health but also mental health, and the additional pressures that can now arise in seeking to achieve a fulfilled life.



Richard Hunt CBE

When increases in the cost of living left many with CF worrying about how they would afford to heat and eat properly this winter, we immediately launched a Winter Hardship Support Fund. Through this Fund, we supported 250 people on low incomes with a grant to fund household essentials such as food and energy, protecting their health through the coldest winter months.

"When increases in the cost of living left many with CF worrying about how they would afford to heat and eat properly this winter, we immediately launched a Winter Hardship Support Fund."

Through our first ever Cost of CF survey, launched in the spring, we want to help highlight and address the economic challenges many in the community are facing and uncover the daily hidden costs of living with a life-limiting condition. We will use the insights from the survey to inform and guide our actions and the actions we call on others to make.

We believe it is important that as many people as possible understand what life with CF is like and in 21/22, we were thrilled to launch #CFTruths, our public awareness campaign. The campaign was devised by Caitlin, who has cystic fibrosis and was struck by how the COVID-19 pandemic made common many of the everyday experiences of the CF community. It's been wonderful to see the response to this campaign, and how the community are using it as an opportunity to increase understanding of CF and kickstart conversations about life with the condition.

Ensuring our community's voice is at the heart of our work is something we always strive for, and we were delighted to partner with QuestionCF in the James Lind Research Priority Refresh that launched back in January. Over 1,600 people shared their views in the first survey telling us what's on their CF research wishlist.

A second survey and online workshops will follow and the refreshed priorities will be published at the end of 2022. At a time of such profound change, we want to make sure we listen to our community and your priorities for the years ahead. This will enable us to make our vision, that every person with cystic fibrosis can live a long and full life, a reality.

I would like to finish by thanking all our wonderful supporters for their passion and determination to support the Trust. In these challenging times, what you do is especially important and we couldn't do what we do without you.

On behalf of the Board, I would also like to thank the Cystic Fibrosis Trust team for all they do to support our CF community. Thank you.

Finally, I would also like to thank my Board colleagues for their time, commitment and support for the Trust. For all of us, it is another unusual year and a busy year. And we know there is always much more to do to fulfil our objectives and ensure everybody with CF can live a life unlimited.

Richard Hunt CBE
Chairman of Trustees

**Uniting for a
life unlimited**



Objectives and activities

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

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

About CF

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. You are born with CF and cannot catch it later in life. One in 25 of us carries the faulty gene that causes it, usually without knowing. More than 10,800 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 at which someone with CF dies is just 36 years old.

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 for the CF community. We have Delivery Review Groups that assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track the progress of projects using our Project Portfolio and 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**



"Thanks to research, the world is looking so much brighter for people with cystic fibrosis. There have been so many advances in the time since my children were diagnosed; however, now is not the time to rest on our laurels. We need to harness the energy across the community and really push forward with supporting future research. This way we can make life with CF the best it can be."

Zoë, mum to Alex and Isobel, who have CF

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.

Understanding and treating lung infections

People with CF are susceptible to developing infections, due to the thick sticky mucus in their lungs. The infections can be extremely difficult to treat, as many bugs are resistant to the antimicrobial medicines available. Left untreated, the infections may cause progressive lung damage and shorten people's lives.

We are funding research into some of the most common and dangerous CF infections through the UK Cystic Fibrosis Innovation Hub, including *Pseudomonas aeruginosa* and *Mycobacterium abscessus*, to develop better treatments and detect infections faster.

In 2021, Trust-funded researchers published two prestigious research reports highlighting new information on how infections caused by the *Mycobacterium abscessus* bacteria are passed on to people with CF, and how these bugs adapt and evolve to live in the unique environment within the sticky mucus in the lungs of people with CF. This information can be used to prevent and treat CF infections in the future.



Tackling the underlying cause of CF

This year, we were delighted to co-fund a new Strategic Research Centre (SRC) on CFTR folding and function. Led by Professor David Sheppard at the University of Bristol, the aim of this SRC is to design new and innovative medicines to act on the CFTR protein that will make a bigger difference for more people with cystic fibrosis.

"For a very long time we could study whether the CFTR protein was working or not, but we had to speculate about what its shape or its structure was," explained Professor David Sheppard, when talking about the impact this SRC could have. **"It is important to look at how the shape of the proteins made from faulty CFTR genes affects their function."**

"Now we have information on how the proteins are working and their structure, we can start to link the two together and understand more about what is causing CF. We are working with colleagues across Europe in this SRC and we're incredibly grateful to the Trust for the funding."

Understanding and treating the symptoms of CF

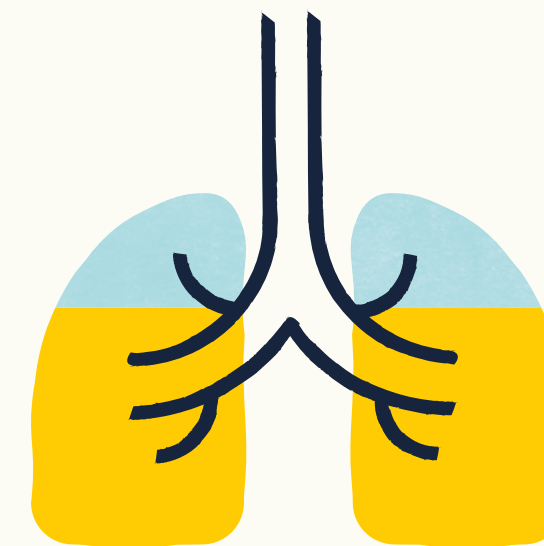
Last year we published a *Research in Focus* report highlighting progress in research studies to better understand and monitor gut symptoms with CF. In 2017, a list of the CF community's top 10 health priorities was published, and relief of GI symptoms was rated as the second highest, so we know that this is a key issue for people with CF.

The Trust is funding research to better understand how the biochemical and physiological changes within the gut of those with CF lead to these symptoms. This will hopefully mean the development of more effective, less invasive, and better tolerated treatments for conditions such as Distal Intestinal Obstructive Syndrome (DIOS), and ultimately a better quality of life for people with cystic fibrosis.

Professor Alan Smyth, Dr Christabella Ng and their colleagues at the University of Nottingham have been investigating the best method for studying these symptoms as they happen in people with CF in hospital-based studies. They've shown that Magnetic Resonance Imaging (MRI) methods can be used to study these symptoms, as opposed to the more invasive and radiation-based methods that are usually used.

Professor Soraya Shirazi-Beechey at the University of Liverpool is leading a lab-based SRC to develop better tolerated and more effective treatments for DIOS, which is when people with CF experience serve blockages in the intestine. The SRC team have shown that it is possible to enhance the intestinal fluidity using already-licensed drugs. The results provide a strong basis for the planning of future clinical trials to test the effect of these drugs in treating DIOS in people with cystic fibrosis.

"Digestive problems are a debilitating issue for people with CF and we're urgently looking for ways to treat and manage these symptoms. We hope the results of the research we're funding will set the direction for future treatments," said Dr Lucy Allen, our Director of Research.



Dr Lucy Allen

Digital health research

Since 2016, Trust-funded CF researchers have been exploring how digital ways of monitoring health could be applied to improving and personalising CF care. Digital health approaches to CF care could result in a longer, healthier life that is less limited by having cystic fibrosis.

One approach is through Project Breathe, a study to address the current standards of care which require all people with CF to attend their CF centre on a regular basis, regardless of their need or CF condition. The aim of this study is to understand whether home-based remote monitoring combined with machine learning could change how clinical care is delivered and move away from the typical 'one size fits all' approach.

As a first step, home-based remote monitoring is being developed to provide the evidence that a routine clinic outpatient appointment is not needed when the patient is well. Over 400 people have been recruited from four UK sites. A Canadian site is also ready to open and start recruiting.

The ambition of the project is to test a range of monitoring devices, such as cough monitors, which could be added to the devices supported by the platform. This could increase the wealth of predictive data being collected about an individual, in the least burdensome way. This work is in development.



Refreshing the research priorities for CF

Five years ago, the Trust was a partner in the James Lind Alliance Priority Setting Partnership in Cystic Fibrosis, with the aim to find out the top health priorities of people with CF, as well as their families, carers and CF teams. Over 600 people took part and we've acted on what the community told us. The top priorities have guided our decisions on what research to fund. They've also set the topics for research studies around the world.

We know a lot has changed for people with CF in the years since the first research project. Many now have access to CFTR modulators, and due to the pandemic, many people's care will have changed. So this year, we felt it was time to review the research priorities and find out what matters most to the community right now. A priority refresh project was set up – QuestionCF for short – and we are working with researchers at the University of Nottingham, people from the CF community, and the James Lind Alliance team at the National Institute for Health and Care Research (NIHR) to review these priorities and help shape the direction of future research.

Over 1,600 people shared their views in the first survey, with a second survey and online workshops to come. The refreshed priorities will be published in late 2022.



Nicole and son Arlo

"As a CF parent it can feel like you're a bit helpless and there's 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 that we know will benefit so many people with CF. It's refreshing to be part of a project where it's not medical professionals or pharmaceutical companies telling the community what they think the priorities are, but it's actually giving those in the community a voice and a chance to share their own perspective."

Nicole, mum to Arlo, who has CF

**Uniting to ensure
everybody with CF can
access the care and
support they need**



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

COVID-19 has changed how people with CF have experienced care and it is likely to have a long-term impact on how care is delivered in the UK. The Trust has played a vital role in ensuring that people with CF could access the care they needed, despite pandemic restrictions, and that policymakers understood and addressed the challenges facing the community.

In 2021/22, the Trust continued to work closely with the UK CF Medical Association (UKCFMA). The CFMA provides expert advice and opinion to Government bodies, the NHS, and other outside agencies. It represents the CF medical community in discussions with the NHS and Department of Health about provision of services for people with CF.



This year, for the first time ever, the Trust launched a new Exercise Practitioner fellowship, to develop training for exercise professionals and improve access to tailored exercise support for people with CF. The successful candidate is now in post.

We also continued to update our suite of clinical guidelines to support best practice in cystic fibrosis care and treatment, including the development of new guidelines on psychological and social.

The Trust worked with psychological and social care professionals in CF care to understand and begin to address workforce challenges in multidisciplinary teams, and we will continue to campaign on this issue in the future.

With input from our Clinical Trials Accelerator Platform governance board, we fed into the Medicines and Healthcare Products Regulatory Agency (MHRA) on their proposals for legislative changes for clinical trials. This ensured the experience and expertise of CF specialists was at the heart of our response.



The impact of Kaftrio on the CF community

2022 saw the approval of Kaftrio for 6–11-year-olds across the UK. This was a huge milestone in the Kaftrio journey following years of campaigning by people with cystic fibrosis and their families.

More than 1,500 children across the UK and Northern Ireland stand to benefit from this drug and limit the damage CF does in these critical early years.

For Stacey, mother of Katy, 8, who has CF, it was life-changing news:

“Having access to Kaftrio changes Katy’s future. Kaftrio means that we can really dream of Katy becoming a mummy and having a family of her own. My hopes for the future are to watch Katy live a long and healthy life and not miss a single event in life, as that’s what she deserves. I want her to be able to share memories with her brother and sister that don’t involve lots of hospital stays, meds and physiotherapy.”

For all in the CF community, whether they can benefit from modulator therapies or not, the roll-out of Kaftrio has brought a significant change in the CF landscape and led to new information and support needs.

We recently updated our Kaftrio factsheet to recognise the complex and individual responses across the CF community as more people with CF gain access.

We have also been working to understand and respond to emerging needs, developing programmes of support to ensure health improvements from Kaftrio translate into life opportunities. Some have experienced challenges in adapting to improved health and we have been on hand to provide information and to develop safe spaces for people to share their varied experiences.

Kaftrio is not a cure and we continue to deliver vital support services, ensuring everyone has the help they need to stay as well as possible while research continues into new treatments to benefit everyone with CF.

We won’t stop until everyone with CF has access to the support and treatments they need.



Katy

The impact of COVID-19 on the CF community

This year COVID-19 continued to challenge our community, with new variants circulating and cases rising. We focused on encouraging our community to get the COVID-19 vaccines and boosters, as well as informing them about new treatments available for people who are part of the clinically vulnerable group.

Mindful of the particular needs of those in our community who are immunosuppressed, we responded to the changing government policies and the needs of the CF community by providing regular and rapid advice across our channels on the Helpline, website and social media. Our content was regularly updated and proactively shared to provide the latest advice and support.

Our broad Q&A content received over **12,400** views



Our Helpline team responded to enquiries related to COVID-19, providing a listening ear for those worried about infection risk as well as practical information and signposting. Working with the UK CF Medical Association, we shared important clinical guidance with the community as restrictions began to lift across the UK.

Since COVID-19 continued to be unpredictable, we saw varying levels of concern among our community. Our polls continued to show that our advice and support content was “useful” or “very useful”, including our advice for people who are clinically extremely vulnerable.

Shielding guidance throughout the year changed, often with different nations offering different advice. We worked hard to ensure that we were able to respond to and support members of our community wherever they live across the UK.

Our Registry team has continued to record incidents of cases in our community, as well as working closely with our international colleagues to record global cases.

Keeping the community informed

We continued to source and share more personal stories from our community about their experience of life during lockdown. For example, Lucy Baxter shared her frustration at still having to shield while life returned to normal for those around her; and Dr Jamie Duckers, Consultant in CF and Respiratory Medicine at Cardiff and Vale University Health Board, wrote a blog on how health services have changed for people with CF.

Marking the two-year anniversary of COVID-19, Dr Rachel Massey-Chase, co-chair of the UK Psychosocial Professionals in CF group, wrote an open letter to the CF community which acknowledged the mixed feelings many felt as restrictions eased across the UK and provided tips on managing uncertainty and anxiety.

Campaigning hard

Cystic Fibrosis Trust campaigns 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.

In recent years the Trust's focus has been on the Access to Medicines campaign and on the response to the COVID-19 pandemic. The impact of both these issues is having a profound impact on the cost of living for some in the CF community.

Access to modulator therapies (specifically Kaftrio) has ushered in a period of change that could extend and transform the lives and prospects of many people with CF. With this change comes new opportunities and challenges for both those eligible for a modulator therapy and those who are not.



Similarly, because of factors like COVID-19 and the conflict in Ukraine, the cost of living has been rising and the Trust has experienced an increase in demand for advice and support from across the community.

In spring 2022 Cystic Fibrosis Trust launched its Experience of CF survey as part of our Cost of CF campaign. This poll, open to the entire community, asked questions on everything from the daily hidden costs of living with CF to the choices people make about education and work. We aim to repeat this survey every year to build up a regular picture of how the things going on around us are directly impacting those in the CF community. We will also be using the results of the 2022 survey to inform our campaigning work throughout the year ahead.



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. Anonymised Registry data is vital in supporting research, service improvement and information materials.

This year the Registry team supported the running of three drug safety studies and completed a fourth study. More information about how we use Registry data to keep medicines safe can be found at cysticfibrosis.org.uk/registry.

In 2021/22, the Registry also supported the NHS to generate public reports and help with the commissioning of CF services in England.

In 2021, the Registry approved 32 requests for data. In 2022, to date, the registry approved 12 requests for data, bringing the overall total up to 457.

Through working with the NHS and pharmaceutical companies, we were able to generate over £1.8million, this enabled us to provide grants to support centres in their data entry, and fund other key aspects of our work.



The UK CF Registry is playing a pivotal role in evaluating the effect of highly effective modulators following interim access agreements across the UK. The Registry continues to support an observational study of Orkambi, Symkevi and Kaftrio to satisfy the Vertex Data Collection Agreements with NHS England and NHS Improvement, with several interim and outcome reports submitted to NICE during 21/22.

This agreement has continued to boost the Trust's Registry Support Grant programme, with 100% of CF centres committing to opt in to enter three 'encounters' (records of height, weight and lung function) throughout the year. This enables a more robust analysis of the impact on rate of change in lung function due to these new medicines.



Through forging formal partnerships with Health Data Research UK, SAIL databank and its BREATHE innovation hub, we have taken the first steps towards linking UK CF Registry data to wider NHS data sources, and migrating data into a Safe Haven, also known as a Trusted Research Environment.

The Registry-based clinical trial CF STORM was launched in summer 2021, with the addition of electronic consent which helped enhance the capabilities of the Registry. This trial is designed to find out whether people with cystic fibrosis can safely withdraw mucolytic therapy aiming to reduce treatment burden for people with CF.

Annual data report

The UK CF Registry annual data report on 2020 data was published in December 2021, including data on COVID-19 infections and the impact of the pandemic. 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 in the report.

We submitted anonymised 2020 data to the European CF Society Patient Registry, which published its reports at www.ecfs.eu/projects/ecfs-patient-registry.



Quality improvement

In 2021/22, the Quality Improvement (QI) team analysed over 1,500 responses to its patient-reported experience surveys. For the first time, the team then provided tailored feedback reports to all children's and adult CF centres that had taken part in the surveys. These centre-level reports help CF services to better understand local patients' experiences, to evidence existing best practice and to identify areas for quality improvement.

The QI team also captured further information about staffing levels in CF centres in 2021 and started to develop a QI Strategy together with our QI Working Group, which is made up of people with CF, family members and CF health professionals.

**Supporting access
to medicines at
every step from
laboratory to
medicine cabinet**



Clinical Trials Accelerator Platform

The Clinical Trials Accelerator Platform (CTAP) has continued to expand and develop over the last year. CF trial activity has increased significantly, despite an initial drop due to the COVID-19 pandemic. Relations with pharmaceutical companies have strengthened, and the pipeline of CF clinical trials (both early and late phase) looks strong for the coming years.

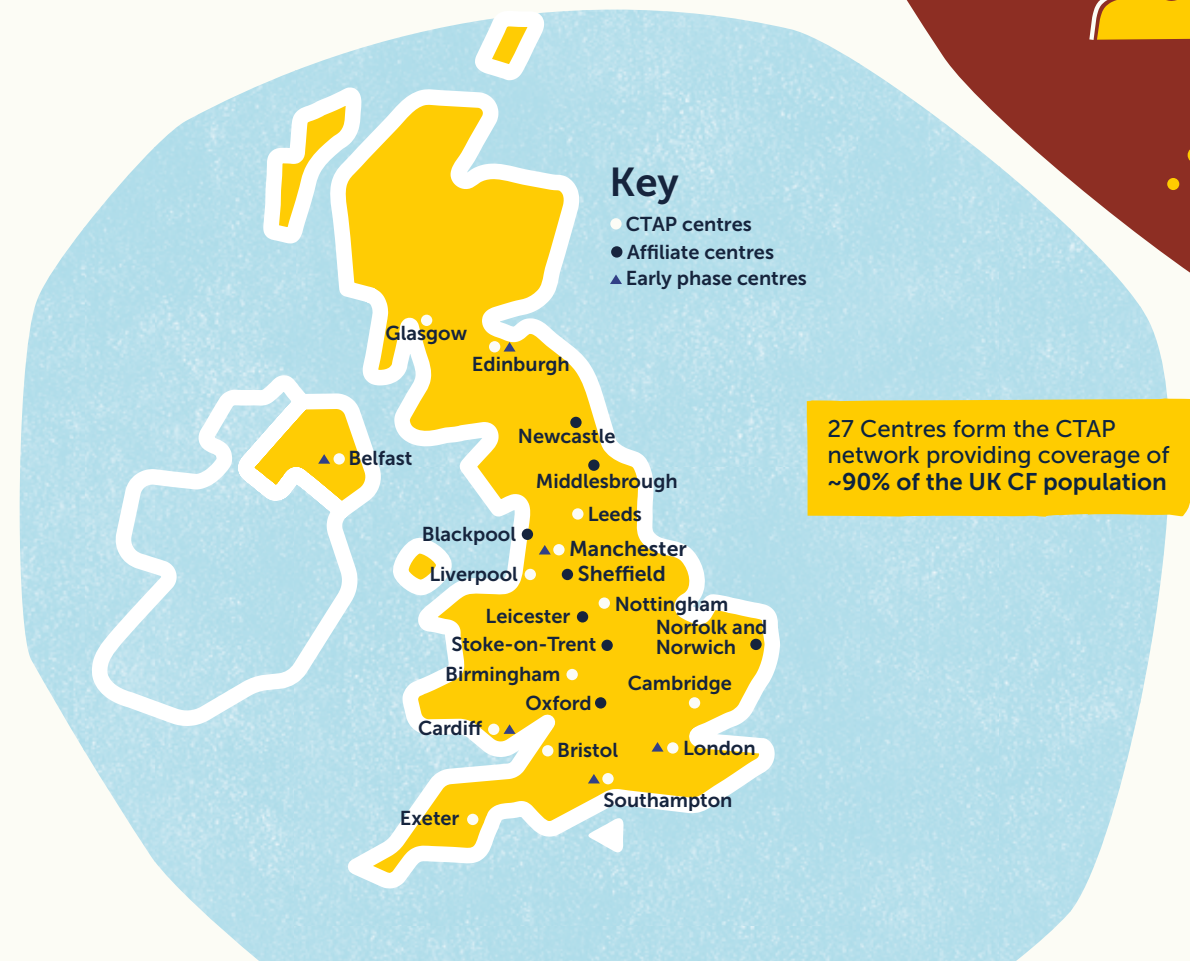
Network of CTAP centres

The CTAP network of 27 centres supported by 18 CTAP Trial Coordinators aims to support and accelerate the set-up and delivery of CF clinical trials ensuring the CF community can gain timely access to these trials. The network of centres covers around 89% of the UK CF community.

The CTAP network of centres work together to share expertise and best practice, and work collectively to address shared clinical research challenges, and discuss recruitment strategies.

Early phase coordinator pilot

Six CTAP centres within the network were competitively selected to lead in the delivery of early phase CF trials as part of a newly funded CTAP programme to support translational research in the UK. Each of these centres were awarded an additional early phase trial coordinator grant. Through this new infrastructure, we are well placed to ensure the UK continues to be a worldwide leader in early phase CF trial delivery.



Impact of CTAP

Since CTAP's official launch in September 2017, a total of:



1,339 people with cystic fibrosis have been **screened** for a clinical trial within the CTAP network (468 in the last 12 months)



1,047 people with cystic fibrosis (535 children, 512 adults) have **enrolled** on to a CTAP clinical trial (321 in the last 12 months)



42 CF clinical trials have been **supported** by CTAP (eight in the last 12 months).

CTAP's new five-year strategy

Over the last year, we have seen significant changes in the clinical and research landscape due to access to new modulator therapies, and also changes in the delivery of clinical care in response to the pandemic. In response to these changes, a new five-year CTAP strategy was developed in collaboration with the CTAP governance board, CTAP centres and, most importantly, representatives from the CF patient community. CTAP's vision for the next five years is:

To sustain the UK's position as a world leader in delivering a broad and innovative portfolio of clinical research in cystic fibrosis, accelerating the development of new and improved treatments for cystic fibrosis whilst acting as an exemplar for condition-specific clinical trial networks.

A \$6m funding proposal was successfully submitted to the Cystic Fibrosis Foundation (CFF) which will allow us to extend and expand the CTAP programme for a further five years, with a commitment to deliver the new CTAP five year vision.





Shad

Community involvement

Our CTAP community involvement work is key to ensuring that the clinical research studies being delivered and supported by the UK, whether they are being led by companies or clinical academic researchers, have been developed in partnership with the CF community. Active engagement of the CF community in research not only ensures that research studies include the insights and lived experience of people living with CF, but that these insights can also inform future research requirements and shape clinical trial designs.

The CTAP Youth Involvement Group is a group of young people, aged 12 to 25, who have attended workshops to develop their understanding of the research and clinical trials process, learning how and where their insights are valuable and informative. Through this supported group, they have reviewed project proposals and participant information sheets, developed guidance for sponsors, and information for the community on how best to involve and engage young people in research.

“Engaging with Cystic Fibrosis Trust has been a blessing. Through their support, I have had the courage to speak up and share my story. The Trust has been the missing advocate for me. It is also fantastic to be a part of their Involvement group, as it gives me the opportunity for my voice to be heard on a range of topics that will shape future support for people with CF, so that we’ll all able to live a life unlimited.”

Shad, who has CF

Aligning the UK’s Clinical Research Infrastructure

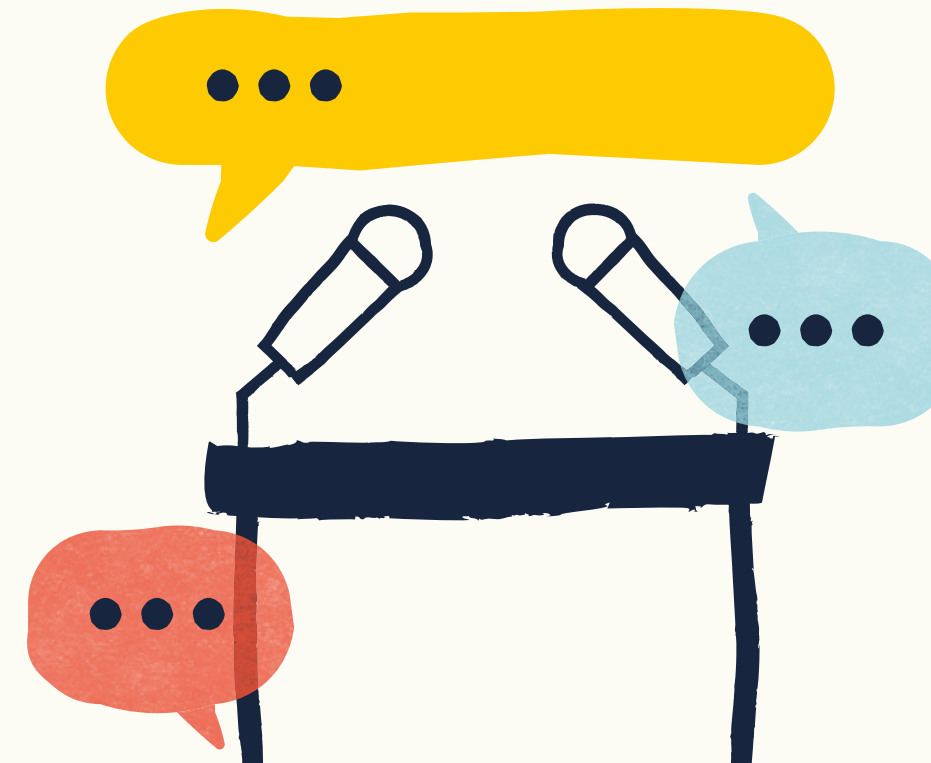
The infrastructure in the UK to support CF clinical research delivery is broad ranging, and often complex. In partnership with key stakeholders, such as the UK’s National Institute for Health and Care Research (NIHR) and the European Cystic Fibrosis Society’s Clinical Trials Network (ECFS-CTN), CTAP is working to align and streamline the various services and processes helping those wanting to set up research studies in the UK to do so more effectively and efficiently.

Delivering the UK CF Clinical Trials Conference

The first annual clinical trials conference took place in 2018 and it brought together CF teams, representatives from pharmaceutical companies, and Cystic Fibrosis Trust to share information and hold focused talks relating to the changing CF clinical trials landscape.

This year, with the conference now in it’s fourth year, the Trust agreed to manage this important event for the clinical research community.

Members of the CTAP, Events, and Corporate Sponsorship teams successfully co-led the organisation of the March 2022 event, with 73 delegates attending in person and over 60 online.



CF Clinical Trials Hub

The CF Clinical Trials Hub provides a wealth of information about taking part in clinical trials and includes the CF Trials Tracker database.

Since launching in September 2017:



The Hub has been visited over **13,000** times, with over 2,100 visits in the past year



The Trials Tracker database has been visited **20,000** times, with over 2,500 visits in the last year.

**Providing day-to-day
support; and reaching
people with cystic
fibrosis when they
need us most**



Day-to-day support

Over the past year, we've continued to provide dedicated information and support to the cystic fibrosis (CF) community. Together, we have navigated the ongoing impact of the pandemic; the exciting new challenges and new support needs that have arisen as a result of Kaftrio; and the increased financial pressures as the cost of living has rapidly increased. We have continued to adapt our services and resources to meet these changing needs; and we've worked with the CF community to understand and develop responses to emerging issues.

Grants

Last year, we provided over **940** grants, totalling over **£292,000**. These grants helped to protect the health of people with CF by supporting those in urgent need to buy the basics needed to stay well, as well as providing access to goods and services to promote long-term health and wellbeing.

Our grants supported people with CF, such as Annie*, a toddler who has CF and requires a specific diet to keep her well. The family are on a low income with no money to spare each month, and through no fault of their own an error with their benefits had left them without enough money for food. Without a grant from us, they would have had to manage with empty shelves and only enough money for very basic food which wouldn't meet Annie's needs.

*names have been changed to protect identity



Fiona with daughter Zara

When rapid increases in the cost of living left many with CF worrying about how they would afford to eat properly this winter, we immediately launched a Winter Hardship Support Fund. Through this Fund, we supported 250 people on low incomes with a grant to fund household essentials such as food and energy, protecting their health through the coldest winter months. All those we supported through this Fund were offered additional support from our welfare advice team to support their longer-term financial stability.

We also provided over £21,000 in homecare grants to support people who are experiencing particularly poor health or a personal crisis, ensuring they can be safe and comfortable at home.

"For my husband and I, the Trust is a one-stop shop for all information about CF. It gives us hope for an improved future for Zara. We feel part of a community, knowing we don't have to deal with this alone. The Trust's vision that everyone with CF can live a life unlimited means everything to us. We want Zara to be able to experience life the same as everyone else, seizing as many opportunities as possible."

Fiona, whose daughter Zara has CF

Through the Joseph Levy Education Fund, we awarded 87 grants totalling just under £47,000 to support people with CF into higher education or vocational training, ensuring they have the support to pursue their education and career goals.

Benefits advice

Since 2016, our Welfare and Rights Advice service has provided expert dedicated benefits advice. This year, we supported 305 people to navigate the benefits system, ensuring they can access the long-term financial support they need to manage the extra costs of living with CF.

Our Income Maximisation Service has supported 93 people to increase their household finances by an average of £4,269 per household, further building their financial security.

Our student support service continues to help students with CF access the support they may need to get the most out of their studies and enjoy student life.

We also continue to offer a benefits advice service in Northern Ireland through a specialist partnership, providing expert advice on the benefits system.

In 2021/22, Cystic Fibrosis Trust helped people to access at least £1.025 million in benefits.



Helpline

This financial year, our Helpline responded to over 4,200 enquiries from people affected by CF and continued to provide support to the community through the COVID-19 pandemic, as well as on a broad range of other issues.

Many people who come to us need practical answers to their questions, but they also need our support and understanding. The Helpline has continued to provide helpful information and signposting, as well as a listening ear and a safe space for people with CF and those who care for them to talk through any worries and concerns. This year, following work to ensure the Helpline is as easy to access as possible, the number of Helpline enquiries received via social media increased significantly.



Kareem

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

Kareem, who has CF

Information

We continued to develop our extensive information library, developed in collaboration with people with CF and specialist CF clinicians. Resources including airway clearance, portacaths, and genetic screening were updated.

We published a new resource on fasting during Ramadan and CF, recognising the diverse information needs of the CF community, which was well-received by both people with CF and clinicians alike. As understanding of Kaftrio continued to grow, we updated our resource ***Kaftrio – Complex and Individual Experiences***.



Work on several consensus documents continued, including, for the first time, new psychological and social care and treatment guidelines.

We also continued to develop the COVID-19 hub to ensure people with CF could readily access the latest information about the pandemic.

We're grateful to the people with CF and their families, as well as the expert CF clinicians, who gave their time to help us develop and improve our information resources.

Youth programme

Building Brighter Futures is a programme of online events for children with CF and their siblings aged 6–18, funded by BBC Children in Need. The programme continued to attract both new and returning participants. Events on offer included six-week workshops on arts and crafts, drama, and enhanced coding skills, alongside our popular game nights, movie nights and new activities such as baking.

Demand for these events remains high and feedback from both parents and participants shows that children gain a great deal from the chance to come together safely online with others with CF, have fun and learn new skills.

Our Youth Advisory Group (YAG), comprising of young people affected by CF aged 14–25, continued to shape the direction of the Trust's youth work. This year, YAG led the alphabexercise project, a fun social media initiative to promote physical activity in young people.



Amy

"It has made me think about how I can help people who are younger than me to get the best out of life – can my experience help them in some way?"

Amy, young person with CF and member of YAG



Illustrations taken from the YAG AlphabExercises programme

Reaching all people with CF



This year, we've continued to find more ways to engage with more people affected by CF. From our active youth programme to growing our presence on the social media platform TikTok, we've prioritised finding even more ways to engage with younger audiences. We've sourced a greater range of voices in the stories we tell on our website, the media stories we place and in our fundraising packs. To ensure that we continue to reflect the broad range of experiences and backgrounds of our community, all of our key external activities, like CF Week and #CFTruths, have been shaped and influenced by involvement groups.

CF Week 2021: a great success

CF Week is our annual awareness and fundraising week, with a focus on community engagement and sharing the CF community's stories. The 2021 theme for CF Week was 'we won't stop', which allowed us to introduce our evolved strategic goals: physically well, mentally well, and fulfilled.

This year:

- over **£135,000** was raised, which exceeded our target and continues the trend of year-on-year growth
- we had high-profile media coverage:
 - top 25 articles having a combined total reach of 176 million people
 - a feature article in *The Lady* with Jenny Agutter
 - an interview with Richard Madeley on ITV's *Lorraine*
 - BBC News feature on BBC Morning Live. The BBC programme has an average audience of 1.5million viewers
- we launched an out-of-home marketing campaign on 48 Clear Channel digital billboards in a diverse range of locations across the country
- we shared a range of stories from the community
- time spent on our relevant CF Week pages increased by 18.5% year on year
- we delivered an anxiety session for parents and promoted the Student Support Service.



"I would love if #CFTruths empowered people with CF to own conversations around their condition. Some people find it difficult to talk about, as it is extremely personal and I think there is sometimes a fear that you will be treated differently."

Caitlin

#CFTruths

In March 2022 we launched #CFTruths, a public awareness campaign devised by Caitlin, who has CF, and developed *pro bono* with Ogilvy Health. The campaign sought to raise awareness of CF amongst the general population, to provide a space for our community to tell their own CF Truth, and to enable easier conversations about life with CF, especially in education and in the workplace. The campaign is still live, but since its launch we've seen a 120% increase in cystic fibrosis-related keyword search terms leading to our website. The campaign has generated strong regional media coverage, with a potential reach of over 300,000 people, and has been visible on over 1,000 Clear Channel digital advertising billboards, with a media value of over £200,000. Our paid social advertising had a reach of almost 500,000 people on launch.

CF Live

CF Live, our online programme of speaker events uniting the CF community, has continued to be popular. Hundreds of attendees tuned in to hear from a range of experts talking about Kaftrio, financial support, and the UK CF Registry, among other topics.

Growing 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.

Our brand

As we revised our vision, mission and goals, we evolved our brand story and messaging in order to communicate this in an engaging and motivating way. We want to make sure it's clear what the Trust is trying to achieve, and why people should get involved to give their time, money or voice.

We refreshed our brand positioning and expression (such as our visual identity and tone of voice) so that it's more accessible and relevant.

We shaped our brand around the changing context for people affected by CF, including:

- the need for research and new therapies post-Kaftrio, as not everyone can benefit from modulator drugs
- the uncertain economic environment and cost of living crisis
- increased focus on mental health due to external insights including our Kantar research
- increased focus on diversity and inclusion including content for key festivals, our photography and stories.

Website

We launched our new website in March 2021 and have continued to improve the user experience based on analysis, polling, user testing and internal feedback. Users now stay on the website longer and our bounce rate has reduced by over 10%. Site speeds have improved and, when polled, a majority of users have told us that the website is either excellent or good. We are continuing to improve the website with a current focus on the navigation. We're also carrying out a content audit to ensure our content is as relevant and accessible as it can be.

Caitlin

Volunteering

Over the last year, we've been really grateful that the hard work of our volunteers, supporters, and branches and groups has continued, despite the interruptions caused by the pandemic.

Our volunteers come from a wide range of backgrounds and different life stages, ranging from those who already have a connection to someone with cystic fibrosis (CF), to university students, people working directly for companies partnering with the Trust, or those who have more time to give in their careers and wanting to use the skills they have developed to help us do more for people with CF.

COVID-19 restrictions have caused challenges for volunteering. We've responded to that by opening up more volunteering activities from home, which has allowed some volunteers to continue to support us that otherwise couldn't.

Being an effective organisation

The Trust's ability to achieve our vision depends on our effectiveness as an organisation, which is supported by our employees' skills, passion and energy. We nurture this by providing benefits that our staff value, such as flexible working; holiday and parental leave allowances, which exceed statutory requirements; learning and development opportunities; and good communications, such as a two-weekly online and face-to-face briefing led by our CEO.

"I chose to volunteer for Cystic Fibrosis Trust initially to raise funds and awareness. I organised two large-scale events and aimed to do more. When the pandemic hit and large events weren't possible, I used my background in publishing to lend a hand to the comms and marketing team. I would thoroughly recommend volunteering with the Trust; not only are they an absolutely wonderful bunch of people, but you get to help out a great cause and it looks great on your CV! I've been lucky enough to work on some amazing campaigns and projects and can't wait to see what comes next!"

Lian

The Executive Team shares information with the People Committee on key human resources measures and projects to improve our inclusivity as an organisation and the engagement of our people. The People Committee also reviews the outcomes reported from the annual staff survey, which again this year had a high response rate of 81% and positive 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 yet again by the COVID-19 pandemic, which has resulted in a high volume of work for all teams at the Trust. Reduced fundraising activity due to COVID-19 resulted in a reduction of 25% net income. This meant we had to restructure and make several redundancies across fundraising.

As we move into 2022/23, we are in the process of introducing a new performance and development process; updating policies to make our workplace even more inclusive; and reviewing pay and benefits.

**Uniting in
fundraising**



We would like to thank all the fantastic individual donors and supporters, organisations, charitable trusts, foundations and corporate partners who support our work to make sure everybody with CF can live a life unlimited. We simply couldn't do what we do without you!

The Trust continues to build back after the reduction in income due to COVID-19. In 2021/22, £7.4 million gross income was raised and £5.54 million net income, which is slightly higher than income raised in 2020/21 but lower than pre-pandemic net income by 25%. The difference is that although we were delighted that our community and events income was significantly higher than in 2020/21 with events and activities taking place, we saw a reduction in legacy, corporate partnerships and trusts income in 2021/22. This is in addition to the one-off COVID-19 emergency appeal in 2020/21 which raised £829,000 and was not repeated in 2021/22.

We continue to innovate and adapt our fundraising plans with both physical and virtual events continuing to take place. Examples of new innovations include our online shop, which was launched in November 2021; a focus on engaging schools with fundraising; a new Festive 5k, and promotion of gifts in Wills.

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

We will be transparent about our work
We will be respectful
We will listen and respond
We are committed to high standards
We are fair and responsible



Beatriz and son Yoel

"The Trust have been there for me when I didn't know who to speak to. They have shown me that I'm not alone and provided the right information and support when I needed it most. The Trust give me an opportunity to believe."

Beatriz, mum to Yoel, who has CF

Supporter experience

The Trust is so grateful to our committed and passionate supporters, who regularly go the extra mile to raise vital funds for everyone affected by cystic fibrosis. Improving our supporter experience is a key focus for the Trust at every interaction. We continuously analyse and use feedback collected from supporters including face-to-face, online or offline. We are constantly reviewing our communications, ensuring that we provide the right materials for their fundraising and in particular, communicate how their hard work is making an impact to the lives of people living with cystic fibrosis.

The Trust received 24 complaints in 2021/22. This was broadly in line with the 28 received in 2020/21, and remains lower than pre-pandemic levels (46 in 2019/20) as a result of fewer in-person fundraising activities in early 2021. Complaints are closely monitored and reviewed by senior management on an ongoing basis. In addition, we regularly review our complaints policy and processes to make it easier for people to give us feedback, and to ensure that we listen and learn from what our supporters and the community are telling us.

Regular gifts

We'd like to express our gratitude to our loyal regular donors who provide invaluable ongoing support that enables us to plan effectively for the future. These supporters contributed just over £775,000 in 2021/22, including Gift Aid.

During this year, we carried out a telemarketing campaign through Ethicall, our professional telephone fundraising agency. Ethicall have a 'respect and dignity' policy that turns marketing calls into 'thank you' calls if they suspect the person that they are speaking to is vulnerable. These campaigns (a regular giving upgrade and a direct debit recruitment campaign) resulted in an additional annual income of £20,000.

Community and event fundraising

The COVID-19 pandemic has continued to impact on community and event fundraising, and our focus has been on building back our activities and income following the uncertainty of recent years.

We developed a hybrid portfolio of activity which was fully embraced by our amazing supporters, and despite the lockdown restrictions they faced, we were so grateful that so many people continued to fundraise for us in a variety of ways.

Our Team CF runners were finally able to take on the Great North Run and London Marathon, raising **£60,000** and **£419,000** respectively.

Our virtual Great Strides™ My Way challenge raised **£63,000** and our Running Festival raised **£26,000**.

Our loyal branches and groups across the country raised a fantastic **£93,000**.

Our annual Wear Yellow Day continues to go from strength to strength and raised **£135,000**.

We'd hoped festive favourite Carols by Candlelight would be able to go ahead in person, but again due to COVID-19 was moved to online. We were joined by an array of celebrity speakers and raised **£55,000**. Our other festive fundraising activities, including the Festive 5K virtual run, raised an additional **£50,000**.

Corporate partnerships

The Trust continues to work in partnership with companies to raise funds and awareness of cystic fibrosis. We also work in partnership with companies to maximise the valuable benefits they can give through *pro bono* and gift-in-kind support. For example, this year we were delighted to have the support of Ogilvy, a leading marketing agency whose generous *pro bono* support enabled us to launch our brand-new campaign #CFtruths. This campaign shed light on the realities of living with CF and shared stories of some of the day-to-day challenges that having CF can bring.

We are incredibly grateful for the ongoing support from our advertising partners such as Clear Channel, Talon and Goodstuff, who provide gift-in-kind outdoor advertising and campaign advice, which is incredibly valuable in helping us promote our work.

We would also like to thank Chaucer, a strategy consultancy who supported us with *pro bono* advice across a range of projects, from fundraising campaigns to our own Helen Barrett Bright Ideas Awards.

We were delighted to be supported by employees and their companies such as XTX Markets, B&Q and Stark Software. We also continued to work on commercial partnerships with companies such as Prestige Flowers and Amazon Smile. Any commercial activities where the Trust benefits from the sale of products in exchange for use of our logo operates against a formal agreement and are monitored closely.

This year also saw sponsorship from the pharmaceutical industry for the UK CF Clinical Trials Conference, the CF Registry Annual Meeting, and UKCFC. We look forward to working with our sponsors again next year.

Gifts in wills

We received 92 legacies in 2021/22 from supporters who generously included a gift to the Trust in their Will, as well as 49 supporters who told us they have pledged a gift.

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



In memory

We continue to remember with respect and affection those who have lost their lives because of cystic fibrosis and we thank all our supporters who fundraise in memory of their loved ones. In 2021/22, we received more than £249,000 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.

Philanthropy

The support we receive from charitable trusts, foundations and individual supporters continues to play a crucial role in funding the work we do.

This year we have been pleased to continue our partnerships with the Joseph Levy Foundation, which supports our Information and Support work; BBC Children in Need, which supports our CF Youth programme; Sport England; and the National Lottery Awards for All, which supports the development of our Helpline.

In addition, we have worked with generous individuals who are long-standing supporters of our work, and our loyal Sixty-Five Roses Club members have also continued their amazing support, despite another challenging year.



(Photo: Jake Sugden Photography)

Support for the UK Cystic Fibrosis Innovation Hub continues to grow, with cash and pledges from trusts, corporates and individuals – including our two cornerstone funders, AJN Steelstock and the Robert Luff Foundation – totalling over £3.1m to date.

We were delighted to welcome members of the CF community to a reception at St James's Palace with His Royal Highness The former Prince of Wales, KG, KT, GCB, OM, who became our Patron in 2014 in our 50th year. This was to mark the progress that has been made since the CFTR gene that causes CF was discovered over 30 years ago. The event highlighted the challenges still facing people affected by the life-limiting condition, and the importance of continued investment in research and treatments to help those with CF live a life unlimited.

**Looking to
the future**



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 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:

- **Being physically well:** together, we can live without the physical challenges of cystic fibrosis.
- **Being mentally well:** together, we can manage the mental pressures of cystic fibrosis.
- **Fulfilment:** together, we can lead the life we want as part of a connected community.

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

We also know that in order 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
- adopting a virtual first workstyle
- being great and innovative fundraisers
- making effective use of data and analytics, including a new data strategy and quantitative impact framework
- working in ways that brings together our diverse community and staff, such as improving diversity in clinical trials, reviewing internal policies and processes, and implementing a new performance development system.

Being great fundraisers

Raising funds is vital to enable us to continue our work to support people with CF to live a life unlimited. We will continue to work closely with our incredible supporters, branches and groups at a local level and with our trusts and corporate partners. We know the cost of living pressures everyone is experiencing right now, and it makes the support of the cystic fibrosis community so incredibly special to us.

In order to provide the very best experience when supporting the Trust, we will continually review and update our engagement and processes.

Innovation remains a key pillar of our strategy to diversify our income and engage new supporters. We will ensure our portfolio of activity provides a hybrid offering which is accessible to all, irrespective of age and ability, and we will continue to maximise the potential of our campaigns including Wear Yellow Day, Run for Research and Great Strides™. We are looking forward to the 20th year of Carols by Candlelight in December.



Campaigning hard

Our Cost of CF campaign has already begun to highlight the additional cost pressures facing the CF community, such as:

- paying for life-changing drugs when other conditions are exempt from prescription charges in England
- the challenge of rising domestic fuel prices over the winter of 2021/22 and the concern about further increases ahead of the next winter
- the need for specific reform of the way that social security assistance is paid to those with lifelong conditions – including reviewing whether it is necessary to place additional stresses on people's health by requiring them to undergo regular reassessments for financial support.

We will continue to campaign hard to make sure our community can live without the limits of cystic fibrosis.

Day-to-day support

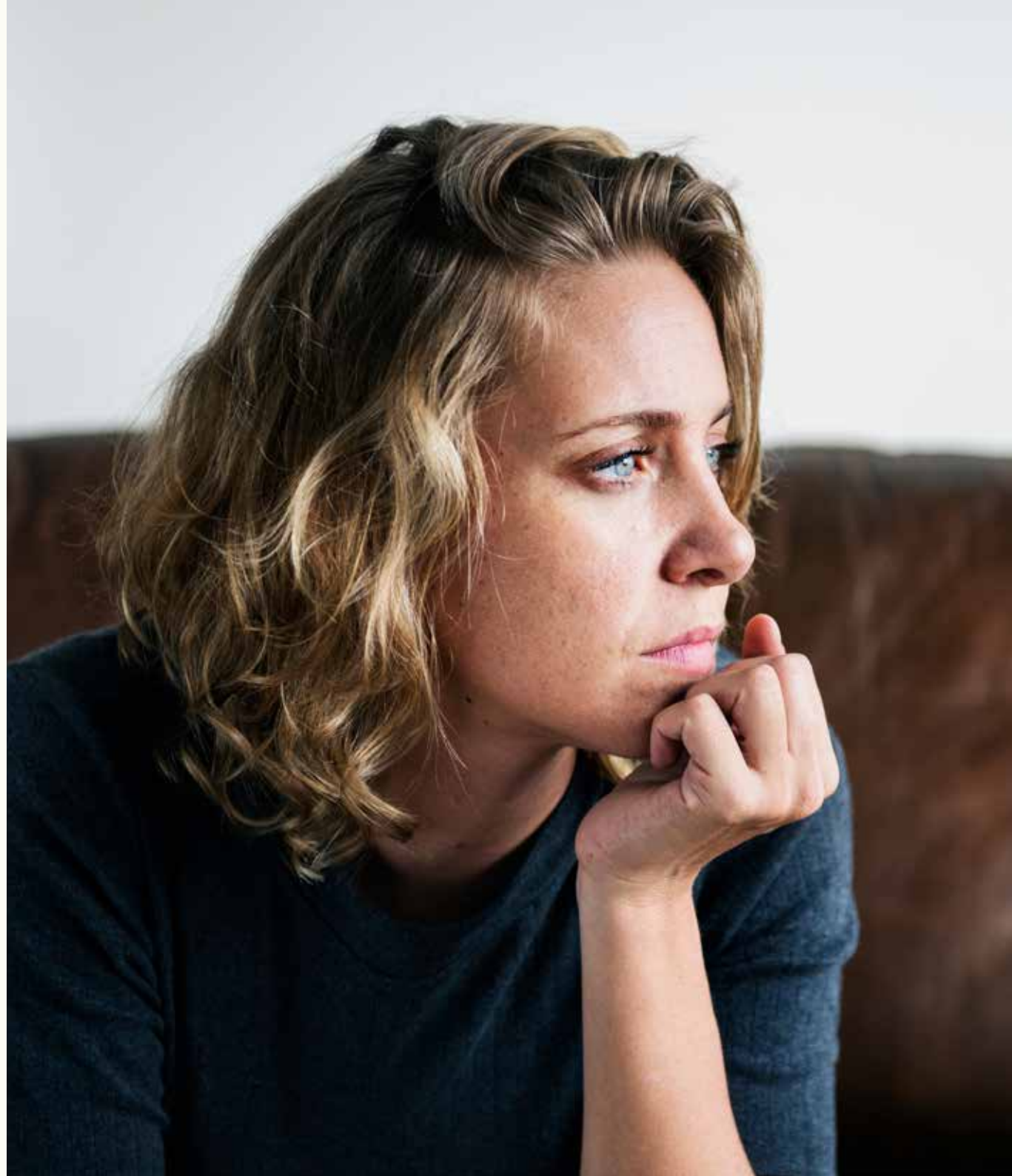
We will continue to respond to immediate needs as the community copes with the cost of living crisis, adjusts to the changing CF landscape, and recovers from the impact of the pandemic.

Our core services and resources will continue to provide expert, dedicated help with the day-to-day challenges CF brings. We'll also develop new programmes of work, including an ambitious programme of employment support, empowering people with CF to access secure, fulfilling work without compromising their health.

We will be developing our information library, updating key resources such as our new diagnosis pack, as well as new consensus guidelines which reflect the changing nature of CF care and treatment. We'll continue to run our successful youth programme, providing more opportunities for children and young people with CF to take part in fun social events and skill-building activities, while building confidence and making new friends.

We'll also continue our drive to ensure all our services and resources are accessible, relevant and representative of a diverse CF community, and we'll explore innovative new ways to deliver information and support.

We look forward to relaunching our forum, creating a safe space for anyone affected by CF to come together online and discuss issues that matter to them.



UK CF Registry

The UK CF Registry Annual Report 2021 will be published later in 2022. The Trust will report the final analysis of the efficacy of CFTR modulators to NICE as part of the Interim Access Oversight Committee in October 2022, with the final report submitted in June 2023.

The Annual Registry Meeting will return as an in-person meeting in Winter 2022, allowing colleagues across the country to come together once again for this important meeting. The team will continue to hold virtual workshops and coffee mornings for Registry users to provide support and guidance throughout the year.

Our validated data sets will become available within a Data Safe Haven, enhancing our abilities to link UK CF Registry data with other healthcare data sets as part of approved research projects.

2022 will also see the relaunch of the Data Validation Visits programme, with a new format enabling both virtual and in-person validation visits.

Quality improvement

We will publish UK-level reports, sharing the insights from all the QI team's data collections, in the summer of 2022. These reports will summarise current data on patient experiences in children's and adult CF services, as well as staffing levels, across the UK. We will also look to re-run the staffing tool as well as the patient experience survey for children's CF centres in the autumn of 2022. This will enable us to understand how experiences and staffing levels change over time.

The QI team will also continue to work with the QI Working Group to deliver our QI Strategy, and to improve our data collections and feedback offer for CF services.



Financial review



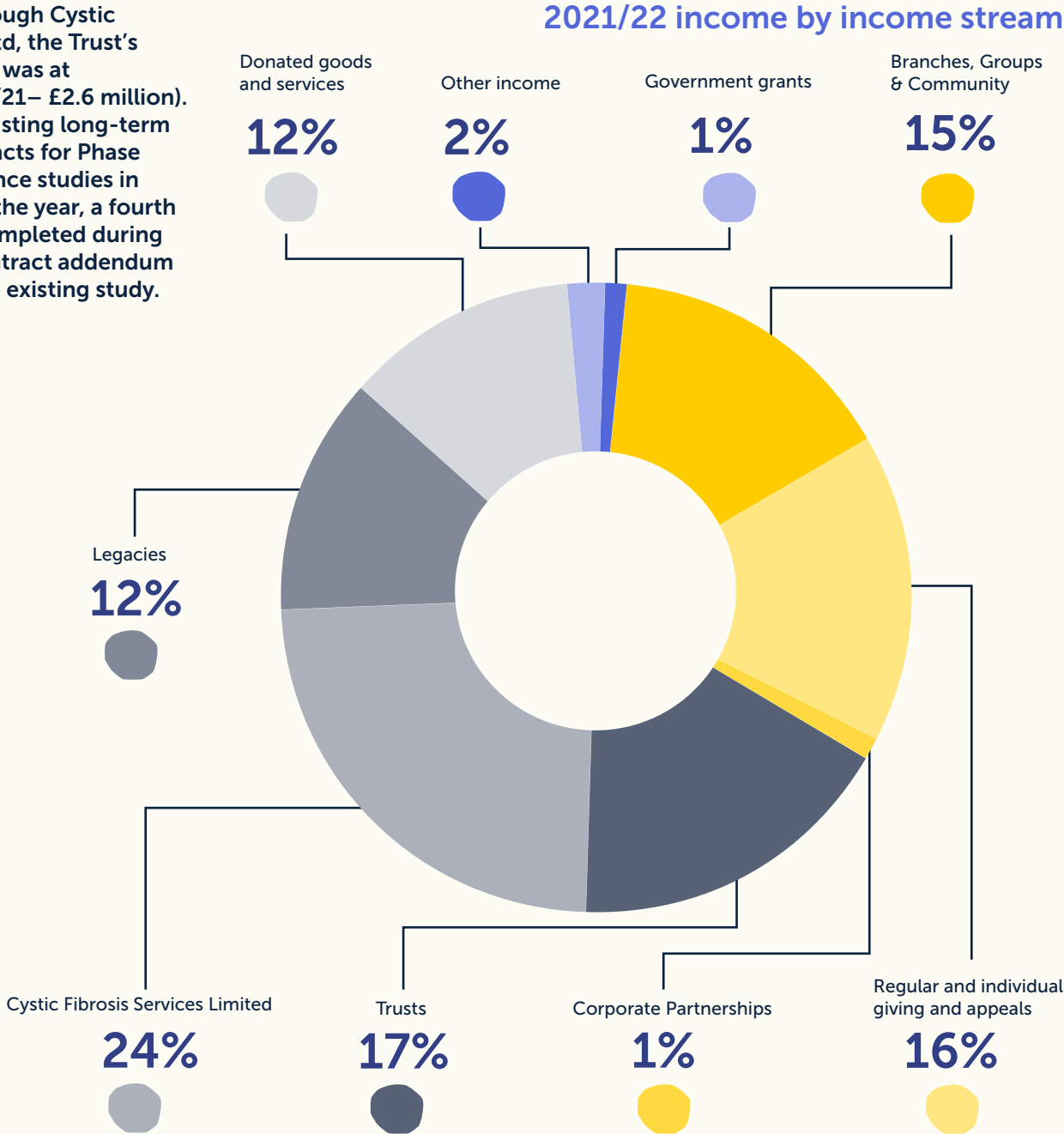
Income

The Trust's income from normal activities for the year to March 2022 was £15.7 million, an increase of 9% over the previous year.

75% of the Trust's total income is made up of donations and legacies, totalling £11.2 million, (2020/21 – £11.7 million). This percentage is 6% lower than in the previous year, although our Community and Events income was significantly higher than in 2020/21, we saw a reduction in legacy, corporate partnerships and trusts income in 2021/22, in addition to the one off COVID-19 emergency appeal in 2020/21 which raised £829,000 and was not repeated in 2021/22.

We once again gratefully received donated unsold advertising space from Clear Channel as part of their 'Platform for Good' in the year, worth £1.8 million – this value was 15% higher due to the successful uptake of our two awareness campaigns. In the prior year, we had fewer advertising opportunities during the pandemic due to their focus and allocation of COVID-19 public health campaigns.

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £3.7 million (2020/21 – £2.6 million). As well as three existing long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, a fourth contracted was completed during the year, and a contract addendum was signed for one existing study.



Expenditure

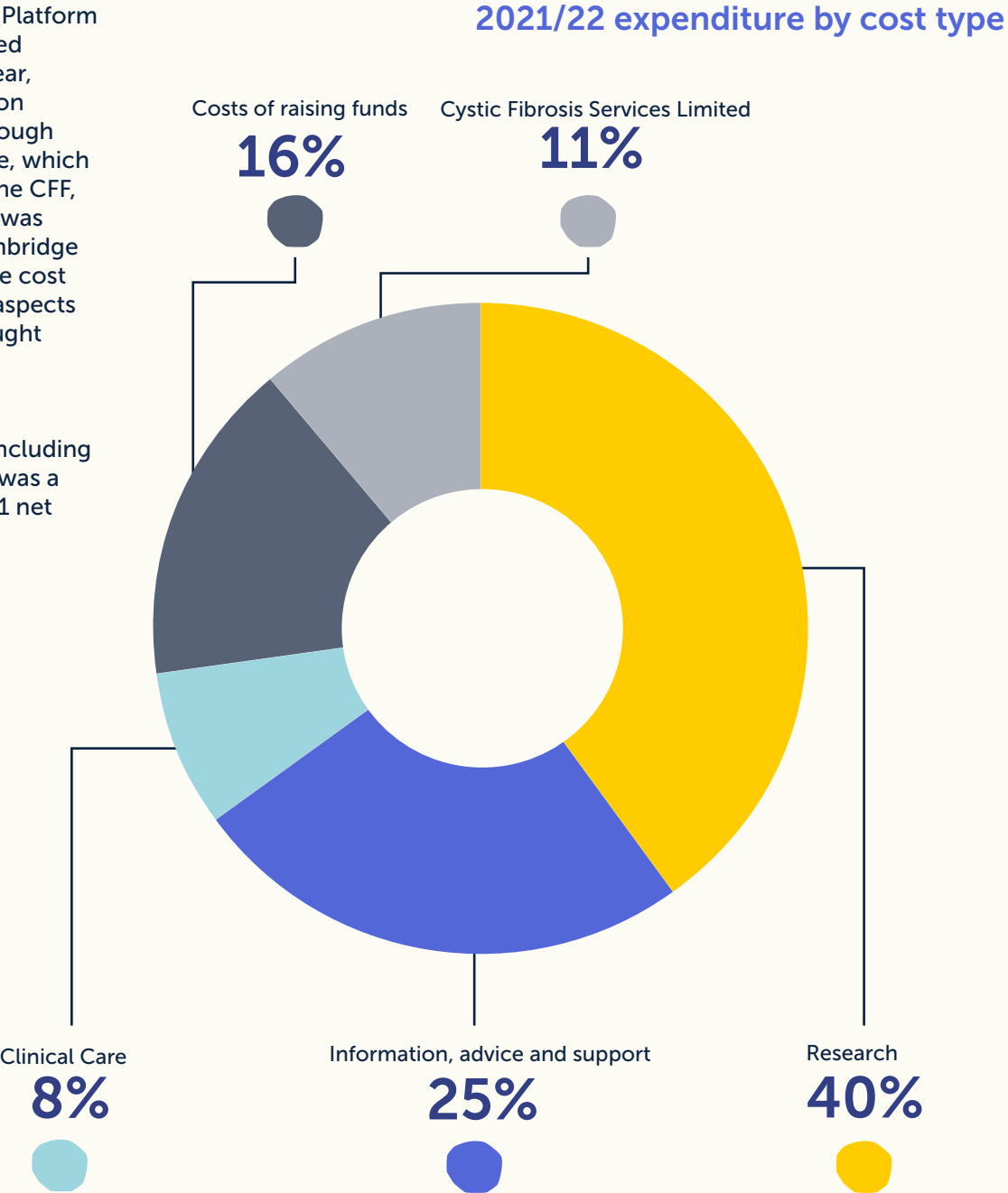
The Trust's total expenditure for the year was £16.0 million, a 15% increase compared to the previous year. The largest area of spend was on charitable activities at £11.8 million (2020/21 – £10.2 million), accounting for 74% of total spend. This comprises programmes of research, information, advice and support and clinical care.

The remainder was spent on activities for generating funds, including £1.6 million paid to NHS cystic fibrosis clinical centres across the UK to support the resources necessary to add patient data to the CF Registry.

Total grant commitments in the year were £5.5 million (2020/21 – £3.8 million), of which £4.6 million (2020/21 – £3.5 million) were committed to a range of institutions, including £1.8 million committed for two Strategic Research Centres and some agreed cost extensions (2020/21 – £2.3 million for three centres). The remaining £0.3 million (2020/21 – £0.3 million) was awarded to individuals through our ongoing Welfare Grant programme.

The Clinical Trial Accelerator Platform flagship programme continued to develop throughout the year, with total spend of £0.8 million (2020/21 – £0.8 million). Through the Digital Health Programme, which is funded by an award from the CFF, £0.7 million of grant funding was awarded to University of Cambridge and partner organisations; the cost of some remote monitoring aspects of this programme were brought forward in response to the COVID-19 pandemic.

The final result for the year, including movements on investments, was a net Surplus of £155k (2020/21 net surplus of £1.3 million).



Investment policy

The Finance Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to maintain real long-term capital value, looking to balance short-term volatility and protection against inflation with a moderate risk tolerance. The Trust does not permit direct investment in tobacco. General funds are invested in a balanced portfolio that includes some exposure to less liquid assets such as property, and utilises funds that do not invest in tobacco. A number of small endowment funds are invested on a Total Return basis, enabling the Trust to utilise both income generated by the funds and increases in capital value, while protecting the original inflation-adjusted endowment values. We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance Committee.

Review of investments in the year

The value of the investment portfolio (included endowment funds) has increased by £0.4 million this year (2020/21: decrease by £0.5 million). No change was made to the allocation between amounts held as stocks and shares and that held as cash. Income generated on investments totalled £0.1m, which realised and unrealised gains on the investment portfolio totalled £0.4m.

Reserves

The Trust’s reserves, as of 31 March 2022, totalled £9,671,000 (2021 – £9,516,000). Reserves are held in order to ensure the continuity of service provision, as well as enabling the Trust to move forward with strategically important programmes of work as and when opportunities arise. The Trustees maintain the following reserves:

- Designated reserves – the Trustees have opted to set aside free reserves for the following purposes:
 - A fixed asset reserve, equal to the net book value of the Trust’s fixed assets (£19,000) is held to ensure these are not considered to be realisable.
 - A deficit has been recognised being the difference between the £2million grant awarded to the Innovation Hub at Cambridge and the £3.75million of income committed so far for the corresponding project. This deficit has been under-written by Cystic Fibrosis Trust while we continue to attract supporters and partners.
- Operating reserve – held at a value (£3,411,000) sufficient, as a minimum, to cover six months’ operating costs, major fluctuations in income from budget, contingencies for long-term commitments and any deficit on restricted reserves due to over commitment or payment on those projects.
- Retained Reserves (£6,209,000) to be deployed in financing our strategic ambitions in a way that maximises the impact for people with cystic fibrosis. Retained reserves are expected to be utilised through a managed spend programme over the next 36 months. The impact on income generation from the cost of living crisis, the continuing fall out from the COVID-19 pandemic and the war in Ukraine means that these reserves are likely to be utilised over a shorter period. It is the intention to use retained reserves while maintaining the Operating reserve as described above.
- Restricted income funds (£271,000) – relating to donations restricted to various specified activities.
- Endowment funds (£1,046,000) - 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.

More information about the reserves can be found in note 17a to the accounts.

The Trustees keep reserves policy under regular review to ensure it is set at the appropriate level to reflect changes in the business outlook as they materialise. The reserves as outlined above meet the Trust’s reserves policy.

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.



Our approach to reserves

The Trustees have a policy, informed by Charity Commission guidance, of maintaining an Operating Reserves equivalent to six months’ core running costs. We currently estimate that to be c.£3.4 million.

The Board is also committed to maintaining our impact for the benefit of people with cystic fibrosis at a point when we believe it will still take considerable time for fundraising income to recover to pre COVID-19 pandemic levels. The cost of living crisis is also impacting our community and is expected to continue to do so for some time to come. The Board have, therefore, approved a deficit budget for the year ended 31 March 2023 and we also anticipate that planned deficits are likely in the subsequent two financial years.

This will have the effect of substantially reducing our free reserves, to ensure that we can:

- Invest in research, programmes of work and resources to ensure that we remain responsive and relevant to the changing needs of the cystic fibrosis community
- Mitigate the risks associated with our fundraised income and enable us to support innovation to diversifying our income base
- Ensure that we can invest sufficient funding into the Trust’s activities and infrastructure to ensure long term sustainability

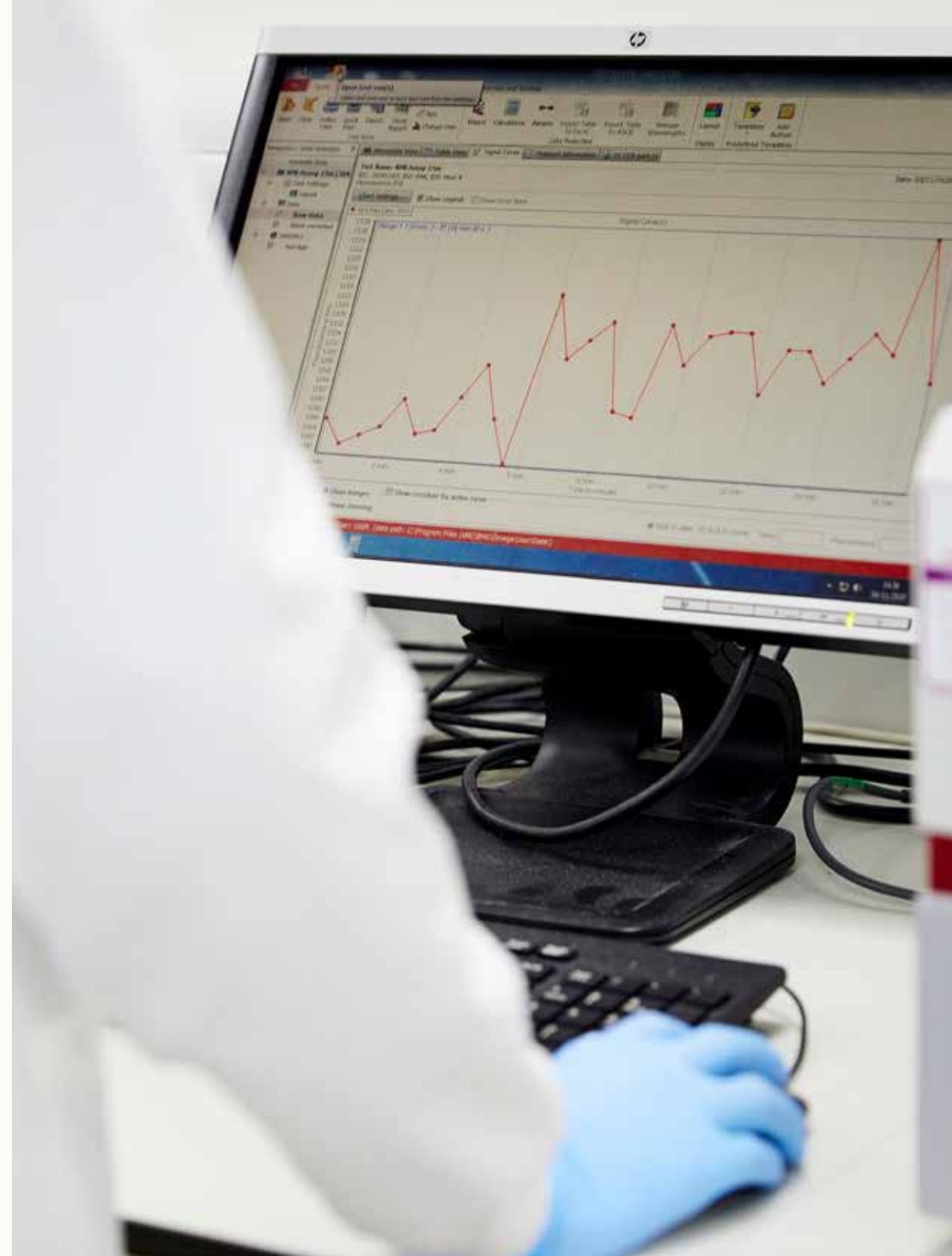
Principal risks and uncertainties

The Board of Trustees is responsible for ensuring effective risk management and internal controls to manage the major risks the charity faces, including agreeing the organisation'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 charity. It is regularly monitored (quarterly) to support informed decision-making and ensure appropriate mitigations and controls are in place to effectively manage any risks to our objectives.

The main strategic risks and uncertainties that management and Trustees have identified include: the risks of failing to remain relevant to the changing needs of our community; delivering a financially sustainable model in the midst of the cost of living crisis; keeping Trust/Registry data secure; getting our message across; influencing key stakeholders, maintaining business continuity; delivering effective people strategies; maintaining our autonomy; and managing our reputation.

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 on progress against both its audit plan and the recommendations made in its reports.
- The Board of Trustees has received a comprehensive risk management report to assist it in ensuring that an effective process is in place. This report provided an update on the risk reviews undertaken, and provided 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, such as the Life Unlimited programme, to ensure that these are properly planned, managed and implemented.



Our work with the pharmaceutical industry

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

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

We run the following flagship programmes involving industry partners:

Clinical Trials Accelerator Platform

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

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

Venture & Innovation Awards (VIAs)

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

The UK Cystic Fibrosis Registry

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

In 2021/22 Cystic Fibrosis Services Ltd, the Trust's subsidiary, received £3.7m in fees for this service. As well as the three existing long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, a fourth contracted was completed during the year, and a contract addendum was signed for one existing study.

Sponsorship and donations

Sponsorship from pharmaceutical companies helps pay for our annual UK Cystic Fibrosis Conference, enabling us to stage a free event to keep healthcare professionals and people affected by CF informed on all aspects of clinical care and research. In 2021/22, we received sponsorship for the UK Cystic Fibrosis Conference and would like to thank the following companies: PARI Medical, Gilead, Vertex and Chiesi. In 2021/22 we also received sponsorship from TEVA for the online Annual Registry Meeting held in June 2021.

For the first time, the Trust was involved in organising the UK CF Clinical Trials Conference held in Nottingham in March 2022. We received an Independent Medical Education grant from Vertex towards the cost of the event. We also secured sponsorship from Vertex, Abbvie, Boehringer-Ingelheim, Chesi and KrystalBio. We would like to extend our thanks to PARI Medical, Gilead, Vertex and Chiesi, who sponsored the 2021 conference.

"Cystic Fibrosis Trust, to me, means hope. Without it we wouldn't have had the funding to conduct the research that has changed so many people's lives, not only for people with CF, but their loved ones too. The Trust always gave me hope that one day, through research, the lives of those with CF and especially my brother, would be changed for the better forever."

Alice Collins, early career researcher whose brother has CF



Statement of Trustees' responsibilities

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

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

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

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

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

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

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

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

This Trustee's Report incorporating the Strategic Report was approved and authorised for issue by the Board of Trustees in November 2022 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 2022 which comprise the Consolidated Statement of Financial Activities, Consolidated Income and Expenditure Account, the Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows, and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group’s and of the parent charitable company’s affairs as at 31 March 2022 and of the group’s and parent charitable company’s net movement in funds, including the income and expenditure, for the year then ended

- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

- the information given in the Trustees’ Annual Report (which includes the strategic report and the directors’ report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements
- the strategic report and the directors’ report included within the Trustees’ Annual Report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the parent charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees’ Annual Report (which incorporates the strategic report and the directors’ report).

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

- adequate accounting records have not been kept by the parent charitable company or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees’ remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies’ regime and take advantage of the small companies’ exemptions in preparing the trustees’ report and from the requirement to prepare a strategic report.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees’ responsibilities statement (set out on page 67), the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor’s responsibilities for the audit of the financial statements

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

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

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to fundraising regulations, charity and company law applicable in England, Wales and Scotland, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Act 2011 and payroll taxes.

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

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

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

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

Use of our report

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



Kathryn Burton (Senior Statutory Auditor)
For and on behalf of Haysmacintyre LLP, Statutory Auditor

10 Queen Street Place,
London
EC4R 1AG

Cystic Fibrosis Trust
Consolidated statement of financial activities
For the year ended 31 March 2022

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2022 £'000	Total Funds 2021 £'000
Income and endowments from:						
Donations and legacies	2a	8,161	3,627	-	11,788	11,678
Charitable activities						
Other trading activities	12	3,703	-	-	3,703	2,580
Investments	2b	59	19	-	78	128
Other income		112	-	-	112	-
Total income		12,035	3,646	-	15,681	14,386
Expenditure on:						
Raising funds	3a	4,183	-	1	4,184	3,721
Charitable activities						
Research	3a	3,239	3,215	3	6,457	4,975
Clinical care	3a	431	914	-	1,345	1,132
Information, advice & support	3a	3,874	106	2	3,982	4,077
Total charitable activities		7,544	4,235	5	11,784	10,184
Total resources expended	3a	11,727	4,235	6	15,968	13,905
Net income/(expenditure) before investment gains/losses		308	(589)	(6)	(287)	481
Realised investment gains/(losses)		5	-	71	76	17
Unrealised investment gains/(losses)		374	-	(8)	366	793
Net investment gains/(losses)		379	-	63	442	810
Net (expenditure)/income		687	(589)	57	155	1,291
Transfers between funds	17a	(612)	612	-	-	-
Net movement in funds		75	23	57	155	1,291
Reconciliation of funds						
Total funds brought forward		8,279	248	989	9,516	8,225
Total funds carried forward	17a	8,354	271	1,046	9,671	9,516

All of the operations are continuing. There were no recognised gains or losses other than those stated above. A prior year comparative Consolidated Statement of Financial Activities has been included in the notes to the accounts (note 18)

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 2022

	All income funds 2022 £'000	All income funds 2021 £'000
Income	15,603	14,258
Gains/(losses) on investments	379	711
Investment income	78	128
Gross income in the reporting period	16,060	15,097
Expenditure	15,950	13,876
Interest payable	-	-
Depreciation and charges for impairment of fixed assets	18	23
Total expenditure in the reporting period	15,968	13,899
Net income before tax for the reporting period	92	1,198
Tax payable*	-	-
Net Income for the financial year	92	1,198

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 2022

	Notes	Consolidated		Charity	
		Total 2022 £'000	Total 2021 £'000	Total 2022 £'000	Total 2021 £'000
Fixed assets					
Tangible assets	5	19	37	19	37
Investments	6	5,604	5,196	5,604	5,196
		5,623	5,233	5,623	5,233
Current assets					
Debtors	7	3,948	3,301	2,824	2,337
Cash held as short term investment		11,265	11,256	11,265	11,256
Cash at bank and in hand		5,197	3,366	4,777	3,246
		20,410	17,923	18,866	16,839
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	9	(6,229)	(7,407)	(6,229)	(7,407)
Creditors and accrued charges	10	(2,708)	(1,410)	(3,107)	(1,404)
		(8,937)	(8,817)	(9,336)	(8,811)
Net current assets					
		11,473	9,106	9,530	8,028
Creditors: amounts falling due after one year					
Grants payable	9	(7,425)	(4,823)	(7,425)	(4,823)
Total net assets		9,671	9,516	7,728	8,438

Continued on the next page

	Notes	Consolidated		Charity	
		Total 2022 £'000	Total 2021 £'000	Total 2022 £'000	Total 2021 £'000
The funds of the charity:					
Endowment funds	17a	1,046	989	1,046	989
Restricted income funds	17a	271	248	271	248
Unrestricted funds:					
Designated reserves					
Fixed asset reserve		19	37	19	37
Appeal deficit		(1,285)	(421)	(1,285)	(421)
Strategic reserve		-	200	-	200
Total designated reserves		(1,266)	(184)	(1,266)	(184)
Operating reserves					
Retained reserves		3,411	3,448	3,411	3,448
		6,209	5,015	4,266	3,937
Total charity funds					
		9,671	9,516	7,728	8,438

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

The net movement in funds for the Trust for the year ended 31 March 2022 was +£1,788,000 (2021: -£219,000). As permitted by Section 408 of the Companies Act 2006, no separate Statement of Financial Activities or Income and Expenditure account has been presented for the charity alone.

Approved and authorised for issue by the Trustees on 16 November 2022 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 2022

	2022 £'000	2021 £'000
Net cash provided by operating activities (Note A)	1,728	329
Cash flows from investing activities:		
Dividends and interest	78	128
Purchase of property, plant and equipment	0	(36)
Purchase of investments	(1,082)	(116)
Movement in cash awaiting investment	8	(4)
Proceeds of sales of investments	1,108	1,404
Total cash flows provided by investing activities	112	1,376
(Increase)/decrease in cash held as short term investments	(9)	(1,278)
Increase/(decrease) in cash (Note B)	1,831	427

Notes to Cash Flow Statement

A. Reconciliation of net income/(expenditure) to net cash flow from operating activities

	2022 £'000	2021 £'000
Net (expenditure)/income for the reporting period (as per the statement of financial activities)	155	1,291
Adjustment for:		
Depreciation charges	18	23
Dividends and interest from investments	(78)	(128)
(Gains)/losses on investments	(442)	(810)
Decrease/(increase) in debtors	(647)	(682)
Increase/(decrease) in creditors	2,722	635
Net cash provided by operating activities	1,728	329

Continued on the next page

B. Reconciliation of cash and cash equivalents in the reporting period

	2022 £'000	2021 £'000
Cash and cash equivalents at the beginning of the reporting period	14,622	12,917
Change in cash and cash equivalents in the reporting period	1,831	427
Increase in short-term investments	9	1,278
Cash and cash equivalents at the end of the reporting period	16,462	14,622
(being cash at bank and in hand and cash held as short-term investments)		
	2022	2021
Analysis of cash and cash equivalents:	£'000	£'000
Cash on hand	5,197	3,366
Notice deposits (less than 3 months)	11,265	11,256
Total cash and cash equivalents	16,462	14,622

Cystic Fibrosis Trust
Notes to the Financial Statements
For the year ended 31 March 2022

1. Accounting policies

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

a) Basis of preparation

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

Group financial statements have been prepared in respect of Cystic Fibrosis Trust and its wholly owned trading subsidiary, Cystic Fibrosis Services Limited. In accordance with the Companies Act 2006 and SORP 2015, no separate Statement of Financial Activities is presented for Cystic Fibrosis Trust.

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

b) Charity status

The charity (registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 102. In the event of the company being wound up, the liability in respect of the guarantee is limited to £1 per member of the company.

c) Consolidation

The financial statements include the results and assets and liabilities of the charity and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own Statement of Financial Activities under section 408 of Companies Act 2006. The deficit for the parent charity was £1,788,000 (2020/21- surplus of £219,000).

The subsidiary’s net surplus of £1,943,000 will be donated in full to the parent charity after the year end.

d) Income

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

Donations and legacies income are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable. Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

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

e) Resources expended

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

Expenditure is recognised on an accruals basis as a liability is incurred, and includes irrecoverable VAT where applicable.

Expenditure is classified under the following activity headings:

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

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the estimated amount of time spent by the support area on each activity category. The basis for allocation was reviewed in the year in order to give a more accurate view of the level of support provided within different business areas. The prior year allocations have been restated in order to be consistent with the revised allocation basis.

f) Grants

Grants committed and awarded during the year are expensed.

g) Foreign currency transactions

Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the Statement of Financial Activities.

h) Employee benefits

- Short term benefits - Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.

- Employee termination benefits - Termination benefits are accounted for on an accrual basis and in line with FRS 102.

- Pension scheme - The Charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Charity pays fixed contributions into a separate entity. Once the contributions have been paid the Charity has no further payment obligations. The contributions are recognised as an expense in the Statement of Financial Activities when they fall due.

i) Taxation

No charge to taxation arises on the result for the year because the company is able to take advantage of the tax exemptions available to charities.

j) Leases

The trust recognises expenses under “operating leases” relating to capital equipment which it does not own. The annual rentals are charged to the Statement of Financial Activities on a straight line basis over the lease term.

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2022

k) Funds
Unrestricted reserves are those which the Trustees are free to use for any purpose in furtherance of the charitable objects.

Designated reserves are set aside out of unrestricted reserves by the Trustees, for particular purposes.

Restricted reserves are monies, which have legal restrictions on their use where donors have specified the funds can only be spent on certain of the charity’s activities.

Endowment Funds are funds where the Trustees are required to hold capital, as represented by the investments, and are not entitled to spend it. Income arising from these funds is either restricted income or unrestricted income depending upon the details included with the original gift.

l) Fixed assets and depreciation
Tangible fixed assets costing £500 or more are capitalised and are depreciated by equal annual instalments over their estimated useful lives. The current estimated rates of depreciation are:

Furniture & fittings	33.33%
Computer hardware	33.33%
Computer software	33.33%
Website development	33.33%
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.

m) 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.

Profits and losses on the realisation 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 subsequent to the first day of the financial year. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value. Realised and unrealised investment gains and losses are combined in the Statement of Financial Activities.

n) 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

- Debtors – 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 in hand – 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 – 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.

o) Critical accounting judgements and estimates
In preparing these financial statements, management has made judgements, estimates and assumptions that affect the application of the Charity’s accounting policies and the reported assets, liabilities, income and expenditure and the disclosures made in the financial statements. Estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. The key areas that are deemed to be material for these financial statements is as follows:

- Accruing for income derived from legacies where complicated issues surrounding the measurement of the group’s entitlement to income existed at the year end.
- The value of the contribution of the many thousands of hours donated by its unpaid volunteers has not been reflected in these accounts. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

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

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

2a. Income from donations and legacies

	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	Total 2022 £'000	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	Total 2021 £'000
Branches, Groups & Community	2,201	28	2,229	1,546	8	1,554
Legacies	1,574	321	1,895	2,082	185	2,267
Individual donations	291	93	384	394	32	426
Corporate	191	4	195	269	107	376
Regular giving and appeals	1,108	23	1,131	1,285	39	1,324
Trusts	94	2,521	2,615	97	2,551	2,648
Appeal for Innovation Hub	-	636	636	-	658	658
Donations in kind	1,892	-	1,892	1,648	-	1,648
Gift Aid	566	1	567	345	-	345
Government grant income	129	-	129	304	-	304
NHS National Services England and Scotland	115	-	115	128	-	128
Total income from donations and legacies	8,161	3,627	11,788	8,098	3,580	11,678

2b. Investment Income

	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	Total 2022 £'000	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	Total 2021 £'000
Income from listed investments	59	19	78	46	18	64
Bank interest	-	-	-	64	-	64
Total investment income	59	19	78	110	18	128

Donations In Kind refer to non-monetary donations received from partner organisations. In 2021/22 £1,892,000 was donated in the form of digital and cinema advertising space and professional fees (2020/21: £1,648,000). This was used to raise awareness of cystic fibrosis and the work of the Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, Advice and Support.

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

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

3a. Expenditure

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

The net unrestricted grants relating to Clinical Care are negative - this is due to the release of a commitment made in a prior year. See note 3b for more information.

Analysis of allocated Support Costs – current year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	Total 2022 £'000
Fundraising	78	25	104	47	87	341
Research	203	67	269	121	226	886
Clinical care	42	14	56	25	47	184
Information, advice and support	125	40	166	75	140	546
Governance	-	-	-	-	-	-
Total costs	448	146	595	268	500	1,957

Costs are allocated based on identifiable activities undertaken by central teams to support the wider organisation.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

3a. Expenditure continued

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	Total 2021 £'000
Raising funds					
Fundraising	-	-	1,902	382	2,284
Trading and merchandising	-	1,376	61	-	1,437
Charitable activities					
Research	1,891	1,255	998	831	4,975
Clinical care	299	48	596	189	1,132
Information, advice and support	262	88	3,046	681	4,077
Governance	-	-	-	-	-
	2,452	2,767	6,603	2,083	13,905

Analysis of allocated Support Costs – prior year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	Total 2021 £'000
Fundraising	62	52	105	50	113	382
Research	136	114	228	109	244	831
Clinical care	31	26	52	25	55	189
Information, advice and support	112	94	187	90	198	681
Governance	-	-	-	-	-	-
Total costs	341	286	572	274	610	2,083

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

3a. Expenditure continued

Net (expenditure)/income in the year:	2022 £'000	2021 £'000
Auditors remuneration excluding VAT	20	22
Depreciation	18	23
Operating leases – building	272	244
Operating leases – other	5	6
Trustees' travel expenses	-	-

3b. Grants

Grants were awarded during the year as follows:

	2022 £'000	2021 £'000
Grants to institutions	6,744	4,870
Grants to individuals	361	350
	7,105	5,220

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

	2022 £'000	2021 £'000
Balance at start of year	12,230	12,299
Adjustment to opening balance	-	-
Awarded in the year	7,105	5,220
Paid in year	(5,681)	(5,289)
Balance at end of year	13,654	12,230
Falling due within one year (note 9)	6,229	7,407
Falling due after more than one year (note 9)	7,425	4,823

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

3b. Grants continued

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

	2022 £'000	2021 £'000
Innovation Hub Cambridge	1,500	832
University of Nottingham	880	-
University of Liverpool	-	769
University of Bristol	-	749
UCL Great Ormond Street	750	750
University of Cambridge	365	-
Medical Research Council	267	17
Queen Elizabeth University Hospital	-	180
Cystic Fibrosis Canada (Fibrose Kystique) CFC	141	-
University Hospital Llandough	-	120
RNID	105	-
Diabetes UK	105	-
MDC (CF AMR Syndicate)	95	-
University of Edinburgh	70	2
Imperial College London / Royal Brompton Hospital	70	56
Belfast City Hospital	50	-
Medicines Discovery Catapult	-	50
University Hospital Llandough	45	-
Newcastle University	37	-
University of Copenhagen	-	27
Aston University	25	-
The University of Manchester	23	-
Queen's University Belfast	-	21
Other Insititutions (less than £20k)	39	9
	4,567	3,582

	2022 £'000	2021 £'000
Add: Trial Coordinator commitments made to CTAP centres (see note)	685	298
Add: Registry support grants made to various CF centres	1,571	1,376
Add: Other adjustments	-	15
Less: Release of grants made in previous years (see note)	(79)	(401)
Total grants made to institutions	6,744	4,870

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform programme. In most cases the trial coordinators are now in their fourth year of funding. In addition, a new cohort of Affiliate Centres were awarded funding in the year.

Various grants totalling £79,000 were released during the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful.

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.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

4. Staff costs

Staff costs comprise the following:

	2022 £'000	2021 £'000
Salaries	3,898	4,220
Redundancy and other termination payments	34	34
Temporary Staff	16	75
Social security costs	412	432
Other pension costs	227	254
	4,587	5,015

Analysis of total average monthly headcount by category:

	2022 No.	2021 No.
Research	14	16
Clinical care	6	6
Information, advice and support	33	36
Fundraising	36	42
Management	2	2
Finance	5	7
IT and project management support	8	8
HR & OD	5	4
Facilities	1	1
Total average monthly headcount	110	122

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

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

£34,000 in redundancy and other termination payments were paid to three longstanding staff members (2020/21: paid to two staff members costing £34,000) following a review of the fundraising team structure due to the impact of COVID-19, which will result in a long-term recurring cost saving for the Trust.

Pension contributions to defined contribution pension schemes for these employees totalled £51,049 (2020/21: £53,168).

Remuneration of key management personnel: The total remuneration paid to key management personnel, including pension and social security contributions, was £584,529 which relates to 8 individuals who served on the Senior Leadership Team during the year (2020/21: £524,283 paid to 7 individuals).

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

5. Fixed Assets

	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 31 March 2021	630	870	243	403	183	2,329
Additions	-	-	-	-	-	-
Disposals	-	-	-	-	-	-
At 31 March 2022	630	870	243	403	183	2,329

Depreciation						
At 31 March 2021	630	834	243	402	183	2,292
Disposals	-	-	-	-	-	-
Charge for the year	-	17	-	1	-	18
At 31 March 2022	630	851	243	403	183	2,310

Net book value at 31 March 2022	-	19	-	-	-	19
Net book value at 31 March 2021	-	36	-	1	-	37

6. Investments

Group and Charity	Total 2022 £'000	Total 2021 £'000
Market value as at 31 March	5,196	5,670
Adjustment to brought forward balance	(14)	-
Additions at cost	1,082	116
Disposals at opening book value	(1,018)	(1,376)
Net gains/(losses) on investments	366	782
	5,612	5,192
Change in cash	(8)	4
Market value as at 31 March	5,604	5,196

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

6. Investments (continued)

Represented by:	Total 2022 £'000	Total 2021 £'000
Equities	343	3,921
Fixed Interest and multi-asset funds	4,767	495
Property	292	575
Cash	202	205
	5,604	5,196

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment. The following asset was held at 31 March 2022. This is the only asset that is more than 5% of total investments:

	Total 2022 £'000
Responsible Multi Asset Fund	4,566

In 2014/15, the Trustees decided to exclude tobacco related stocks from investments. This change was implemented in 2015/16 and the investment portfolio is now fully ex-tobacco.

7. Debtors

	Group 2022 £'000	Group 2021 £'000	Charity 2022 £'000	Charity 2021 £'000
Trade debtors	1,124	1,085	-	-
Amount due from subsidiary undertaking	-	-	-	121
Prepayments and accrued income	2,784	2,151	2,784	2,151
Other debtors	40	65	40	65
	3,948	3,301	2,824	2,337

8. Cash held as short-term investment

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

9. Grants Payable

	2022 £'000	2021 £'000
Grant creditor at 31 March	12,230	12,299
Prior year adjustment	(17)	-
Grants paid during the year	(4,019)	(3,914)
Grants approved before 31 March 2021 awarded but withdrawn	-	-
Grants approved in prior years and underprovided	-	-
Grants for Welfare approved and payable within the year	-	-
Grants approved before 31 March 2022 and payable within one year	3,379	2,347
Grants approved before 31 March 2022 and payable after one year	2,081	1,498
Grant creditor at 31 March	13,654	12,230
Represented by		
Grants committed and awaiting claim at 31 March	-	-
Grants due within one year at 31 March 2022	6,229	7,407
Grants due > 12 months	7,425	4,823
	13,654	12,230

10. Creditors

	Group 2022 £'000	Group 2021 £'000	Charity 2022 £'000	Charity 2021 £'000
Trade creditors	668	408	655	408
Other creditors	108	120	523	120
Accruals and deferred income	1,932	882	1,929	876
	2,708	1,410	3,107	1,404

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

11. Financial Instruments (Assets and Liabilities)

	Group 2022 £'000	Group 2021 £'000	Charity 2022 £'000	Charity 2021 £'000
Financial assets measured at amortised cost (Note A)	17,593	15,718	16,048	14,520
Financial assets measured at fair value (Note B)	5,604	5,196	5,604	5,196
Financial liabilities measured at amortised cost (Note C)	(16,255)	(13,529)	(16,238)	(13,521)
Net financial assets measured at amortised cost	6,942	7,385	5,414	6,195

(A) 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.

(B) Financial assets held at fair value include assets held as investments.

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

12. Interest in subsidiary

Cystic Fibrosis Services Limited is incorporated in England (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. The profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March can be summarised as:

	Total 2022 £'000	Total 2021 £'000
Sales and sundry income	3,703	2,580
Cost of sales and administration	(1,691)	(1,437)
Intercompany recharges	(69)	(71)
Net contribution to parent charity	1,943	1,072

The balance sheet of Cystic Fibrosis Services Limited at 31 March can be summarised as:

	Total 2022 £	Total 2021 £
Current assets		
Debtors	1,538,869	1,077,967
Cash at bank	420,745	120,205
	1,959,614	1,198,172
Creditors: amounts falling due within one year	(16,226)	(127,506)

	Total 2022 £	Total 2021 £
Net current assets	1,943,388	1,070,666

Net assets	1,943,388	1,070,666
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Capital and reserves

Called up share capital	2	2
Profit and loss account	1,943,386	1,070,664

Shareholder's funds	1,943,388	1,070,666
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The charity owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd, which comprises 100 ordinary shares of £1 each. 2 shares have been allotted, which are called up and fully paid.

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

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

13. Leasing commitments

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

	2022 £'000	2021 £'000
Within one year	271	271
Between two and five years	543	814

A 10-year property lease with a five-year break clause was signed on 1 April 2015 for a new office in central London, with annual rent of £271,425. The break clause was not exercised and as such the remaining three years of the lease are now committed.

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

	2022 £'000	2021 £'000
Within one year	9	9
Between two and five years	14	20

The charge to the Statement of Financial Activities for all of these commitments is shown in note 3a.

14. 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 year was £14,428 (2020/21: £27,729). In addition 7 of the trustees (2020/21: 5) were involved in fundraising activities carried out by regional fundraising branches.

Any other transactions between the Trust and its trustees are disclosed in note 4.

15. Post balance sheet events

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

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

16. Analysis of funds

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

Prior year funds

	Unrestricted	Endowment funds	Gene Therapy restricted	Other restricted	2021 £'000
	£'000	£'000	£'000	£'000	
Tangible fixed assets	37	-	-	-	37
Investments	4,207	989	-	-	5,196
Current assets	17,660	-	-	263	17,923
Internal obligations	-	-	-	-	-
Current liabilities	(8,817)	-	-	-	(8,817)
Liabilities due in more than one year	(4,808)	-	-	(15)	(4,823)
	8,279	989	-	248	9,516

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

17a. Current year fund movements

	Balance 31 March 2021 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Fixed asset reserve	37	-	-	-	(18)	19
Appeal deficit: Innovation Hub at Cambridge	(421)	-	-	-	(864)	(1,285)
Strategic reserve	200	-	-	-	(200)	-
Total designated reserves	(184)	-	-	-	(1,082)	(1,266)
Operating reserve	3,448	-	-	-	(37)	3,411
Retained reserves	5,015	379	12,035	(11,727)	507	6,209
Total general reserves	8,463	379	12,035	(11,727)	470	9,620
Total unrestricted funds	8,279	379	12,035	(11,727)	(612)	8,354
Restricted income funds:						
Appeal: Innovation Hub at Cambridge	-	-	636	(1,500)	864	-
Restricted funds related to research:						
Genetic Therapies	87	-	28	-	(115)	-
General medical research	-	-	171	(171)	-	-
Sport England – Helping the active stay active	7	-	-	-	-	7
Imperial SRC: <i>Pseudomonas aeruginosa</i>	-	-	15	-	(15)	-
Imperial SRC: Targeting immuno therapy for fungal infections	-	-	4	-	(4)	-
Sheffield SRC: Gastrointestinal Cancer	-	-	2	-	(2)	-
UCL/Great Ormund St SRC – Therapeutic gene editing	4	-	41	-	(45)	-
Bristol SRC: CFTR Folding and Function	-	-	208	(208)	-	-
SRC costed extensions	-	-	267	(267)	-	-

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

17a. Current year fund movements (continued)

	Balance 31 March 2021 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
SRC024 University College London (UCL)	-	-	375	(375)	-	-
Life Expectancy Project	(23)	-	-	-	23	-
Transition Information Resources	15	-	-	-	-	15
Quality Improvement Project	-	-	35	-	-	35
Other research related restricted funds	(7)	-	5	-	6	4
Total funds related to research	83	-	1,151	(1,021)	(152)	61
Restricted funds related to Information and Support						
E W Joseph/Homecare grants	18	-	7	(22)	-	3
Joseph Levy/Education Grants	(15)	-	37	(48)	30	4
Young Lives programme	28	-	50	(21)	(28)	29
Support services (including welfare grants)	80	-	148	(2)	(114)	112
Forum	-	-	-	-	22	22
CF Connect (Youth and Parents)	26	-	-	-	(26)	-
Young entrepreneurs	-	-	16	(13)	-	3
Total funds related to Information and Support	137	-	258	(106)	(116)	173

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2022

17a. Current year fund movements (continued)

	Balance 31 March 2021 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Other funds – various categories:						
Coombe Hill	8	-	-	-	-	8
SmartCare CF	(10)	-	-	-	10	-
Clinical Trials Accelerator Programme (CTAP)	(10)	-	914	(914)	10	-
Digital Health Research Programme (Project Breathe)	-	-	684	(684)	-	-
CTAP Digital conference	-	-	3	(10)	-	(7)
CF Registry	(12)	-	-	-	12	-
Consensus documents	21	-	-	-	(21)	-
HDRUK grant award	(5)	-	-	-	5	-
Other older funds	36	-	-	-	-	36
Total other funds	28	-	1,601	(1,608)	16	37
Total restricted reserves	248	-	3,646	(4,235)	612	271
Endowment funds:						
Ena Bennie Endowment	491	42	-	(3)	-	530
EW Joseph Endowment	165	11	-	(1)	-	175
Joseph Levy Endowment	285	10	-	(2)	-	293
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other Endowment funds	28	-	-	-	-	28
Total endowment funds	989	63	-	(6)	-	1,046
Total funds	9,516	442	15,681	(15,968)	-	9,671

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2022

17a. Funds (continued)

Designated Funds: The designated fixed assets reserve matches the net book value of the charity's tangible fixed assets, the existence of which is fundamental to the charity being able to perform its charitable work and thereby achieve its charitable objectives. The value represented by such assets should not, therefore, be regarded as realisable.

Appeal Deficit: Innovation Hub at Cambridge – In 2017/18 we committed £2.0 million in the form of a research grant to the University of Cambridge as part of the Innovation Hub flagship programme. To date we have received £1.842m from donors in funding for this grant (shown in the separate restricted fund line, see below). The Trust has underwritten this grant, and we continue to work to secure additional pledges in order to fund the commitment in full and free up core funds to be made available where there is the greatest need.

General reserves: The operating reserve is held in order to provide, as a minimum, cover for six months operation costs, major fluctuations in income and contingencies for long term commitments, and any deficits arising on restricted funds.

Retained reserves are held for future initiatives.

Restricted income funds: Restricted income funds are held when donors specify a particular use for their donation. For the purposes of this report, the restricted income funds have been divided into the following categories:

- **Appeal for Innovation Hub at Cambridge:** We have received £1.842m to date in funding towards the £2.0m commitment made to the University of Cambridge. As further income is received it will be recognised within this restricted fund and matched against the commitment made in 2017/18 through a transfer to the designated fund (see above).

- **Restricted funds related to research:** Donations relating to grant commitments made by the Trust to research institutions. On occasion the donations were made in a different financial year to the original grant commitment; in such cases a transfer has been made to retained reserves to back-fill the original payments.

The following funds are held related to research:

Gene Therapy Research – funds available for gene therapy related activity.

General medical research – where the donor did not specify a particular research grant award.

- Matched against selected Strategic Research Centres.
- Matched against selected Venture Innovation Awards.
- Matched against selected Clinical Excellence and Innovation Awards.

Sport England funded work – A project at Exeter University: Helping the active stay active.

SRC costed extensions – Funding was secured from the Medical Research Council in 2022 to fund the extensions of SRC projects that had been delayed to the COVID-19 pandemic

Other research related restricted funds – including funding for grants to individuals for cystic fibrosis related summer student projects or travel to cystic fibrosis related conferences.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

17a. Funds (continued)

- **Restricted funds related to information and support:** Donations relating various activities supporting people with cystic fibrosis and their families.

The following funds are held related to Information and Support:

- **EW Joseph/Homecare grants** – funding the promotion of increased care at home rather than in hospital for people with CF, and improvements in home care by education. See comments about the corresponding endowment fund below.
- **Joseph Levy/Education grants** – funding people with cystic fibrosis in their educational studies. See comments about the corresponding endowment fund below.
- **Young Lives Programme** – funding a youth programme supporting young people with cystic fibrosis. This fund is supported by Children In Need.
- **Support Services** – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
- **CF Connect Youth/Parents** – funding for projects to provide peer to peer telephone support service for young people with cystic fibrosis, and parents of children newly diagnosed with cystic fibrosis.

• **Other restricted funds:**

Coombe Hill – funding education about cystic fibrosis.

SmartcareCF – funding the development of the SmartcareCF platform, including both adult and paediatric study.

Clinical Trials Accelerator Platform – funding this flagship programme.

Digital Health Research Programme – funding this flagship programme, in collaboration with **Cambridge University and Papworth Hospital**, on digital health monitoring.

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

The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.

The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home (see EW Joseph/Homecare Grants above).

The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education (see J Levy/Education Grants above).

The Sally Wrigley Memorial Fund.

Transfers between funds – the following transfers were made between funds:

- A transfer was made between the Strategic Reserve and Retained Reserves to clear the balance within Designated Reserves
- A transfer was made between the Appeal Innovation Hub at Cambridge and the Appeal Deficit Innovation Hub at Cambridge.
- A transfer was made to the Fixed Asset Reserve to match against the current balance on Fixed Assets.
- Some transfers were made between Retained Reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been back-filled by restricted donations.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2022

17b. Prior year fund movements

	Balance 31 March 2020 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2021 £'000
Fixed asset reserve	24	-	-	-	13	37
Appeal deficit: Innovation Hub at Cambridge	(1,079)	-	-	-	658	(421)
Strategic reserve	-	-	-	-	200	200
Total designated reserves	(1,055)	-	-	-	871	(184)
Operating reserve	3,366	-	-	-	82	3,448
Retained reserves	4,778	712	10,788	(11,057)	(206)	5,015
Total general reserves	8,144	712	10,788	(11,057)	(124)	8,463
Total unrestricted funds	7,089	712	10,788	(11,057)	747	8,279
Restricted income funds						
Appeal for Innovation Hub at Cambridge	-	-	658	-	(658)	-
Restricted funds related to research:						
Gene therapy research	45	-	42	-	-	87
General medical research	-	-	179	(179)	-	-
Imperial College SRC: Pseudomonal infection	-	-	50	-	(50)	-
UCL SRC: Personalised Engineered Cell Therapies	-	-	3	-	(3)	-
Sport England -Helping the Active Stay Active	-	-	7	-	-	7
Imperial SRC: <i>Pseudomonas aeruginosa</i>	-	-	14	-	(14)	-
Targeting Immuno Therapy for Fungal Infections-SRC15	-	-	2	-	(2)	-
RNA Interference of ENAC as Therapy for CF VIA 12	-	-	20	-	(20)	-
SRC020-Prof Stephen Hart-Therapeutic gene editing	-	-	379	(375)	-	4
SRC022-Co-funded with CFF	-	-	375	(375)	-	-
Life Expectancy Project	(20)	-	-	(3)	-	(23)
Transition Information Resources	15	-	-	-	-	15
Other research related restricted funds	1	-	5	(13)	-	(7)
Total funds related to research	41	-	1,076	(945)	(89)	83

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2022

17b. Prior year fund movements (continued)

	Balance 31 March 2020 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2021 £'000
Restricted funds related to Information & Support:						
E W Joseph/Homecare grants	36	-	7	(25)	-	18
Joseph Levy/Education Grants	13	-	18	(46)	-	(15)
Young lives programme	6	-	61	(39)	-	28
Support services (inc. welfare grants)	81	-	224	(225)	-	80
CF Connect (youth and parents)	26	-	-	-	-	26
Total funds related to Information & Support	162	-	310	(335)	-	137
Other funds – various categories:						
Coombe Hill	8	-	-	-	-	8
SmartCareCF	(10)	-	-	-	-	(10)
CTAP – Clinical Trials Accelerator Platform	-	-	455	(465)	-	(10)
Digital Health Research Programme	-	-	1,024	(1,024)	-	-
CF Registry	(5)	-	-	(7)	-	(12)
Patient Reported Experience Measures	2	-	-	(2)	-	-
Consensus documents	23	-	-	(2)	-	21
HDRUK Grant Award	(14)	-	9	-	-	(5)
Other older funds	32	-	66	(62)	-	36
Total other funds	36	-	1,554	(1,562)	-	28
Total restricted reserves	239	-	3,598	(2,842)	(747)	248
Endowment funds:						
Ena Bennie Endowment	443	51	-	(3)	-	491
EW Joseph Endowment	150	16	-	(1)	-	165
Joseph Levy Endowment	257	30	-	(2)	-	285
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other endowment funds	27	1	-	-	-	28
Total endowment funds	897	98	-	(6)	-	989
Total funds	8,225	810	14,386	(13,905)	-	9,516

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2022

18. Prior year Consolidated Statement of Financial Activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2021 £'000	Total Funds 2020 £'000
Income and endowments from:						
Donations and legacies	2	8,098	3,580	-	11,678	15,196
Charitable activities	-	-	-	-	-	-
Other trading activities	12	2,580	-	-	2,580	1,078
Investments	2b,6	110	18	-	128	149
Other income:						
Other income	2	-	-	-	-	104
Total		10,788	3,598	-	14,386	16,527
Expenditure on:						
Raising funds	3a	3,718	-	3	3,721	3,563
Charitable activities						
Research		3,008	1,966	1	4,975	4,432
Clinical care	3a	664	468	-	1,132	2,132
Information, advice and support	3a	3,667	408	2	4,077	6,373
Total charitable activities		7,339	2,842	3	10,184	12,937
Governance costs		-	-	-	-	-
Total resources expended	3a	11,057	2,842	6	13,905	16,500
Net income/(expenditure) before investment gains/losses		(269)	756	(6)	481	27
Realised investment gains/(losses)		17	-	-	17	38
Unrealised investment gains/(losses)		695	-	98	793	(391)
Net investment gains/(losses)		712	-	98	810	(353)
Net (expenditure)/income		443	756	92	1,291	(326)
Transfers between funds	17a	747	(747)	-	-	-
Net movement in funds		1,190	9	92	1,291	(326)
Reconciliation of funds:						
Total funds brought forward		7,089	239	897	8,225	8,551
Total funds carried forward	17a	8,279	248	989	9,516	8,225

Structure, governance and management

Patron

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

Honorary President

- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees

Chairman

- Richard Hunt CBE

- Professor Andrew Jones (term ended July 2021)
- Michael Winehouse (term ended July 2021)
- Louise King (term ended 2021)
- Ffiona Dawber (term ended March 2022)
- Professor Rosalind Smyth CBE FMedSci
- Sean Collins
- Anne Byrne
- Richard Hoey
- David Titmuss (resigned June 2022)
- Michelle Shore
- Joanna Barrett
- Sophie Pierce (appointed July 2021)
- Sonya Trivedy (appointed July 2021)
- Professor Martin Walshaw MD FRCP (appointed July 2021)

Marketing, Communications & Income Generation Committee

Chairman

- Richard Hoey

- Sean Collins
- Joanna Barrett
- David Titmuss (resigned June 2022)
- Joanne Hilditch (Independent member resigned May 2022)

Finance Committee

Chairman

- Sean Collins

- Anne Byrne
- David Sawyer (Independent member)
- Michelle Shore
- Ed Rushton (Investments Committee)
- Nick Wood (Investments Committee)

People Committee

Chairperson

- Michelle Shore

- Sonya Trivedy
- Joanna Barrett

Charity Management

- David Ramsden – Chief Executive
- Louise Honeysett FCA –Director of Finance and Resources (resigned January 2022)
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising
- Rebecca Cosgriff – Director of Data and Quality Improvement (resigned June 2022)
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research
- Simon Hawkins – Director of Finance and Resources (appointed February 2022)

Company Secretary

- Simon Hawkins – Director of Finance and Resources

Principal and Registered Office

One Aldgate
London
EC3N 1RE

020 3795 1555

enquiries@cysticfibrosis.org.uk
cysticfibrosis.org.uk

Company Limited by Guarantee
Company registration number:
3880213
Charity registration number:
England & Wales —1079049
Scotland —SC040196

Auditors

Haysmacintyre LLP
10 Queen Street Place,
London EC4R 1AG

Bankers

Natwest Plc
15 Bishopsgate London EC2N 3NW

Investment Managers

Cazenove Capital Management
12 Moorgate London EC2R 6DA

Recruitment, induction and training of Trustees

Trustees consider the relevant skill set required to enable effective oversight and proper governance of the organisation. New Trustees are appointed after a rigorous recruitment process, which includes advertising in the national press and on the basis of recommendation.

Upon appointment to the Board, in order to help facilitate their understanding of the current issues concerning the organisation, each new Trustee is provided with specific tailored information, and opportunities are also provided for the new Trustee to meet with the Chair and Chief Executive Officer, as well as meeting staff working within their own specialist area.

Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Charity 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 taking into account the skills required and the complexity of individual roles. The process, including the award of annual pay uplift, is overseen by the Remuneration Panel made up of Trustees and chaired by the Chairman of the Trust.

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.

Legal structure

Cystic Fibrosis Trust (‘the Trust’) is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1964 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

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

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 10 Trustees with a range of skills. Several committees such as the Finance and Audit Committee, Nomination and Development Committee, Strategic Advisory Board, Strategic Implementation Board and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Committed VIAs

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA005	Dr Emma France	Stirling University	SCooP (Supporting Children's Physiotherapy for cystic fibrosis) Development of interventions to increase adherence to physiotherapy among young children with cystic fibrosis – Medical Research Council's complex intervention framework phase I study.	£20,000
VIA035	Dr Fred Piehl	Imperial College London	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA036	Dr Fred Piehl	Imperial College London	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA039	Ms Laura Birch	Bristol University	Dietary manipulation to improve glycaemic control in young people with cystic fibrosis and altered glucose handling: a feasibility study	£25,000
VIA045	Professor Chris van der Gast	Manchester Metropolitan University	Detection of CF lung pathogens using engineered bacteriophages	£45,950.50
VIA051	Dr Tanmay Bharat	Action Medical Research	Elucidating the structural role of filamentous bacteriophage in <i>Pseudomonas aeruginosa</i> biofilms for disrupting infection in cystic fibrosis airways	£89,917.50
VIA052	Professor Jane Davies	Imperial College London	Exploring the utility of novel 'antimicrobial resistance breakers' on strains of <i>Pseudomonas aeruginosa</i> obtained from patients with cystic fibrosis	£50,000
VIA059	Dr Joseph Jacob	UCL	Quantifying bronchiectasis severity in cystic fibrosis	£50,000
VIA061	Prof Alan Smyth	University of Nottingham	Gut Imaging for Function and Transit in CF – The GIFT Study	£35,369
VIA062	Prof Miguel Camara	University of Nottingham	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000
VIA063	Prof Stephen Hart	University College London	Development of in vitro Transcribed mRNA Therapeutics for Cystic Fibrosis	£51,545
VIA064	Dr Andrew Jones	University of Manchester	Arthropathy in Adults with Cystic Fibrosis	£34,000
VIA067	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

Committed VIAs

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA068	Professor Jane Davies	Imperial College London	The idealised LCI (i-LCI): tuning in on the 'silent years' of paediatric CF	£98,594.93
VIA070	Dr Laura Nolan	Imperial College London	Understanding interbacterial competition in the Cystic Fibrosis lung to identify opportunities for intervention	£30,000
VIA071	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA072	Dr Charles Haworth	Papworth Hospital	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis	£36,000
VIA073	Dr Viek Dua	University College London	Modelling and machine learning to aid the design of CF therapy	£50,000
VIA076	Dr Luke Allsopp	Imperial College London	In the thick of it: Competitive Microbial Interactions in Biofilms	£20,000
VIA077	Prof Chris van der Gast	Manchester Metropolitan University	Organisation and function of the gut microbiota in cystic fibrosis	£47,000
VIA078	Prof Chris van der Gast	Manchester Metropolitan University	Non-tuberculosis mycobacteria infection and the wider lung microbiota in cystic fibrosis	£48,000
VIA079	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFG1-SRC)	£32,600
VIA081	Dr Anand Shah	Imperial College London	FREAL – Fungal Resistance Evolution and Acquisition in chronic Lung disease	£38,000
VIA082	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£21,304
VIA083	Dr Paul McNally	Our Lady's Children's Hospital	RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in	£97,297
VIA085	Professor Jane Davies	Imperial College London	People with CF)	£50,000
VIA086	Dr Christabella Ng	Univeristy of Nottingham	Exploring the utility of quorum sensing inhibitors and biofilm disruptors on growth and virulence behaviours of <i>Pseudomonas aeruginosa</i> obtained from patients with cystic fibrosis	£65,000
VIA088	Prof Kevin Southern	University of Liverpool	Gut Imaging for Function & Transit in cystic fibrosis Study 3	£18,931.70

Committed VIAs

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA090	Prof Michael Givskov	University of Copenhagen	Co-therapy of a novel <i>Pseudomonas aeruginosa</i> biofilm disruptor with standard of care antibiotics	£26,500
VIA091	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA092	Dr James Reihill	Queen's University Belfast	The ubiquitylation system as a therapeutic target in CF	£15,000
VIA093	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
VIA094	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro carbon copy of lung disease	£40,000
VIA095	Dr Beverley Isherwood	Medicines Discovery Catapult	CF AMR Biorepository	£49,500
VIA098*	Dr Jonathan Cox	Aston University	Discovery of new and repurposed β -lactamase inhibitors for improving <i>Mycobacterium abscessus</i> treatment	£25,000
VIA099*	Professor Chris Ward	Newcastle University	An implementation study investigating the feasibility of using gastrointestinal patient related outcome measures in people with cystic fibrosis	£37,000
VIA101*	Gerry McCauley	OmniSpirant Limited	Electrophysiology assessment of OS001 CFTR exosomes	£4,200
VIA102*	Kidney Research UK (KRUK)	MRC, KRUK, Bloodwise, Vasculitis UK	The MELODY Study	£50,000
VIA103*	Mr Andy Short	Ockham Biotech Ltd	Development of a non-anticoagulant heparin derivative as a therapy in CF	£50,000

*Awarded in the 2021/2022 financial year.

Currently active SRCs

SRC Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
SRC004*	Dr Siobhan Carr	Royal Brompton Hospital	Cystic Fibrosis Epidemiological Network (CF-EpiNet) – Harnessing Data to Improve Lives	£747,259
SRC005*	Dr David Sheppard	University of Bristol	The F508del-CFTR SRC	£749,933
SRC006*	Prof Stephen Hart	University College London	Personalised Engineered Cell Therapies for cystic fibrosis	£718,602
SRC007*	Prof James Shaw	Newcastle University	The Cystic Fibrosis Related Diabetes Strategic Research Centre (CFRD-SRC)	£750,000
SRC008*	Prof Craig Williams	University of Exeter	Physical Activity, Exercise, Sport and Recreation Promotion for Adolescents with CF	£750,000
SRC009*	Prof Michael McDermott	St James' University Hospital	Targeting joint disease in cystic fibrosis: identifying therapeutic targets in CF arthropathy	£371,399
SRC010*	Professor Andres Floto	MRC Laboratory of Molecular Biology Cambridge Biomedical Campus	Novel Therapies for <i>Mycobacterium abscessus</i>	£749,941
SRC011**	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFG1-SRC)	£749,694
SRC012**	Dr Daniel Peckham	St James' University Hospital	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC013**	Dr Mike Gray	Newcastle University	Personalised Therapies for all: Restoring airway function in CF using Alternative Chloride Channels	£750,000
SRC014**	Prof Jane Davies	Imperial College London	Personalised Approach to <i>Pseudomonas aeruginosa</i> (PAPA)	£750,000
SRC015**	Dr Darius Armstrong-James	Imperial College London	TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis	£750,000

Currently active SRCs

SRC Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
SRC016**	Prof Pietro Cicuta	University of Cambridge	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC017**	Dr Martin Welch	University of Cambridge	Gas, food and lodging; understanding the physiological and metabolic requirements of <i>Pseudomonas aeruginosa</i> in the cystic fibrosis airways	£748,538
SRC018	Professor Steven Renshaw	University of Sheffield	Preventing Gastrointestinal Cancer in cystic fibrosis	£749,214
SRC019	Professor James Shaw	University of Newcastle	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes	£750,000
SRC020	Prof Stephen Hart	University College London	Therapeutic gene editing of CFTR	£740,142
SRC021	Prof David Sheppard	University of Bristol	The CFTR Folding and Function SRC	£747,972
SRC022	Dr Jo Fothergill	University of Liverpool	An evidence-based preclinical framework for the development of antimicrobial therapeutics in cystic fibrosis (PIPE-CF)	£749,373

* Grant in the process of closing – awaiting final invoicing and financial report

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

Summer Studentships

Supervisor	Host Institution	Student & Project
Dr Malcolm Brodlie	Newcastle University	Miss Simone Soars – Clinical characteristics and outcomes for children with cystic fibrosis admitted to paediatric intensive care in the UK
Dr Siobhan Carr	Royal Brompton Hospital	Mr Ciaran O’Toole – Reliability of paediatric home spirometry in the clinical setting
Prof Deborah Gill	John Radcliffe Hospital	Miss Ashwini Kurunatha – Investigating the potential of a lentiviral vector to mediate long-term transgene expression in the airway
Dr Bettina Schock	Queen’s University Belfast	Ms Ariana Axia – Self-supervised machine learning to decipher patient variability in the immune response to infection
Prof Stephen Todryk	Northumbria University	Miss Hannah Munslow – Immune responses against anaerobic (air-hating) bacteria in patients with cystic fibrosis
Prof Craig Williams	University of Exeter	Miss Ieva Jakaityte – The impact of physical activity on cystic fibrosis related diabetes: a mixed-methods feasibility study

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