

# Cystic Fibrosis why we're here

## **Cystic Fibrosis Trust** **Annual Report and Financial Statements**

For the year ended 31 March 2021

Company Registration No. 3880213  
Charity No. 1079049 (England and Wales)  
OSCR No. SC040196 (Scotland)

Fighting for a  
Life Unlimited

## Contents

<b>Introduction</b>	<b>4</b>	<b>Supporting access to medicines at every step from laboratory to medicine cabinet</b>	<b>18</b>
<b>Chairman's statement</b>	<b>4</b>	<b>Clinical Trials Accelerator Platform</b>	<b>18</b>
<b>Objectives and activities</b>	<b>5</b>	National collaborations	18
<b>About cystic fibrosis (CF)</b>	<b>5</b>	Network of CTAP centres	18
<b>About us</b>	<b>6</b>	Membership renewal	19
<b>Our mission</b>	<b>6</b>	Early Phase Coordinator Pilot	19
<b>Our vision</b>	<b>6</b>	Impact of CTAP	20
<b>Measuring success</b>	<b>6</b>	Lung Clearance index	20
<b>Success in research</b>	<b>6</b>	Engagement with Sponsors	20
<b>Achievements and performance</b>	<b>6</b>	Community Involvement	20
Strategic Research Centres (SRCs)	6	Clinical Trials Digital Hub	21
Venture and Innovation Awards	9	Core outcome sets	21
Summer Studentships	9	Youth Involvement Group	21
CF Syndicate in AMR	9	Trial Results Reporting	21
Innovation Hub	10	CTAP remit expansion	22
Cellular Therapy	11	<b>Providing day-to-day support; and seeking to reach all people with cystic fibrosis when they need us most</b>	<b>22</b>
Machine learning approaches to personalised medicine	11	<b>Day to day support</b>	<b>22</b>
Digital health research programme	12	Welfare grants	23
<b>Collaborating and supporting the clinical community to promote the highest Quality of care</b>	<b>13</b>	Benefits advice	23
<b>The impact of Kaftrio on the CF Community</b>	<b>14</b>	Information	23
<b>Impact of COVID-19</b>	<b>15</b>	Helpline	24
Shielding	15	Youth programme	24
Emergency grants	15	<b>Reaching all people</b>	<b>24</b>
Coronavirus hub	15	Effectively engaging with our community and the public	24
Registry	15	Events	25
<b>Campaigning hard</b>	<b>16</b>	Social media	25
<b>Clinical Fellowships</b>	<b>17</b>	CF Week	26
<b>Data and quality improvement</b>	<b>17</b>	<b>Communicating with supporters</b>	<b>26</b>
Registry Annual Meeting	17	Volunteering	26
Annual data report	18	<b>Being an effective organisation</b>	<b>27</b>
Quality improvement	18	Supporter experience	28
		<b>Fundraising</b>	<b>28</b>
		Fundraising events and activities	28
		Gifts in Wills	29
		Regular gifts	29
		Corporate partnerships	29
		<b>Philanthropy</b>	<b>29</b>

<b>Plans for the future</b>	<b>30</b>	<b>Consolidated statement of financial activities</b>	<b>43</b>
Research and UKCFC	30		
Improving the quality of care	30		
UK CF Registry	31	<b>Consolidated income and expenditure account</b>	<b>44</b>
Improving trial outcomes	31		
Campaigning hard and raising awareness	31		
Day-to-day support	31	<b>Consolidated and charity balance sheets</b>	<b>45</b>
Being great fundraisers	32		
Being an effective organisation	32	<b>Consolidated statement of cash flows</b>	<b>46</b>
<b>Financial review</b>	<b>33</b>	<b>Notes to the financial statements</b>	<b>47</b>
Income	33		
Expenditure	34	<b>Structure, governance and management</b>	<b>68</b>
Investment policy	35	Recruitment, induction and training of Trustees	69
Review of investments in the year	35	Senior Leadership Team	69
Reserves	35	Public benefit	69
<b>Principal risks and uncertainties</b>	<b>36</b>	Legal structure	69
<b>Our work with the pharmaceutical industry</b>	<b>37</b>	<b>Currently active VIA Awards</b>	<b>70</b>
Clinical Trials Accelerator Platform	37		
The UK Cystic Fibrosis Registry	37	<b>Committed VIA Awards 2020/21</b>	<b>73</b>
Venture & Innovation Awards (VIAs)	37		
<b>Sponsorship and donations</b>	<b>38</b>	<b>Summer studentships</b>	<b>74</b>
<b>Statement of Trustees' responsibilities</b>	<b>39</b>		
<b>Independent auditor's report</b>	<b>40</b>		
Opinion	40		
Basis for opinion	40		
Conclusions relating to going concern	40		
Other information	40		
Opinions on other matters prescribed by the Companies Act 2006	40		
Matters on which we are required to report by exception	41		
Responsibilities of trustees for the financial statements	41		
Auditors responsibilities for the audit of the financial statements	41		
Use of our report	42		

**The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2021.**

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 43 to 67 also form part of the Trustees' report.

## Chairman's statement

I am pleased to present the Cystic Fibrosis Trust's Annual Report for 2020/21.

This year represented the final year of our current three year 'Strategic Framework', however it was a twelve months unlike anything we or anyone else could have envisaged when we set out our initial course. Despite everything, it truly was a year not only of the many deep lows of the COVID-19 pandemic but also special highs!

Shortly before the start of the Financial Year, all people with cystic fibrosis were required to 'shield', which meant limiting their social interaction to the absolute minimum. Many faced new challenges such as, securing regular supplies of food, financial hardship, disruption to their usual care as well as the understandable anxiety about the virus itself.

The Trust responded rapidly by offering direct support where possible, as well as a wide range of specific information and guidance and continuously advocating for the needs of the Community at the highest level. At the same time, we moved to being a fully 'working from home' organisation requiring innovation in all areas of operation and in particular fundraising as many of our usual events and activities were unable to take place.

In this difficult period it was wonderful when at the end of June last year, it was announced that a deal had been agreed to fund Kaftrio. Initially in England, when as anticipated, it completed its regulatory steps over the summer months. This was quickly followed by similar agreements across all nations of the UK.

The breakthrough in access built on the 2019 announcements about Symkevi and Orkambi was the culmination of years of campaigning by the Cystic Fibrosis Community, which has been reflected in previous Annual Reports. As we now look back on these years we might comment that no group of people dealing with a life limiting condition should have to fight so hard to access life-saving drugs, nevertheless, everyone should feel really proud of what they have achieved. Kaftrio has already made a difference to so many lives but we are very mindful that there is still much more to do.

Over these last few months we have seen an incredibly rapid roll-out of Kaftrio and extensions to its license. This has been more great news, but we still remain focused on the fact that it is not a cure and it's not suitable for everyone with CF. That is why we are fully committed to a diverse and innovative research portfolio that includes projects from basic science, through to treatments.

During the year we have expanded our portfolio of Strategic Research Centres, funded the key Venture and Innovation Awards and promoted the next generation of CF Researchers through a Summer Student Scheme.



**Richard Hunt CBE**

In spite of some inevitable disruption, the Innovation Hub that we co-fund with the University of Cambridge, has continued to make significant progress. It has also been an important year of further development for our Clinical Trails Accelerator Platform, our work in Anti-Microbial Resistance and the use of digital health tools to deliver more effective care. Informing much of our work have been the insights gained from the continued excellence of the UK CF Registry.

The pandemic has meant that, like many organisations, we have needed to find new ways of working, communicating and engaging. What seemed like an initially daunting set of circumstances has actually driven innovation. Indeed, in the particular circumstances of CF and the usual risk of cross infection, many of the new approaches have enabled us to reach more people and to do so in a truly accessible way.

This has also been a period when we have reflected on ensuring that in all our activities we are working to support our whole community and recognising its diversity.

In summary, it is customary to thank people for all they have done over the last year to support the Trust in its efforts to change the lives of people with cystic fibrosis across the UK.

This year thank you seems insufficient to express the depth of gratitude I feel for so many people who have done so much during such a critical period. To my colleagues in the Trust and on behalf of the Board I simply say; thank you. You have worked wonderfully despite all the challenges and changes and with a tremendous spirit!

We therefore end this unprecedented year with energy and determination to deliver our vision of a 'life unlimited' for all those living with cystic fibrosis both now and in the years to come.

*Thank you*

**Richard Hunt CBE**  
Chairman of Trustees

The last year has been a time of exceptional challenge, change and opportunity for the cystic fibrosis community with the impact of the COVID-19 pandemic and the licensing of Kaftrio. It was also the last year of our three-year corporate strategy, prompting us to reflect on what we have achieved and where we will focus as we look to the future.

## 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, and
- the education of the general public about the causes and effects of cystic fibrosis.

## About cystic fibrosis

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. More than 10,600 people in the UK live with the condition and have to undergo a brutal daily regime 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.

---

**According to the 2019 UK Cystic Fibrosis Registry Report, the median age of those who died in 2019 is just 31. The median predicted survival age of people born with CF in the UK today is 49.**

---

## ➔ About us

### Our mission

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited for everyone affected by cystic fibrosis. Our mission is to create a world where being born with CF no longer means carrying a life-long burden; where everyone living with the condition will be able to look forward to a long, healthy life. In 2018 we launched a new three-year Strategic Framework.

We committed to:

- invest in a dynamic portfolio of research and innovation,
- collaborate with and support the clinical community to promote the highest quality of care,
- support access to medicines at every step from laboratory to medicine cabinet,
- provide day-to-day support; and
- seek to reach all people with cystic fibrosis when they need us most.

## ➔ Our vision

We believe that through innovation, empowerment and accelerating the pace of change, we can beat CF for good. A Life Unlimited by cystic fibrosis continues to be our ambition.



## 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.

## ➔ Successes in research

**By working together, we can be stronger and more effective and one of the main areas we achieve this is with our research.**

### Achievements and performance

#### > Strategic Research Centres (SRCs)

Strategic Research Centres (SRCs) are virtual centres of research excellence and are intended to create multidisciplinary teams to address questions of strategic relevance to people with cystic fibrosis. A maximum of £750k is available per SRC, with funding provided over three to four years.

#### Our SRCs aim to:

- create clusters of world-class researchers;
- bring experts from different disciplines together to tackle the complex problems caused by cystic fibrosis;
- widen awareness of CF research by attracting high-quality investigators from different research fields; and
- recruit the brightest and best young researchers into CF research.

Each SRC typically includes funding for five or six early-career researchers who work alongside experts, building a life-long interest in the field of CF research. The centres investigate the big issues affecting people with CF, such as CF-related diabetes, that are too big for smaller projects to tackle. The long-term nature of these centres allows an in-depth exploration of the issues and possible solutions.

Governance for funding for the SRCs at the Trust is overseen by the Strategy Implementation Board (SIB). Applications undergo a rigorous external peer-review process before being considered by the SIB, which recommends the highest-quality applications for funding. We maintain a balanced portfolio of high-quality research activity to address the varied issues associated with living with CF, from diagnosis to all stages of life.

This year, eight highly competitive preliminary applications were submitted at the Expressions of Interest stage in April 2020. Of these, three were progressed to the full application stage.

These applications underwent rigorous external specialist peer review in the autumn period, and the resulting scores and comments from the external peer reviewers and SIB members, as well as the rebuttal from the applicants, were deliberated in detail by the SIB. Following scrutiny of the applications based on the excellence of the science and the strategic relevance of CF, two applications were recommended by the SIB for funding.

The Board of Trustees agreed with these recommendations and agreed to fully fund the highest scoring SRC. In addition, the Board stated a commitment to exploring options for co-funding the second SRC with appropriate partners, which is currently ongoing.

#### > **The CFTR Folding and Function SRC**

**Lead investigator:** Prof David Sheppard, University of Bristol

**Co-investigators:** Prof Ineke Braakman (Utrecht University), Dr Cedric Govaerts (Université Libre de Bruxelles), Dr Isabelle Callebaut (Sorbonne Université)

Excitingly, in this financial year, we have also been able to co-fund a third SRC from the 2019/20 SRC competition in partnership with the Cystic Fibrosis Foundation (CFF) in the United States of America.

#### > **Therapeutic Gene Edition of CFTR**

**Lead investigator:** Dr Stephen Hart, University College London

**Co-investigators:** Prof Deborah Baines (St George's University of London), Dr Paola Bonfanti (The Francis Crick Institute), Dr Patrick Harrison (University College Cork), Prof Isabelle Sermet-Gaudelus (Hôpital Necker Enfants Malades, Paris)

This new Strategic Research Centre aims to understand faulty CFTR to aid in the design and testing of novel therapies to rescue all forms of faulty CFTR, informing the development of innovative treatments for all people with CF including those for whom modulators are not yet available.



A list of currently active SRCs (as of March 2021) can be found below.

SRC	Principal investigator	Institution	Amount	Title
SRC004	Dr Siobhan Carr	Royal Brompton Hospital	747259	Cystic Fibrosis Epidemiological Network (CF-EpiNet) – Harnessing Data to Improve Lives
SRC005	Dr David Sheppard	University of Bristol	749933	The F508del-CFTR SRC
SRC 006	Prof Stephen Hart	University College London	718602	Personalised Engineered Cell Therapies for cystic fibrosis
SRC 007	Prof James Shaw	Newcastle University	750000	The Cystic Fibrosis Related Diabetes Strategic Research Centre (CFRD-SRC)
SRC 008	Prof Craig Williams	University of Exeter	750000	Physical Activity, Exercise, Sport and Recreation Promotion for Adolescents with CF
SRC 009	Prof Michael McDermott	St James' University Hospital	371399	Targeting joint disease in cystic fibrosis: identifying therapeutic targets in CF arthropathy
SRC 010	Professor Andres Floto	MRC Laboratory of Molecular Biology Cambridge Biomedical Campus	749941.02	Novel Therapies for <i>Mycobacterium abscessus</i>
SRC 011	Professor Soraya Shirazi-Beechey	University of Liverpool	749694	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)
SRC 012	Dr Daniel Peckham	St James' University Hospital	750000.61	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis
SRC 013	Dr Mike Gray	Newcastle University	750000	Personalised Therapies for all: Restoring airway function in CF using Alternative Chloride Channels
SRC 014	Prof Jane Davies	Imperial College London	750000	Personalised Approach to <i>Pseudomonas aeruginosa</i> (PAPA)
SRC 015	Dr Darius Armstrong-James	Imperial College London	750000	'TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis'
SRC 016	Prof Pietro Cicuta	University of Cambridge	743852	Mucociliary clearance – from fundamentals to personalised treatment
SRC 017	Dr Martin Welch	University of Cambridge	748538	Gas, food and lodging; understanding the physiological and metabolic requirements of <i>Pseudomonas aeruginosa</i> in the cystic fibrosis airways
SRC 018	Professor Steven Renshaw	University of Sheffield	749214	Preventing Gastrointestinal Cancer in cystic fibrosis
SRC 019	Professor James Shaw	University of Newcastle	750000	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes
SRC 020	Prof Stephen Hart	University College London	740142	Therapeutic gene editing of CFTR

We would like to take this opportunity to thank the members of SIB for their commitment to the Trust and this review process.

### > Venture and Innovation Awards (VIAs)

The Venture Innovation Award (VIA) scheme forms part of our five-year research strategy. By awarding grants to innovative new research projects that leverage funding from external sources, we can allow CF researchers to respond rapidly to new developments, gain additional funds for potentially transformational opportunities and to add value to our investment in research. VIA grants are awarded on a rolling basis by an internal committee that assesses the validity and value of individual projects against an agreed set of criteria.

The awards are contingent on projects undergoing the rigour of the peer review process of the partner organisation.

Due to the impact of the COVID-19 pandemic on the fundraising activities of the Trust, the difficult decision was taken to reduce the amount of budget available to support research projects through the VIA scheme. However, as shown in the table below, we have successfully supported the funding of research projects with a range of funding partners, including the NIHR, industry, research charities and other funders. The investment of £189k in research funding this year from the Trust through the VIA scheme has the potential to leverage an additional £2.48m in research funding for cystic fibrosis.

A list of currently active VIA awards (as of March 2021) can be found on pages 70 to 72



### > Summer Studentships

Seven Summer Studentship grants of £1,500 each were awarded in 2020, with five being funded by the CF Trust and two being funded by the Asthma UK British Lung Foundation Partnership. These studentships provide living expenses for promising undergraduate students to carry out a research project over their summer academic break. In addition, the students are required to attend the UKCFC or a related conference and present their work in poster form.

Due to national COVID-19 lockdowns and labs being inaccessible over summer 2020, four of these studentships have been deferred until 2021, with the invitations left open for them to attend the next in-person research conference.

The Trust 2020/21 awarded studentships are detailed on page 74.

### > CF Syndicate in AMR

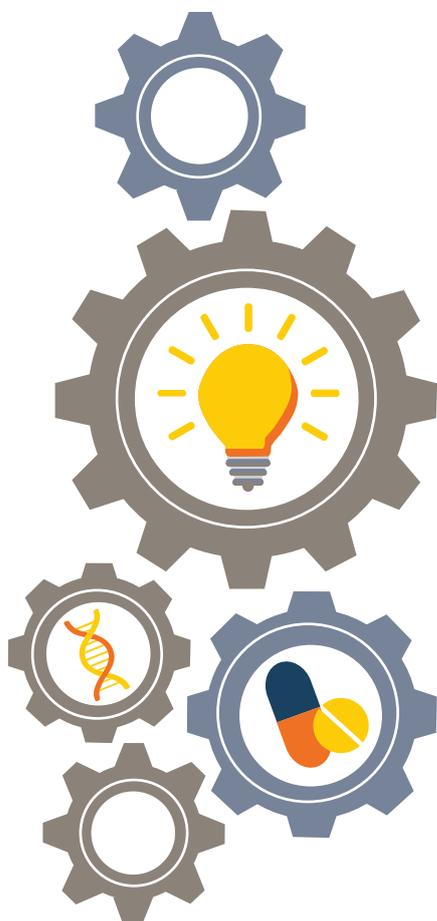
Antimicrobial resistance (AMR) is a growing concern, particularly for people with CF who frequently suffer from antibiotic failure. The NHS and the UK Government have highlighted AMR as an urgent priority. The Trust has partnered with the Medicines Discovery Catapult (MDC) to create the CF Syndicate in AMR, which was launched in September 2019.

The aim of the Syndicate is to accelerate the translation of novel antimicrobials to the clinic. To do this, the current aims of the Syndicate are to:

1. Streamline and enable access to clinically relevant samples for the preclinical screening and testing of CF antimicrobials.
2. Map and validate the preclinical screening and testing pathways to provide faster routes of bringing CF antimicrobials to the clinic.
3. Develop guidance for industry on the key characteristics and requirements that CF antimicrobials should meet in order to address the needs and priorities of people with CF, through the development of Target Product Profiles.

**In the past year, the Syndicate has made significant progress and has successfully:**

- engaged widely with the UK CF infection research community in academia and industry;
- established a Steering Committee of committed experts from academia, the clinic, industry and people with CF;
- developed a robust research agenda, aligned to the key challenges above identified in CF antimicrobial discovery;
- started to develop a 'toolkit' of enabling resources to address these challenges via collaborative research programmes, which includes developing a guidance document on strains to use for CF antimicrobial testing, a virtual biorepository of clinically relevant samples for CF AMR research and a set of patient-focused TPPs; and
- engaged with other potential funders to explore funding opportunities required to deliver these resources and support further development of the Syndicate.



**>Innovation Hub**

The UK Cystic Fibrosis Innovation Hub, based at Cambridge University, is a ground-breaking partnership between the Cystic Fibrosis Trust and the University of Cambridge. Launched in 2018, its aim is to harness multidisciplinary world-class research to accelerate progress towards preventing lung damage and the subsequent loss of lung function in people with CF. The Trust aims to raise £5 million over five years for the Innovation Hub, which the University of Cambridge has already committed to matching pound for pound.

The Innovation Hub was established in 2018 and significant progress has been made during the 1st phase of the Hub (Feb 2018 – March 2021) against three key challenges which are summarised below.

**Antibiotic and anti-inflammatory drug**

**discovery:** This workstream aims to develop new antibiotics and anti-inflammatory drugs, as well as novel methods that could be used to accelerate drug discovery by industrial and academic researchers around the world.

- Novel antibiotic compounds have been developed that have activity against *M. abscessus* in vitro.
- New AI-based methods have been developed to rapidly develop antibiotics to potentially work against any bacteria, which could have a major impact on efforts to combat AMR globally.
- Key genes responsible for, and involved in, mycobacteria evolution and *M. abscessus* virulence have been identified, and the data published in the leading journal '[Science](#)'.
- It has been shown that immune cells from people with CF behave differently, both as a direct result of CFTR dysfunction and because of genetic scarring due to chronic inflammation.

### >Cellular therapy

This workstream aims to develop new stem cell therapies that could eventually be used to regenerate lungs damaged by CF with a person's own cells.

- Methods have been developed to create epithelial cells (the cells that line the airways in the lungs) and ionocytes (the cells with the most CFTR protein in them that seem to regulate the amount of liquid produced in the airways) from blood-derived stem cells.
- It has been shown that these cells can be introduced into a mouse, and can find areas of damaged lung and survive long term, paving the way for eventual cellular therapy in CF patients.

### >Machine learning approaches to personalised medicine

Bringing together the rich data available from the home monitoring programmes (SmartcareCF, Project Breathe) and from National patient registries (in the UK, US and Canada), the aim of this workstream is to develop machine learning (ML) and artificial intelligence (AI) methods to predict when people with CF may become ill, and to help forecast their future health trajectories.

- Machine learning methods have been developed to predict the onset of clinical deterioration (pulmonary exacerbations) in adults with CF using home monitoring data.
- UK CF Registry data was successfully employed to develop new ML methods to predict the individual clinical trajectory of individuals with CF using interpretable deep-learning approaches.



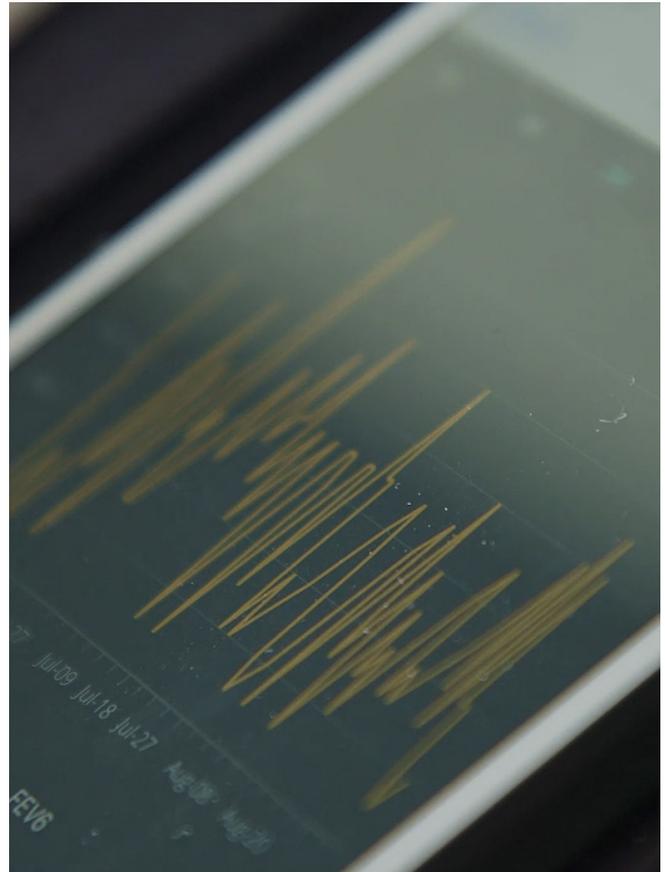
### > Digital health research programme

The digital health research programme, 'Personalised Medicine: development of novel clinical decision-making tools', is a three-year programme of work funded by a £2.5 million grant from the Cystic Fibrosis Foundation (CFF) that started 1 October 2019. The programme seeks to explore the application of advanced data analytics to the understanding and management of people with CF, with the aim of gathering evidence to safely deliver Personalised Medicine. Two separate but complementary approaches are being pursued.

The first approach, Project Breathe, addresses the current standards of care which require all people with CF to attend their CF Centre on a regular basis, regardless of their need. The aim is to use home-based remote monitoring using Bluetooth devices combined with machine learning to redesign the clinical care packages and move away from the current 'one size fits all' approach to one where the clinic focusses on the needs of the individual at the optimal time for that individual's health. As a first step, home-based remote monitoring is being developed to provide the evidence that a routine clinic outpatient appointment is not necessarily needed.

The aim of the first year of Project Breathe was to build on the successful SmartCareCF study, which used frequent home-based measurements and supervised machine learning to identify pulmonary exacerbations, with the recruitment of patients to the project at one UK site, Royal Papworth Hospital. Interim analysis of the Papworth data at six months indicated that the home-based data resulted in a safe reduction of what would have been 'routine' outpatient visits by at least 50%; saving the individual time and cost of travel, lost time from work or education and avoidance of exposure to cross-infection risk. The feedback from users, (i.e. adults taking part in the study and specialist MDT using the data display dashboard) has enabled significant and ongoing improvements to be made to the app to improve its use.

Given the encouragingly positive results at this interim analysis stage, the project team sought permission from the CFF to accelerate the rollout of the research study to an additional three UK sites (Edinburgh, Glasgow and Cardiff). Set-up of this research study is also ongoing at sites in Canada.



The augmented intelligence approach to exploring in-depth analysis of CF registries is the second approach to Personalised Medicine. The team at the Alan Turing Institute, led by Professor Mihaela van der Schaar, have been analysing data focused on:

- predicting individual clinical trajectories using deep-learning and AI approaches to help predict future changes in health and response to medications, as well as potentially identifying subgroups of individuals who may be at greater risk of developing certain CF-related complications; and
- developing AI-based hypothesis testing methods to allow more accurate analysis of noisy or incomplete clinical metadata to better enable comparisons between and within groups of individuals. For example, this has allowed the team to start to accurately determine individual effect sizes for medications (such as ivacaftor) and understand determinants/predictors of response.

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

The global pandemic (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.

The Trust coordinated international projects to understand the impact infection with Covid-19 would have on people with CF and together with the CFMA, provided regular updates to our community.

One area of focus was on remote monitoring where the Trust lobbied successfully for equipment to be provided which subsequently accelerated the next phase of our own digital health project to widen access.

The Trust, in partnership with the CFMA, ensured a rapid rollout of highly effective modulators for those who would benefit from them.

We are involved in the NHSE review of specialist CF care and will ensure people with CF are involved in the process, and that discussions are informed by accurate data and information.

The Trust has supported the formation and work of the UKCFMA throughout the year, supporting the establishment of a lung transplant working group, hosting their Annual General Meeting at the UK CF Conference, and organising meetings at European Cystic Fibrosis Society (ECFS), the North American CF Conference (NACFC), and their own annual event. We have also co-produced and collaborated with the UKCFMA on policy work and information about COVID-19. We have encouraged the collaboration of the UKCFMA with leads of the other allied health professional groups. Our Clinical Advisory Group (CAG) now consists of the chairs of all the clinician groups and four new representatives of people with CF and parents, including the chair of the UKCFMA.



## The impact of Kaftrio on the CF Community

2020 saw a landmark deal for access to Kaftrio in England which was announced amidst the COVID-19 pandemic.

A collaboration between NHS England and Vertex resulted in a commercial agreement for access to Kaftrio, the first triple combination therapy for the treatment of cystic fibrosis (CF). This ground-breaking deal marked a significant and exciting moment for thousands of people living with CF. The deal subsequently led to further agreements for access to Kaftrio across the rest of the UK in Wales, Northern Ireland, Scotland, and the Crown Dependencies.

Kaftrio is a modulator therapy currently licensed for use in the UK for those age 12 and over with at least one copy of the F508del mutation. It has helped to transform the lives of many by treating the underlying cause of the condition. The deal meant that many more thousands of people with CF who had been unable to benefit from previous modulator therapies including Kalydeco, Orkambi and Symkevi could finally access these treatments for the very first time on the NHS.

The breakthrough followed years of relentless campaigning alongside the CF community, supporters, and parliamentarians to fight for access to new medicines, that included parliamentary debates, protests, and a health committee inquiry.

Clinical trial data show that many people taking Kaftrio will have improvements in gastrointestinal (GI) issues and overall quality of life. Further studies are underway to better understand the long-term effects Kaftrio will have on the overall health of people with CF, including infections, inflammation, mucus clearance, GI health, blood sugar, growth, and liver function.



For Lucy Baxter who has CF, having access to Kaftrio has been life changing. She reflects on the moment she found out she heard about the Kaftrio agreement and how this has positively impacted her life. She recalls:

"When I found out the Kaftrio deal was announced, I saw it on Facebook in my room and started crying. I rushed downstairs and told my mum and we both hugged and cried together. It was a life changing moment and it made me feel that my future was secured. One year on, I am still so thankful and don't take it for granted how lucky I am to be able to have this treatment. I feel so much better and healthier."

Whilst Kaftrio is not suitable for everyone, the Trust continues to commit to finding a treatment for those who are not able to take advantage of it. Chief Executive David Ramsden says:

"We re-commit to doing all we can to ensure that everyone who can benefit from Kaftrio gets rapid access to it and that we will continue to invest in research to find treatments for those who can't. We will not stop."

The Trust will continue to invest money into dedicated research with the goal of finding treatments for all to ensure that no one is left behind.

## Impact of Covid-19

The impact of COVID-19 on the CF community cannot be overstated; from the initial guidance to commence shielding, the impact of the pandemic on routine clinical care, work/employment rights, the financial burden, through to the effectiveness of vaccines on those post-transplant, the Trust has worked tirelessly to provide timely information and support to those with CF and their families.

### >Shielding

People with CF were identified as extremely vulnerable to COVID-19 by the Government and instructed to shield immediately. The shielding process was initially set for 12 weeks, but as the crisis unfolded, measures remained in place for over four months. As a result, people with CF struggled to access essentials such as food and exercise, which are crucial necessities to manage their condition and stay healthy.

The demand for our services rocketed at an unprecedented rate at a time when we ourselves were facing a substantial drop in our fundraising income due to cancellations of many of our key fundraising events. Whilst the advice to shield has been removed, there are, understandably, concerns around the increasing number of cases, emerging variants and further lifting of restrictions.

### >Emergency grants

In response to increased applications for financial assistance, the Trust launched our emergency appeal in Spring 2020.. Our emergency exercise grants enabled people with CF to continue to exercise despite being advised not to leave the house . The increase in demand was driven by the economic hardship caused by the pandemic with most of our grants going to very low-income households: of those who provided data, over 50% of our grants between April and September 2020 (Q1-2) went to households with an income of less than £15,000 per annum.

Thanks to the emergency support of our donors, in our 20/21 financial year, we gave a total of 982 emergency grants, including our COVID emergency exercise grants, at a total cost of £165,723.44, more than double the value of emergency grants in the year before. A huge proportion of these grants—around 80%—were provided between April and September 2020 (Q1-2) when families were most impacted by the pandemic. In Q1 of 20/21 we gave over £100,000 more in emergency grants than in Q1 of 19/20 (up from £12,000 to £120,000). Our emergency grants provide a lifeline for families by supporting them through periods of financial stress and avoiding the spiral into longer-term financial difficulties.

### >Coronavirus Hub

Over the past year, the Trust received a total of 822 Helpline enquiries relating to COVID-19 and provided regular updates through a dedicated 'Coronavirus Hub' on our website and via our social media accounts. This online information became a key information source with the Hub: our broad Q&A content received over 100,000 visits at its peak; our shielding advice pages received over 35,000 views; our Welfare FAQs received almost 20,000 views; and at the peak of the pandemic, our section on our collaboration with the UKCFMA received over 50,000 views.



### >Registry

Although the Government identified people with CF as extremely clinically vulnerable to COVID-19, we entered the pandemic with very little clinical evidence into how COVID-19 would impact a person with cystic fibrosis. Our UK CF Registry team immediately began working closely with global clinical teams to monitor COVID-19 in people with CF across the UK, collecting unique data and updating the information every two weeks. To date, among the 331 people with CF have been reported as having COVID-19, none were receiving in-patient treatment as of the end of March 2021. Sadly, two adults with CF died of complications related to the virus. Whilst the numbers are too low to draw conclusions about the risk factors or outcomes associated with COVID-19, we remain at the forefront of monitoring the impact of COVID-19 in people with cystic fibrosis. We continue to collaborate globally to learn as much as possible and enable us to use the data to support the CF community and their clinical teams.

## Campaigning hard

During 2020, the Trust successfully advocated for people with CF to be prioritised for the COVID-19 vaccine and for effective communications and rollout of the programme. We undertook this activity in parallel with a successful breakthrough in the access to medicines campaign to secure UK-wide access to the latest CF modulator therapy Kaftrio. We have continued to push for a timely and expansive roll out of the new drug to those eligible and continue to call for expanded and equitable access for all who will stand to benefit.

Since the start of the COVID-19 pandemic we have worked to ensure appropriate support for the shielding population across the four nations of the UK, with a particular focus on access to financial support, food and essential services, support for education and employment. As well as advocating for clear and timely communications from the government, particularly around shielding guidance, we also worked to interpret and share the latest guidance with the community. Close liaison with key bodies like the NHS, Department of Health and Social Care and the Deputy Chief Medical Officer ensured that we had the most up-to-date information and enabled us to raise the concerns of the CF community directly with policy makers.

---

**We raised multiple COVID-19 campaign priorities with parliamentary champions in Westminster and the devolved assemblies, met with parliamentarians virtually, attended nine all party parliamentary groups (APPGs) and briefed parliamentarians ahead of debates.**

---

We also drafted and tabled 47 parliamentary questions across the four nations in the UK via our parliamentary champions on issues such as kaftrio, prescriptions charges, shielding support and vaccine priority. The Trust wrote over 20 letters to the NHS, supermarkets, the JCVI and the Vaccines Minister. As a result, home spirometers were provided to over 4,000 people with CF to monitor their condition in the safety of their own home during the pandemic. We secured improved priority access to supermarket deliveries for those that were shielding, and the JCVI made a significant revision to move those who were most clinically extremely vulnerable higher up the Covid-19 vaccine priority list, resulting in faster access to the jab for adults with cystic fibrosis.



## Clinical Fellowships

We have continued to support the recruitment and training of young doctors with our Clinical Fellowship Programme. This programme is more popular than ever, and we are confident that it will continue to enable future CF centre directors and consultants to gain valuable CF-specific training and experience.

## Data and quality improvement

The UK CF Registry is a world-class database that includes data on over 99% of people with CF in the UK who have consented to their data being submitted by their CF team. This year saw two new drug safety studies opening, alongside a further two continuing to run, generating over £1.1 million in income. A significant proportion of these funds was used as grants to support centres in their data entry to the Registry.

More information about how we use Registry data to keep medicines safe can be found at [cysticfibrosis.org.uk/registry](https://cysticfibrosis.org.uk/registry).

The Registry received a further £160,000 from NHS contracts for generating public reports and supporting the commissioning of CF services in England.

Anonymised Registry data supports research, service improvement and information materials. In 2020/21, the Registry approved 41 requests for data, bringing the total up to 413.

---

**The UK CF Registry is playing a pivotal role in evaluating the effect of Orkambi, Symkevi and Kaftrio following interim access agreements across the UK.**

---

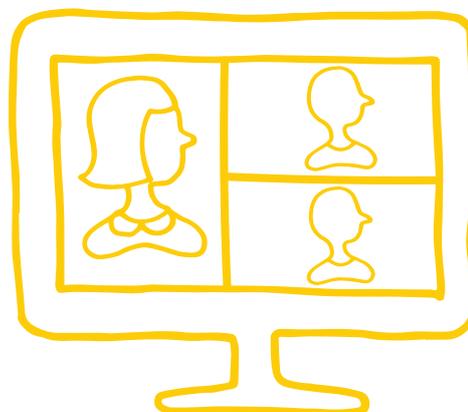
The Registry is supporting an observational study of Orkambi, Symkevi and Kaftrio to satisfy the Vertex Data Collection Agreements with NHS England and NHS Improvement. Data analysis will cover the whole of the UK and be made available to regulators in Scotland, Wales and Northern Ireland.

This includes sufficient funding to boost the Trust's Registry Support Grant programme and enable CF centres that choose to opt in to enter three 'encounters' (records of height, weight and lung function) throughout the year, enabling a more robust analysis of the impact on rate of change in lung function due to these new medicines. You can read more about the study here: [cysticfibrosis.org.uk/news/the-latest-on-interim-access](https://cysticfibrosis.org.uk/news/the-latest-on-interim-access)

The UK CF Registry team, having set up real-time reporting mechanisms for COVID-19 in March 2020, has continued to regularly report to people with CF and their families as well as the UKCFMA during 2020/21. Reporting on COVID-19 and vaccination is now fully embedded within the UK CF Registry system and we were the first Registry in the world to adapt data collection processes to gather important data on COVID-19. The UK CF Registry is at the forefront of international collaborative efforts to monitor COVID-19 within the CF community and ensure rapid publications to support future care.

### >Registry Annual Meeting

In response to COVID-19, the Registry Annual Meeting in 2020 was converted to a virtual event, with a series of videos released over the course of the summer providing updates about the Registry, data entry guidance and important information on the pandemic.



## ➤ Annual data report

The UK CF Registry annual data report on 2019 data was published in August 2020. An accessible 'at-a-glance' summary of infographics highlighting the main trends for that period was also published, helping people with CF and their families to understand the data contained in the report.

We submitted anonymised 2018 data to the European CF Society Patient Registry, which published its reports here: [www.ecfs.eu/projects/ecfs-patient-registry](http://www.ecfs.eu/projects/ecfs-patient-registry)

## ➤ Supporting access to medicines at every step from laboratory to medicine cabinet

Clinical trials are the bedrock of translational research and are an essential element in ensuring new therapies are rapidly and safely translated to clinical use to transform the lives of people with cystic fibrosis. The aim of the Cystic Fibrosis Trust is to ensure that all people with cystic fibrosis can obtain access to new treatments as quickly as possible.

## Clinical Trials Accelerator Platform

CTAP has continued to expand and develop over the last year, utilising the additional £2.1 million in funding provided by the CFF in 2019. The impact of COVID-19 has been significant, affecting trial activity at the centres as well as delaying some of the CTAP initiatives, but we have still seen substantial impact and progress in the four CTAP workstreams detailed below:

### ➤ National collaborations

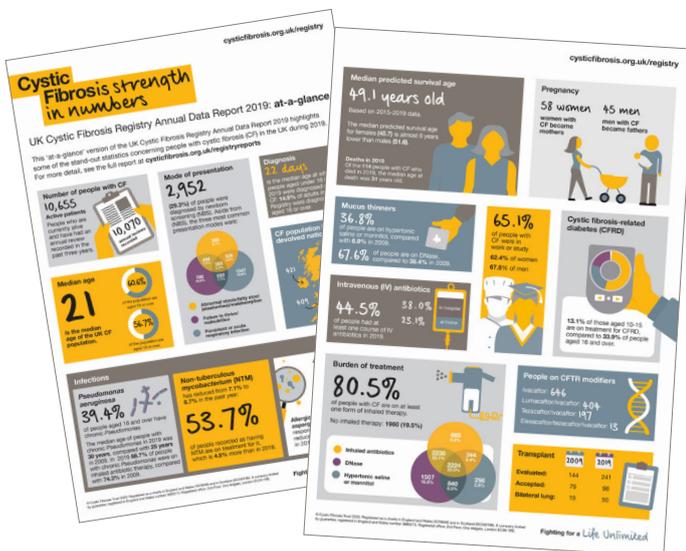
This year we became formal partners of Health Data Research UK's 'Project Breathe' programme, designed to bring together 100 respiratory datasets for research use in a secure anonymised research environment. With this partnership we have secured funding to link UK CF Registry data to NHS health information, which will be made available to answer vital questions about CF towards the end of 2021.

### ➤ Network of CTAP centres

The current CTAP network consists of 27 centres, providing infrastructure to support sponsors with the delivery of CF clinical trials, and the platform to enable the CF community to gain timely access to these trials.

- 18 CTAP centres are funded with a CTAP Trial Coordinator.
- The remaining nine CTAP affiliate centres are formal members of the network and represented to sponsors as recruitment / referral centres, but they are not funded with a CTAP Trial Coordinator
- Collectively the network of centres cover up to ~89% of the UK CF community.
- Six CTAP centres have been awarded an additional early phase trial coordinator grant to support early phase CF trials.

The first site annual metrics reports was sent out to centres in the past year summarising site performance, and progress meetings were held with each centre to review these metrics and discuss future plans.



## ➤ Quality improvement

In 2020, the Quality Improvement (QI) Team published its first national report on Staffing levels in CF care across the whole of the UK. They also finished data collection for national surveys of Patient Reported Experience Measures (PREMs) in both adult and paediatric care, receiving over 1,500 responses. The reports will be published in 2021/22.

The team also set up the Quality Improvement Working Group, designed to guide development of our QI strategy and ensure maximum impact of the reports we generate. You can read more about the work of the QI team here:

[cysticfibrosis.org.uk/qualityimprovement](http://cysticfibrosis.org.uk/qualityimprovement)



### >Membership renewal

In January 2021, the network completed its first CTAP Centre Membership Renewal Scheme. The scheme aims to support the CTAP in recognising performance, commitment and contribution from the CTAP centres, identifying centres that may require additional support and ensuring only high-quality centres are retained in the network.

As part of the renewal process, sites were asked to summarise their experience of the CTAP programme, to which we received some very positive feedback:

**“Our experience since joining the CTAP programme has been rewarding, successful on many levels and, most importantly, life changing for the patients who have been able to participate through their individual research journeys. The engagement and collaborations we have experienced through CTAP has enhanced our study capabilities and enabled us to prioritise the delivery of life transforming clinical trials within our institution. We have developed infrastructure and streamlined our approach to feasibility which has further improved our efficiency in trial set up”.**

**“Our experience of being part of the CTAP programme has been overwhelmingly positive. We have recruited fully to all trials from phase I-III for both our adult and paediatric departments, which would not have been possible without a funded Trials Coordinator and the opportunities that CTAP provides. The peer support and collaboration throughout the programme has been fantastic and we have valued all opportunities, guidance and collaboration which have been made possible through CTAP. Prior to CTAP we were research active, but CTAP has given us resilience, sustainability and improved our capacity for trials metrics data and site intelligence.”**

### >Early Phase Coordinator Pilot

The CTAP is currently rolling out a two-year Early Phase Trial Coordinator pilot. Six Early Phase Trial Coordinators will support delivery of phase 1 and 2 CF trials at six CTAP centres. The specialist team of coordinators will collaborate with each other and the wider team of CTAP coordinators to provide the CF community access to important clinical trial opportunities. Six CTAP centres experienced in delivering phase 1 trials were competitively selected to receive funding for an Early Phase Trial Coordinator and recruitment to these posts is now underway.



### >Impact of CTAP

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

- **871** people with cystic fibrosis have screened for a clinical trial within the CTAP network since CTAPs launch 3.5 years ago (246 of these screenings took place in the last 12 months);
- **726** people with cystic fibrosis (358 children, 368 adults) have enrolled on to CTAP clinical trial since CTAPs launch 3.5 years ago (224 of these enrolments took place in the last 12 months);
- **56%** of the 224 patients enrolled last year were for rollover studies i.e. patients were already on a study and moved over to an open label extension study. 26% of the enrolment was for a paediatric registry study that was able to continue as normal through the pandemic; and
- On average a CTAP centre has been involved in eight CF studies since CTAP started (range = 0 – 23).

### >Lung Clearance Index

The CTAP Lung Clearance Index (LCI) training package provides opportunities for up to two members of staff from each CTAP centre / affiliate centre to become LCI qualified. The package also enabled CTAP to purchase six (reconditioned) LCI machines to support the initial certification of staff, and in the longer-term to be loaned free of charge to CTAP centres for clinical trial use.

Despite initial delays to the roll out of the CTAP LCI training package (due to the pandemic), progress of the training package is going well:

- The format of the training changed in response to the pandemic, with the two-day in-person workshop replaced with a series of e-modules and a webinar.
- 19 professionals from 13 CTAP centres have completed the e-modules, six professionals from one CTAP centre and three affiliate centres are in the process of completing the e-modules.
- 22 professionals have attended at least one of the webinars so far.
- We anticipate six professionals will be certified by June 2021, with a further six certified by September 2021. We anticipate the remaining staff will be fully certified by February 2022.

### >Engagement with sponsors

The CTAP aims to support sponsors (pharmaceutical companies and academic institutes) with the design, feasibility, set-up and delivery of CF clinical trials.

Engagement with sponsors has significantly increased over the last year, reflecting not only the growing CF drug pipeline, but the increasing recognition of the clinical trial infrastructure and resource CTAP has embedded in the UK.

The CTAP Feasibility Service helps sponsors ensure the best-placed centres are selected for trial delivery and has been utilised for a total of 20 clinical trials, six of which were during this financial year. A total of 34 CF trials have been open for recruitment in the CTAP network, 7 over the course of the year.

### >Community involvement

Over 50 CF Trial Ambassadors (people with CF and those that support people with CF, including parents, grandparents and partners) form our CTAP Community involvement group (previously known as Patient & Public Involvement (PPI) Group). It is through these groups that CTAP has created a platform for the CF community to directly engage with sponsors and give meaningful and robust feedback about trial design, from the conceptual stage onwards.

This workstream gives the CF community a voice to communicate with sponsors, making future clinical trials less burdensome on participants, resulting in better recruitment and retention rates. Awareness and recognition of the CTAP's PPI groups has grown over the last year, leading to increased activity. The PPI network of CF Ambassadors has supported a total of 48 different projects with sponsors, helping to shape the design of clinical trials and ensuring they meet the needs of the UK CF community.





**12,000+** visits to the online clinical trials hub since launch in September 2017.

The clinical trials hub provides a wealth of information about clinical trials and what they entail, as well as stories from those that have taken part.

### >Clinical Trials Digital Hub

We have created a Clinical Trials Digital Hub to engage and educate the CF community about clinical trials. See [cysticfibrosis.org.uk/get-involved/clinical-trials](https://cysticfibrosis.org.uk/get-involved/clinical-trials)

---

**Since launching in September 2017, the Hub has been visited over 12,000 times with >2,500 visits in the past year. The Trials Tracker database has been visited 17,000 times, with over 1,000 visits in the last year.**

---

These statistics demonstrate the Trust has been successful in its ambition to establish the Hub as an important place of information for those wishing to find out more about taking part in CF trials.

The programme makes an important contribution to the Trust's campaign for access to life-saving drugs, providing the infrastructure and information to enable the UK CF community to gain the earliest possible access to the newest 'breakthrough' CF medicines being developed by pharmaceutical companies around the world.

### >Core outcome sets

A core outcome set (COS) is an agreed standardised set of outcomes that should be measured and reported in all clinical trials within a specific disease area. Currently there is not an up-to-date, universally recognised COS for CF clinical trials. Development of a CF COS will allow for easy and robust comparison between studies. It will also be instrumental in ensuring CF clinical trials are as meaningful and patient-centred to the CF community as possible.

As well as the CF clinical and patient community, we anticipate both regulators and sponsors will be enthusiastic to adopt a COS for CF, especially one led by the patient community from the conception stage onwards.

The CTAP Involvement team will lead on the community involvement element of developing a CF patient-led COS. The CTAP Coordinating Team will support the project team in securing stakeholder buy-in from sponsors, in collaboration with ECFS-CTN. This project will be subject to funding (NIHR funding application is pending).

### >Youth Involvement Group

Young people's involvement in research is often limited to their parents' feedback. The CTAP Involvement Team wish to provide a platform for young people with CF (12+ years old) to ensure their views and experiences are represented within the research community, and are therefore working to establish a CTAP Youth Involvement Group (YIG). The longer-term ambition of the YIG will be to create a channel to discuss, review and communicate to the research community what young people's research priorities are.

### >Trial Results Reporting

The CTAP annual community survey highlighted that trial participants were not kept aware of trial results after the study had completed, and even if they were, the language would be difficult to understand. This is an area that the CTAP is focused on resolving. We are planning to update the trials tracker to capture all trial results in a lay-friendly language. We will be working with sponsors and the community to develop a robust and timely process so that participants can be well informed of trial outcomes.



**20,000+**  
visits to the online  
Trials Tracker since  
launch in  
September 2017.

The [Trials Tracker](#)  
details all CF  
clinical trials that  
are open  
in the UK.

### >CTAP remit expansion

Although the primary priority of CTAP is to support interventional clinical trials, the CTAP governance board has agreed to extend the remit of CTAP to include a wider breadth of CF studies (see below). This will ensure CTAP is adapting to the fast-changing clinical trials landscape, that there are enough trials in the CTAP portfolio to sustain the large number of network centres and ensure CTAP supports CF studies which are of national priority to the CF clinical, research and patient community.

#### Overview of CTAP's expanded trial remit:

- Interventional clinical trials (medication and non-medication interventions) – commercial and academic
- Real-World Evidence (RWE) studies
- Non-interventional academic studies which are multi-centred and competitively funded CF studies considered to be of national priority or urgency (assessed on a case-by-case basis)

### ➔ Providing day-to-day support; and seeking to reach all people with cystic fibrosis when they need us most.

The last year has demonstrated the critical importance of the day to day support services that we provide to people affected by CF. We saw dramatic increases in people looking for information, advice and support and adapted our provision to meet that need.

The Trust has provided multiple evidence submissions to parliamentary and government inquiries and responded to 23 consultations, including government and NHS England inquiries, to ensure the voice of the cystic fibrosis community was heard clearly by policymakers.

### Day to day support

- 47 CF related Parliamentary questions (PQs) UK wide.
- 30 PQs in England
- Six PQs in NI
- Six PQs in Wales
- Five PQs in Scotland
- 23 policy consultation responses submitted.
- Nine All Party Parliamentary Groups (APPGs)
- Our monthly campaigner newsletter was sent to over 1,500 campaigners.
- Our parliamentary newsletter was sent quarterly to over 240 parliamentarians.
- 20 letters sent to external stakeholders on a range of issues.
- Access to over 4,000 home spirometry monitoring devices



### >Welfare Grants

Last year, we provided over 1,393 welfare grants, totalling £263,000, providing immediate financial support to those in urgent need, as well as providing access to goods and services to promote long-term health and quality of life. We rapidly altered our grant programme in response to COVID-19, pausing our holiday grants but introducing an exercise equipment grant to ensure people with CF could exercise safely at home whilst they adhered to shielding advice which advised against leaving home at all. Our emergency grant programme ensured we could provide immediate help for those struggling to afford food and basic essentials when they had suddenly lost income due to the pandemic, ensuring that their health was protected.



---

**In addition, we were able to provide £26,000 in homecare grants to support people who are experiencing particularly poor health or a personal crisis so that they can be safe and comfortable at home.**

---

We spent over £43,000 on education grants, awarded by the Joseph Levy Education Fund, to support young people with CF into higher education or vocational training, ultimately supporting them to pursue their career goals.

### >Benefits advice

Our Welfare and Rights Advice service provides invaluable dedicated benefits advice. This year, our specialist adviser has supported 314 people in navigating the benefits service. In addition, our new Income Maximisation Service has supported 99 people, and those supported through this service have been able to increase their household income by over £3,800 on average, providing vital income to help with the additional costs of living with cystic fibrosis.

---

**In 2020/21, the Cystic Fibrosis Trust helped people to access at least £1.6 million in benefits.**

---

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

### >Information

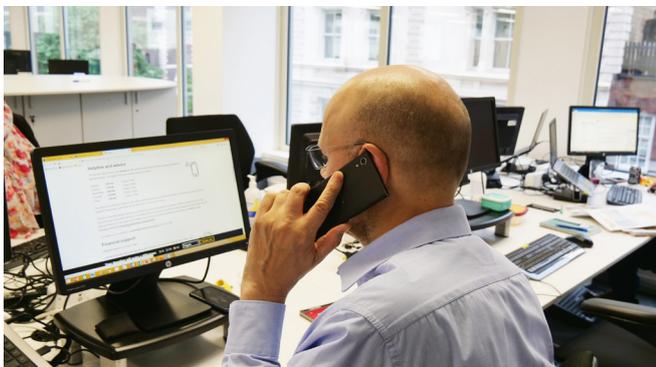
We built on our extensive information library, publishing several new information resources. We added new factsheets on physiotherapy and nutrition, developed in collaboration with specialist CF clinicians. We launched a resource on the emotional impact of Kaftrio, working with psychologists to acknowledge the varying feelings across the CF community. We developed a significant suite of resources on transition to adult care, co-produced with young people with CF and their parents.

We also published new resources on clinical trials aimed at children and teenagers, including a 'Junior Agents' comic for younger audiences. We launched 'My CF Planner', an individual healthcare plan for secondary school students, and developed new information on bowel cancer in cystic fibrosis. Finally, we published detailed new guidelines setting out best practice in physiotherapy treatment for CF teams. We're grateful to the people with cystic fibrosis and their families, as well as the expert CF clinicians, who helped us develop these resources.



### >Helpline

This financial year, our Helpline responded to over 4,400 enquiries from people affected by CF, making it our busiest year ever, providing information, support and a listening ear on a wide range of topics. Over 800 of these queries related to COVID-19, and the helpline team played a critical role in ensuring the CF community could access the information and support they needed at a particularly challenging time. Around 63% of enquiries were received by email, 31% came by phone and a further 5% came via social media. This year we expanded our helpline team, enabling us to explore new channels and promote the helpline more widely.



### >Youth programme

Adolescence can be a period of vulnerability for those with CF, both in terms of physical health and emotional wellbeing. This year, young people also had the challenge of Covid-19 to contend with. We quickly adapted our youth programme, increasing the number of events on offer to create more opportunities for young people to come together, have fun and get active, therefore providing a distraction from the anxieties and isolation of the pandemic.

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. Two YAG-led projects were shared via the Trust's youth social media channels, providing a platform for young people with CF to share their achievements and talk about the issues that matter to them. We also secured a further three years of funding from BBC Children in Need for Building Brighter Futures, our programme of online events for children with CF and their siblings. We increased the number of events we ran to meet increased demand during the pandemic, offering fun new activities, such as juggling, as well as old favourites such as games and movie nights, and opportunities for children to get active. For the first time, we opened these events up to children under 10 to meet emerging demand. We also ran two new six-week workshops on stand-up comedy and creative writing which received very positive feedback.

### Reaching all people

#### >Effectively engaging with our community and the public

Our work relies on the generosity of our supporters—those directly affected by cystic fibrosis as well as the general public. In a year dominated by COVID-19 and Kaftrio, it has been even important that we are relevant and responsive to the diverse needs of the CF community. Through our media work we raise awareness of cystic fibrosis as well as the Trust's aims, ambitions and key campaigns.

---

**This year, we secured 275 pieces of news coverage, achieving a broadcast reach of 4.1m people and print media reach of 4.8m people. These figures include all areas of the Trust's work, ranging from our Christmas campaign, our new fundraising initiative – FeBREWary and our extensive media coverage in response to the coronavirus pandemic.**

---

Highlights included our Christmas campaign, where we achieved our highest broadcast reach when our celebrity ambassador, Jenny Agutter, was interviewed on 'This Morning' and BBC Breakfast to promote our annual Christmas fundraiser, Carols by Candlelight.

Our responses to the news that the lifesaving drug Kaftrio, had been made available on the NHS achieved our widest-reaching print coverage in the Guardian and Daily Mail. In December, we also secured a celebratory piece on the benefits of Kaftrio in the Observer, featuring an interview with Dr Keith Brownlee on the success of this deal.

## >Events

We held a series of regular online information events called 'CF LIVE'. The events took place monthly and were themed to support issues and concerns facing the CF community, as well as to provide Trust updates and information. We ran nine events between July 2020 and February 2021, covering Kaftrio, returning to school, the importance of data, work and money, antimicrobial resistance research, clinical trials, physiotherapy and exercise, involvement, and a Christmas party for the community. Over 800 people attended these events live, with over 3,500 views on YouTube post-event. CF LIVE will return with another series of interactive events in 2021/22.



During CF week, we also ran the Big Yellow Party on Wear Yellow Day, which saw over 100 families joining in. The party finished off a fantastic CF Week and featured a range of performers, including those with cystic fibrosis.



## >Social media

Our social media channels are a key way we engage with our community and showcase our work— from campaigning to fundraising. We also listen and respond to the needs of our community via social media, providing the information and support people need.

Since the start of the coronavirus pandemic, social media has increasingly become an avenue for people turning to us for help and information when they need it most; during this year we saw a 150% increase in incoming messages, with many choosing to direct message us, seeking urgent advice on a range of health and welfare issues. Over the last year we put out over 2.5K posts relating to coronavirus, which were seen over 14 million times.



Our social media presence is a key interaction point with the most engaged members of our community, and is a critical means to update and mobilise them. For many people eager to fundraise for us, it offers an important space for celebrating CF Week and bringing Wear Yellow Day to life.

When this year saw the access to medicines campaign result in a deal for Kaftrio across the UK, our breaking news posts alone reached over 681.5 thousand people

Along with our forum, our social media channels provide valuable insight into the types of things people with CF are talking about, ensuring we keep in sync with their needs and remain relevant.

---

During this year, we saw growth across all of our social media channels (Facebook 2%; Twitter 7%; LinkedIn 12%), particularly Instagram (29%), and an increase in engagement across all channels (325%) which is enabling us to reach an increasing diverse audience, including younger audiences and older people with cystic fibrosis.

---

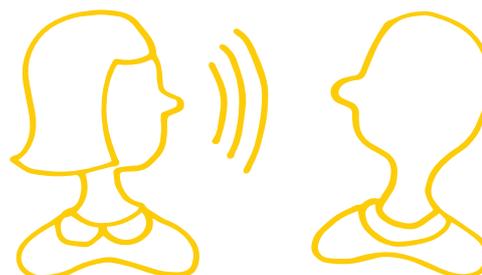
### >CF Week

CF Week focused on the burden of care using the theme of 'balance.' We provided a platform for the CF community to share their stories and discuss issues and solutions, collaborating with the CF community at a challenging time.

We provided interactive ways to participate in the week including a series of online events. In addition to deeper engagement with the community and our content we were able to raise more funds than in 2019 with less money during a difficult climate for the Trust by maximising community stories across our platforms.

### Communicating with supporters

Over the last year we moved to a new website platform to improve the user experience, save money in the longer term and futureproof longer-term digital requirements. Our new website is faster, has an improved search function and a streamlined navigation menu. We improved the donation journey making it quicker, easier and more flexible, including providing PayPal as a payment method. We also have a new home page to better present our key content and help users find the content they need more easily. When we launched our website 72% of those surveyed rated the new website as excellent on our online polls. We will continue to develop the website to provide the best possible service and experience.



### >Volunteering

We have been grateful for the continuing contribution of our volunteers. With most in-person activities being on hold due to the continuing Covid-19 pandemic, the nature of that support has been different, but we remain dependent on the support of nearly 200 registered volunteers.

Volunteers come from a wide range of backgrounds and at different life stages, ranging from those who already have a connection to someone with cystic fibrosis, to university students, through to people working directly for companies partnering with the Trust or possibly winding down in their careers and wanting to use the skills they have developed to help us do more for people with cystic fibrosis.

2020/21 has been a particularly challenging year for our employees with, for legal and infection control reasons, all but a very few having to work at home for most of the year. For some, this was already the norm, but for others it was a new experience and we are grateful for the way people used the available technology helped to serve the needs of the cystic fibrosis community.

## Being an effective organisation

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

Our employees have helped us address the challenges presented by the reduction in our income by agreeing to be put on furlough, where eligible, enabling the Trust to claim money under the HMRC job retention scheme, and we were grateful to the 21 that voluntarily changed their terms and conditions to contribute to a reduction in staff costs. A further saving was made by restructuring the Senior Leadership Team, resulting in a saving of nearly £100,000 per annum going forward. In addition, we have not made a pay award this year. These initiatives and the actions and commitment of staff have enabled us to minimise redundancies, although as we enter 2021/22 we are consulting on some reductions to our community and events team where there has been a significant reduction in activity, which we do not expect to pick up quickly during the next year.



At the same time, other colleagues, particularly those providing information and support directly to people with cystic fibrosis, have experienced a significant increase in the demands placed on them. The Trust is grateful for the way these staff have responded to the change in circumstances with flexibility and good humour.

With many staff working at home there has been a focus on their support needs, both in terms of appropriate equipment to work safely, such as adjustable office chairs, second screens for computers and ergonomic wrist rests. We have also undertaken a lot of activity to support staff wellbeing, having appointed seven mental health first aiders and provided training to support people in managing their time effectively, practicing mindfulness and even sleeping effectively. The value of such initiatives was recognised by many of the staff who completed the annual staff attitude survey, which was again completed by around 80% of employees and showed improvements in the areas we have targeted.

Equality, diversity and inclusion remains a critical priority for us. We have continued to work with Breaking Down Barriers to strengthen our understanding and response to the diverse needs of our community. We have provided training in diversity in recruitment and changed our policy to require staff involved in recruitment to have completed that or similar training.



## >Supporter experience

The Trust is 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 28 complaints in 2020-21 which was a noticeable decrease from 46 in 2019-20. This was due to the decrease in fundraising activities as a result of the Covid-19 pandemic. 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.

## Fundraising

We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice.

We would like to thank all the fantastic individual donors, organisations, charitable trusts, foundations and corporate partners who support our work. The Cystic Fibrosis Trust receives no government funding.

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

2020/21 was a very challenging year for fundraising with many external events and activities cancelled, and COVID-19 restrictions implemented. This impact was seen across the whole charity sector.

We worked quickly to adapt our fundraising plans, move events to virtual where possible and launch new activities. Thanks to the continued commitment of our incredible supporters, donors and partners, the Trust raised £5.6 million net income. This was a 25% reduction compared to 2019-20. The response to our Emergency COVID-19 Appeal was phenomenal and raised £829,000 to ensure our continued support for people with cystic fibrosis during this challenging time.

## >Fundraising events and activities

Our supporters, including our branches and groups, have harnessed the changes and continued to raise funds for us. The total income from our virtual events is £260,000.

The 2.6 Challenge which was organised by a consortium of event companies raised £125,000, with over 150 people taking on a personal challenge, which included laps of their garden, walking up their stairs, bouncing on a space hopper or running. Other popular activities include the virtual Running Festival and Ride for Research.



Our annual Wear Yellow Day took place during the first national lockdown. Supporters held events online and we invited everyone to a virtual Big Yellow party to celebrate the resilience of the CF community. The support from celebrities and young people with cystic fibrosis ensured everyone had a great time and raised over £75,000.

---

**Carols by Candlelight, which is organised by the Alice Martineau Committee, was held online for the first time. Hundreds of people from across the world watched the special event which was pre-recorded at Abbey Road Studios and St Luke's Church in Chelsea. The event raised £61,000.**

---

New fundraising activities were launched this year including FeBREWary—which raised over £17,000 in its first year and engaged many new people—a new gaming product #CFNextLevel and CF face coverings, which flew off the shelf.

#### >Gifts in wills

This year we received 92 legacies from supporters who generously included a gift to the Trust in their Will, as well as 50 who told us they have included us in their Will. We are incredibly grateful to those who have thought of us in this special way or are considering doing so and continue to raise people's awareness of legacy giving.

#### >Regular gifts

We would like to express our thanks to our loyal regular monthly donors, who provide invaluable ongoing support that enables us to plan effectively for the future. Including Gift Aid, these supporters contributed more than £835,000 in 2020/21.

During this year, we carried out two telemarketing activities through Ethicall, who 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. The activities (a regular giving upgrade and a Direct Debit conversion campaign) resulted in a new additional annual income of £18,000.

#### >Corporate partnerships

The Trust continues to work with corporate partners to raise funds and awareness for cystic fibrosis. In 2020-21, this support was more important than ever. The COVID-19 pandemic created challenges for businesses and their staff across the UK. We are incredibly grateful for the companies that supported us this year and helped us to provide vital support to people with cystic fibrosis throughout the pandemic.

Thanks particularly go to Barclays, who donated through their 100 X 100 Community Relief Fund Bridgepoint, Gilead Pharmaceuticals, and Talent84 who supported our COVID-19 Emergency Appeal. It is because of donations like these that we were able to provide emergency support, such as financial grants, to the CF community.

Thank you to companies such as Gaiger Bros, Lloyds, Whiskey Auctioneers Ltd, Sony, Talent84, Clarity Ltd and Stark who together with their staff donated, walked, ran, cycled, baked and barbecued their way through the virtual space to raise money for the Trust.

We're also incredibly grateful to our partners, Clear Channel and Goodstuff, who provide gift in kind outdoor advertising and campaign advice, which was invaluable in helping us promote our COVID-19 response and virtual fundraising throughout the year.

We continued to work with the pharmaceutical industry, who sponsored our Annual Registry Meeting, and we look forward to working with our sponsors on more activities next year.

### Philanthropy

The Trust continues to work with charitable trusts, foundations and individual supporters to fund the work we do. This year we have been pleased to build on existing relationships with the Joseph Levy Foundation, which supports our Information and Support work; BBC Children in Need, which supports our work with young people; and Sport England. In addition, we have worked with generous individuals who are long-standing supporters of our work.

This year, in response to the pandemic, we have also been grateful to receive funding from the Coronavirus Community Support Fund, distributed by the National Lottery, to support core services such as our helpline and our welfare grants programme, to support the cystic fibrosis community through such a challenging and unprecedented time.

## Plans for the future

Despite recent challenges, this is a truly exciting time for the CF community. We are in a period of profound change, that will both extend and transform the lives and prospects of many people with cystic fibrosis. As the only UK-wide organisation focusing on people with CF, the Trust has a vital role in driving forward positive change, and to this end, we have developed a new three-year strategy, updating our vision and objectives for a post-pandemic and post-Kaftrio world, informed by our research and the views and priorities of people with cystic fibrosis and their families.

We have a simple and ambitious vision: that every person with cystic fibrosis across the UK can live a long and full life.

To achieve this, 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 will focus our efforts toward achieving three key goals:

- Being physically well: that all people with CF are living lives free from the symptoms and physical health consequences of having CF.
- Being mentally well: people with CF and their families are supported to deal with the emotional and psychological consequences of living with a long-term, life-limiting condition.
- Reaching potential: that everyone with CF can reach their full potential, in a world that understands their needs and supports them in overcoming the challenges of living 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: adopting a virtual first workstyle; exploring innovative fundraising approaches; making effective use of data and analytics; building international and domestic partnerships; and working in ways that brings together our diverse community.

## >Research and UKCFC

Our Research Strategy 2018–2023 will see the Trust continue to focus on securing access to medicines, ensuring the quality of clinical care, providing effective day-to-day support and reaching all people with cystic fibrosis. Our balanced portfolio of research programmes will continue to take advantage of funding from external sources and use novel approaches to tackle these issues.

Scoping and planning for the 2020/21 conference is ongoing, with the recommendation that the conference itself is held as a one-day research event with a focus on promoting scientific discussion and collaboration. It is also proposed that the next event be held in early 2021 to better align with the other key international respiratory conferences. It is likely that this will be a virtual event in light of current rules regarding mass gatherings.

## >Improving the quality of care

It is essential that the quality of care people with CF experience continues to improve and change recognises the impact highly effective modulators have on their wellbeing and expectations.

We will work in partnership with the UKCFMA and health authorities to embed the learnings gained during the pandemic. We will continue to ensure standards are maintained by providing quality data and information and ensure continuous quality improvement and patient involvement are central to any change in how care is delivered.



### >UK CF Registry

The coming months will see a publication assessing risk to people with cystic fibrosis who are diagnosed with COVID-19, including over 1,400 cases from 22 countries around the world.

The UK CF Registry Annual Report 2020 will be published in summer 2021, including an analysis of the impact of the pandemic.

The Trust will continue to report early results of the efficacy of CFTR modulators to NICE as part of the Interim Access Oversight Committee. The UK CF Registry will also provide analysis to guide NHS England's review of CF Services, due to complete in November 2021.

Summer 2021 will see the launch of the new Registry-based clinical trial, CF STORM. This study is designed to find out whether people with cystic fibrosis can safely withdraw mucolytic therapy once they have started taking CFTR modulators. You can find out more about the study here: [cysticfibrosis.org.uk/news/a-storm-is-coming](https://cysticfibrosis.org.uk/news/a-storm-is-coming)

The Annual Registry Meeting will go ahead as a Virtual Video Series, allowing colleagues across the country to still benefit from this important meeting. Virtual content will be developed over the course of the year, providing sharing of best practice and important updates.

The new CFSPID (Cystic Fibrosis Screen Positive, Inconclusive Diagnosis) Registry will be launched during 2021/22.

### >Improving trial outcomes

CTAP has innovative plans to continue to make the UK the pre-eminent place to deliver trials for CF therapies in Europe.

We will continue to build our reputation with pharmaceutical companies to establish the UK's position as a desirable place to invest in commercial CF trials, including early-phase trials: an increasingly important challenge given the UK's current political and healthcare climates. The early-phase pilot will be a big part of ensuring new early-phase trials are coming to the UK, and we will be working on a number of ideas from Key Opinion leaders to develop the early phase strategy.

### >Campaigning hard and raising awareness

Campaigning hard and raising awareness across the UK, we continue to push for extended agreements to ensure modulator therapy research all who can benefit from them and ensure no one is left behind.

The Trust will continue to work with external stakeholders and parliamentarians across England, Scotland, Wales and Northern Ireland to identify key opportunities for parliamentary and community action to ensure that the issues that matter to those with cystic fibrosis, such as transplants, the future of CF care and welfare, are on the political agenda.

As the UK eases out of another lockdown, we will continue to push on all fronts to ensure that the clinically extremely vulnerable population is not left behind as the economy rebuilds, and that adequate back to work, education, financial and mental health support, is provided.

### >Day-to-day support

We will continue our work to understand the current This year we will be continuing to support the CF community to recover from the impact of the pandemic, as well as looking forward to new and emerging support needs as modulator therapies change the landscape of cystic fibrosis. We will be developing two new advisory groups to make sure that people with CF can shape and develop our information and support, ensuring that we can meet the diverse needs of everyone affected by cystic fibrosis.

We'll continue to develop our youth programme, working with young people to ensure our work is relevant to them. We'll also pilot activities for adults with CF, creating opportunities for them to come together and gain informal peer support through participation in online activities.

We will continue to develop our information library, creating new resources on mental health and wellbeing as well as updated resources for young children and siblings, and new factsheets to meet emerging information needs.

We will also review and improve key resources, such as our new diagnosis pack, to ensure their relevance to diverse audiences, and continue work to improve accessibility of all of our information materials.

### >Being great fundraisers

We will continue to work closely with our network of branches and groups, who are vital to our success at a local level, and develop new and innovative fundraising ideas. We will continue to offer an exceptional event portfolio, which will include virtual events that enable all supporters to take part, irrespective of age and ability. We will also continue to maximise the potential of our Great Strides™ and Wear Yellow Day campaigns. In addition, we will introduce additional processes and procedures to give fundraisers the very best experience when supporting the Trust.



We are also focusing on increasing engagement in our flagship activities such as CF Week, Great Strides™, Christmas and Resolutions (now known as Team CF Superheroes) while offering a diverse and exciting event portfolio.

We will continue to focus on developing multi-year partnerships with individuals, companies and Trusts, enabling us to invest in cutting-edge research, such as our exciting Innovation Hub partnership with the University of Cambridge, alongside providing vital support, information and advice services.

### >Being an effective organisation

We will develop a series of impact indicators to help us track the long-term difference we are making in each area of our work for people with cystic fibrosis.

Increasing diversity will remain a key priority, as will supporting the mental health of all employees. Responding to changes in staffing needs resulting from the continuing COVID-19 pandemic, will also remain a challenge. We plan to maximise our use of government support while this is still available, and ensuring that our working practices are adapted to respond to changing needs will be critical.

To achieve this, 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 will focus our efforts toward achieving three key goals:

- Being physically well: that all people with CF are living lives free from the symptoms and physical health consequences of having CF.
- Being mentally well: people with CF and their families are supported to deal with the emotional and psychological consequences of living with a long-term, life-limiting condition.
- Reaching potential: that everyone with CF can reach their full potential, in a world that understands their needs and supports them in overcoming the challenges of living 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: adopting a virtual first workstyle; exploring innovative fundraising approaches; making effective use of Data & Analytics; building international and domestic partnerships; and working in ways that brings together our diverse community.



## Financial review

### >Income

The Trust's income from normal activities for the year to March 2021 was £14.4million, a decrease of 13% over the previous year.

80% of the Trust's total income is made up of donations and legacies, totalling £11.5million, (2019/20 – £15.2m). This percentage is 24% lower than in the previous year, with the decrease driven by a reduction in community and events income, resulting from events cancellations and restrictions imposed by the government in response to the COVID-19 pandemic. This unfortunately meant that our team of fundraisers, and our fundraising supporters, were unable to maintain their usual level of activity. The fall in income generation in this area was partially offset by a fantastic response to our emergency appeal which raised over £0.8m.

The appeal response included contributions from a number of corporate partners, major donors and trusts and foundations, and led to income from these income streams increasing compared to 2019/20.

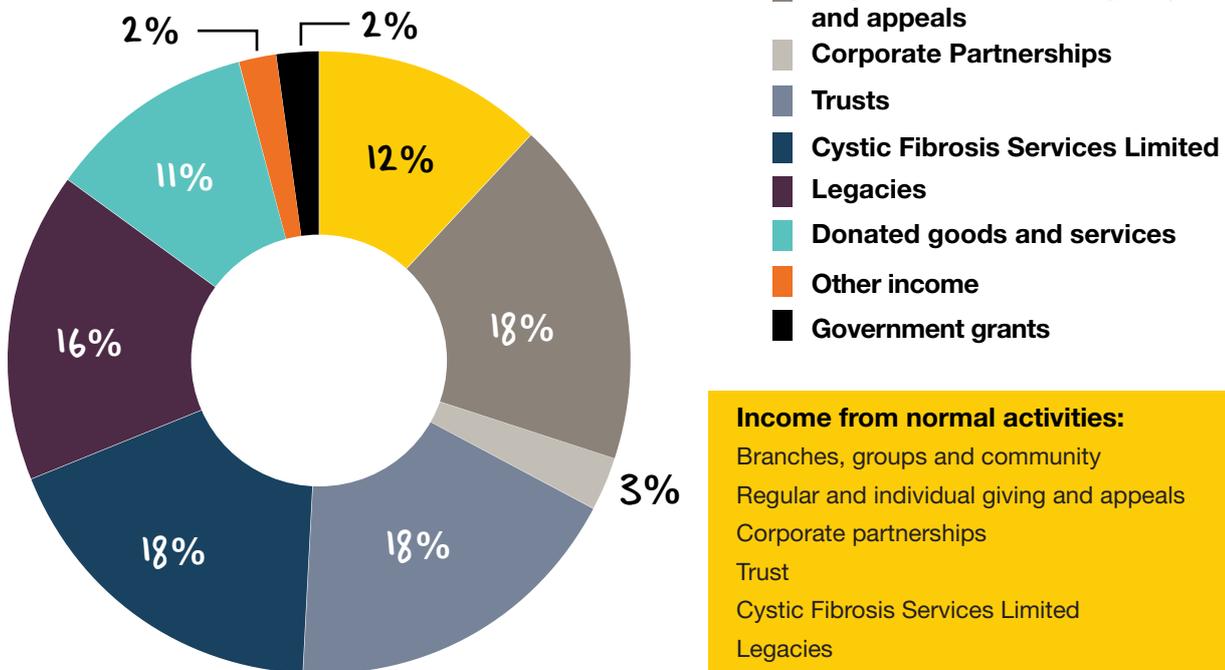
Further support for our Clinical Trials and Digital Health programmes from the Cystic Fibrosis Foundation in the US also drove increased Trust income.

Income from legacies was 22% lower than in 2019/20. We once again gratefully received free digital advertising space from Clear Channel in the year, worth £1.6m – this value was 57% lower than the prior year equivalent due to fewer advertising opportunities during the pandemic, and expansion of Clear Channel's charity advertising programme to benefit more organisations.

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, more than doubled in the year, totalling £2.6m (2019/20 – £1.1m). As well as 2 existing long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, a further four new contracts were signed during the year.

The Trust successfully applied for and received £0.3m through the government's Job Retention Scheme, having put a number of staff on furlough during the year in recognition of a drop in activity as a result of compliance with the government's Covid-19 restrictions.

### > 2020/21 income by income stream



Income from normal activities:	£'000
Branches, groups and community	1,672
Regular and individual giving and appeals	2,626
Corporate partnerships	377
Trust	2,647
Cystic Fibrosis Services Limited	2,580
Legacies	2,276
Donated goods and services	1,648
Government grants (Job retention scheme)	304
Other income	257
<b>Total income from normal activities</b>	<b>14,386</b>

## >Expenditure

The Trust's total expenditure for the year was £13.9m, a 16% decrease compared to the previous year. The largest area of spend was on charitable activities at £10.2m (2019/20 – 12.9m), accounting for 73% of total spend. This comprises programmes of research, information, advice and support and clinical care.

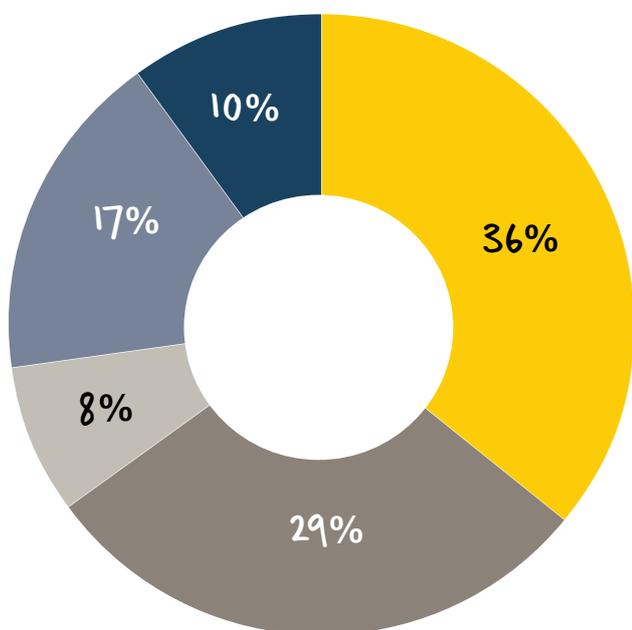
The remainder was spent on activities for generating funds, including £1.4m (2019/20 – £0.7m) paid to NHS cystic fibrosis clinical centres across the UK to support the resources necessary to add patient data to the CF Registry. The amount paid out to the clinical centres more than doubled compared to the prior year, reflecting an increase in the quantity and regularity of data being uploaded by the centres into the UK CF Registry.

Total grant commitments in the year were £3.8m (2019/20 – £4.8m), of which £3.5m (2019/20 – £4.4m) were committed to a range of institutions, including £2.3m committed for three Strategic Research Centres (2019/20 – £1.5m for one centre). The remaining £0.3m (2019/20 – £0.4m) 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 £0.8m (2019/20 – £0.7m). Through the new Digital Health Programme £0.7m of grant funding was awarded to Cambridge University 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 £1.3m (2019/20 net deficit of £0.3m).

## > 2020/21 expenditure by cost type



- Research
- Information, advice and support
- Clinical Care
- Costs of raising funds
- Cystic Fibrosis Services Limited

Expenditure	£'000
Research	4,975
Information, advice and support	4,077
Clinical care	1,133
<b>Charitable activities total</b>	<b>10,185</b>
Costs of raising funds	2,284
Cystic Fibrosis Services Limited	1,437
<b>Total expenditure</b>	<b>13,906</b>

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

**> Review of investments in the year**  
**The value of the investment portfolio (including endowment funds) has decreased by £0.5 million in the year (2019/20: decrease of £0.4 million); while the value of the investment holdings recovered in full from the market falling at the end of the prior year, a transfer of £1.3m was made out of the investments into cash deposits in accordance with the cash management policy. Income generated on investments totalled £0.1million, while realised and unrealised gains on the investment portfolio totalled £0.8 million.**

## > Reserves

The Trust's reserves as at 31 March 2021 totalled £9,514,000 (2020 – £8,225,000). 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 fixed assets (£37,000) is held to ensure these funds are not considered to be realisable

An Appeal Deficit has been recognised, being the difference between the £2.0 million grant awarded to the Innovation Hub at Cambridge and the £1.6 million income fundraised so far for the corresponding appeal. This deficit has been under-written by the Cystic Fibrosis Trust while we continue to appeal to donors for funds.

- Operating reserve – held at a value (£3,448,000) 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 – (£5,013,000) to be deployed in financing the ambitions described in the Trust's Five-Year Business Delivery Plan in a way that maximises the impact for people with cystic fibrosis. Retained reserves had been expected to be utilised through a managed spend programme over the next 36 months. The impact on income generation due to the COVID-19 pandemic 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 – (£248,000) relating to donations restricted to various specified activities.

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.

## 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; embedding a financially sustainable model post-COVID-19; 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.
- The Trust's projects and activities are assessed under a consistent risk assurance framework at inception to ascertain the appropriate level of management and oversight relative to financial, resource and risk exposure.
- Clear and easily accessible whistleblowing procedures are in place. In addition, there are processes in place to investigate and report on any serious incidents, including the implementation of required corrective actions.

## Our work with the pharmaceutical industry

Our mission is to create a world where being born with CF no longer means a lifelong burden of care and an early death; when everyone living with the condition will be able to look forward to a long, healthy life.

Partnerships between medical research charities and the pharmaceutical 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 the infrastructure and funding additional research capacity to support the pharmaceutical 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. In 2020/21 the Trials Accelerator feasibility service was utilised for six clinical trials, generating an income of £1,819,000 for CTAP.

The Trials Accelerator also offers a protocol review service to support pharmaceutical companies with the design, feasibility and planning of clinical trials. In 2020/21 there was one submission from sponsors for protocol review and three additional reviews by the CTAP RSOB were performed on projects/ protocols submitted as part of the NIHR themed call workstreams.



### >The UK Cystic Fibrosis Registry

Long-term 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 Regulator 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](https://cysticfibrosis.org.uk/registry).

In 2020/21 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £2.5 million in fees for this service. There were four long-term commercial contracts for Phase IV pharmacovigilance studies and one contract for a Health Technology Appraisal study in place throughout the year.

### >Venture & Innovation Awards (VIAs)

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



## Sponsorship and donations

The Cystic Fibrosis Trust takes funding from a range of sources including pharmaceutical companies to support our vital work fighting for a life unlimited for people with cystic fibrosis. We assess all funding relationships to ensure that they do not risk the interests of people affected by cystic fibrosis or the independence and reputation of the charity. All funding arrangements must meet the requirements of our Ethical Fundraising Policy, which is overseen by our trustees and we do not accept payment to promote or recommend specific treatments to individuals or influence prescribing practices for specific branded medicines

- The Clinical Trials Accelerator Platform – a UK-wide initiative to increase participation and access to CF clinical trials.
- The UK Cystic Fibrosis Registry – covering the cost of reporting to regulators on the safety and effectiveness of cystic fibrosis medicines, including providing data entry grants to CF care centres.
- Venture and Innovation Awards – supporting transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the pharmaceutical industry.
- The UK Cystic Fibrosis Conference – an event for healthcare professionals and people affected by CF informed on all aspects of clinical care and research.

In 2020/21, our UK Cystic Fibrosis Conference was postponed from February 2021 to May 2021, therefore we received no income for the event for this financial year.

In 2020/21, we received £5,000 in sponsorship from Chiesi for the Annual Registry Meeting.



## 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, and
- 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 Trustees report incorporating the Strategic report was approved and authorised for issue by the Board of Trustees on **13 July 2021** and signed on its behalf by:

**Richard Hunt, Chairman**

---

## Independent auditor's report to the Members and Trustees of the Cystic Fibrosis Trust

### >Opinion

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2021 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 and parent charitable company's affairs as at 31 March 2021 and of the group'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; and
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustees 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 charitable company 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 charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

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

### >Other information

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

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

### >Opinions on other matters prescribed by the Companies Act 2006

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

- the information given in the Trustees' Report (which 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; and
- the strategic report and the directors' report included within the Trustees' 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 charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' 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 requires 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 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

### >Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement set out on page 39, 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 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 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 charitable company and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to the Companies Act 2006 and the Charity Accounts (Scotland) Regulations and the Charities Act 2011 and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered other factors such as income tax, payroll tax and sales tax.



We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and concluded that the risk was low. Audit procedures performed by the engagement team included:

- 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; and
- Challenging assumptions and judgements made by management in their critical accounting estimates

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](http://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 2021

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2021 £'000	Total Funds 2020 £'000
<b>Income and endowments from:</b>						
Donations and legacies	2	8,098	3,580	-	11,678	15,196
Other trading activities	12	2,580	-	-	2,580	1,078
Investments	2b,6	110	18	-	128	149
<b>Other income</b>						
Fixed asset disposals gain	6	-	-	-	-	-
Other income	2	-	-	-	-	105
<b>Total</b>		<b>10,788</b>	<b>3,598</b>	<b>-</b>	<b>14,386</b>	<b>16,527</b>
<b>Expenditure on:</b>						
Raising funds	3	3,718	-	3	3,721	3,563
<b>Charitable activities</b>						
Research		3,008	1,966	1	4,975	4,432
Clinical care	3	664	468	-	1,132	2,132
Information, advice & support		3,668	407	2	4,077	6,373
<b>Total charitable activities</b>		<b>7,340</b>	<b>2,841</b>	<b>3</b>	<b>10,184</b>	<b>12,938</b>
<b>Total resources expended</b>	3	<b>11,058</b>	<b>2,841</b>	<b>6</b>	<b>13,905</b>	<b>16,501</b>
<b>Net income/(expenditure) before investment gains/losses</b>		<b>(270)</b>	<b>757</b>	<b>(6)</b>	<b>481</b>	<b>27</b>
Realised investment gains/(losses)		17	-	-	17	38
Unrealised investment gains/(losses)		694	-	99	793	(391)
<b>Net investment gains/(losses)</b>		<b>711</b>	<b>-</b>	<b>99</b>	<b>810</b>	<b>(353)</b>
<b>Net (expenditure)/income</b>		<b>441</b>	<b>757</b>	<b>93</b>	<b>1,291</b>	<b>(326)</b>
Transfers between funds	17a	747	(747)	-	-	-
<b>Net movement in funds</b>		<b>1,188</b>	<b>10</b>	<b>93</b>	<b>1,291</b>	<b>(326)</b>
<b>Reconciliation of funds</b>						
Total funds brought forward		7,089	239	897	8,225	8,551
<b>Total funds carried forward</b>	17a	<b>8,277</b>	<b>249</b>	<b>990</b>	<b>9,516</b>	<b>8,225</b>

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 16)

The notes on pages 47 to 67 form part of these financial statements.

## Cystic Fibrosis Trust

### > Consolidated income and expenditure account

For the year ended 31 March 2021

	All income funds 2021 £'000	All income funds 2020 £'000
Income	14,258	16,738
Gains/(losses) on investments	711	(219)
Investment income	128	149
<b>Gross income in the reporting period</b>	<b>15,097</b>	<b>16,308</b>
Expenditure	13,876	16,476
Interest payable	-	-
Depreciation and charges for impairment of fixed assets	23	18
<b>Total expenditure in the reporting period</b>	<b>13,899</b>	<b>16,494</b>
<b>Net income before tax for the reporting period</b>	<b>1,198</b>	<b>(186)</b>
Tax payable	-	-
<b>Net Income for the financial year</b>	<b>1,198</b>	<b>(186)</b>

The Consolidated Summary Income and Expenditure Account is derived from the Statement of Financial Activities on page 41 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 47 to 67 form part of these financial statements.

## Cystic Fibrosis Trust

### > Consolidated and charity balance sheets

As at 31 March 2021

	Notes	Consolidated		Charity	
		Total 2021 £'000	Total 2020 £'000	Total 2021 £'000	Total 2020 £'000
<b>Fixed assets</b>					
Tangible assests	5	37	24	37	24
Investments	6	5,196	5,670	5,196	5,670
		<b>5,233</b>	5,694	<b>5,233</b>	5,694
<b>Current assets</b>					
Debtors	7	3,301	2,619	2,337	2,552
Cash held as short term investment		11,256	9,978	11,256	9,978
Cash at bank and in hand		3,366	2,939	3,246	2,672
		<b>17,923</b>	15,536	<b>16,839</b>	15,202
<b>Liabilities</b>					
<b>Creditors:</b> amounts falling due within one year					
Grants payable	9	(7,407)	(7,135)	(7,407)	(7,135)
Creditors and accrued charges	10	(1,410)	(705)	(1,404)	(699)
		<b>(8,817)</b>	(7,840)	<b>(8,811)</b>	(7,834)
<b>Net current assets</b>		<b>9,106</b>	7,698	<b>8,028</b>	7,367
<b>Creditors:</b> amounts falling due after one year					
Grants payable	9	(4,823)	(5,165)	(4,823)	(5,165)
<b>Total net assets</b>		<b>9,516</b>	8,225	<b>8,438</b>	7,897
<b>The funds of the charity</b>					
Endowment funds	17a	989	897	989	897
Restricted income funds	17a	248	239	248	241
<b>Unrestricted funds</b>					
Designated reserves	17a	(184)	(1,055)	(184)	(1,055)
Fixed asset reserve		37	24	37	24
Appeal deficit		(421)	(1,079)	(421)	(1,079)
Strategic reserve		200	-	200	-
Operating reserves		3,448	3,366	3,448	3,366
Retained reserves		5,015	4,778	3,937	4,449
<b>Total charity funds</b>		<b>9,516</b>	<b>8,225</b>	<b>8,438</b>	<b>7,897</b>

The notes on pages 47 to 67 form part of these financial statements.

The net movement in funds for the Trust for the year ended 31 March 2021 was – £219,000 (2020: 12 months +£655,000). 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 **13 July 2021**  
and signed on their behalf by:

**Richard Hunt, Chairman**

Company number 3880213

## Cystic Fibrosis Trust

### > Consolidated Statement of cash flows

As at 31 March 2021

	2021 £'000	2020 £'000
<b>Net cash provided by (used in) operating activities (Note A)</b>	<b>329</b>	<b>(1,171)</b>
<b>Cash flows from investing activities:</b>		
Dividends and interest	128	149
Purchase of property, plant and equipment	(36)	(2)
Purchase of investments	(116)	-
Movement in cash awaiting investment	2	9
Proceeds of sales of investments	116	-
	<b>94</b>	<b>156</b>
Increase/(decrease) in cash held as short term investments	(1,276)	1,436
<b>Increase/(decrease) in cash (Note B)</b>	<b>(853)</b>	<b>421</b>

#### Notes to Cash Flow Statement

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

	2021 £'000	2020 £'000
Net (expenditure)/income for the reporting period (as per the statement of financial activities)	1,291	(327)
<b>Adjustment for:</b>		
Depreciation charges	23	18
Dividends and interest from investments	(128)	(149)
(Gains)/losses on investments	(810)	352
Decrease/(increase) in debtors	(682)	(306)
Increase/(decrease) in creditors	635	759
	<b>329</b>	<b>(1,171)</b>

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

	2021 £'000	2020 £'000
Cash and cash equivalents at the beginning of the reporting period	12,919	13,931
Change in cash and cash equivalents in the reporting period	(853)	424
Increase in short-term investments	1,276	(1,436)
<b>Cash and cash equivalents at the end of the reporting period</b>	<b>13,342</b>	<b>12,919</b>
(being cash at bank and in hand and cash held as short-term investments)		
	<b>2021</b>	<b>2020</b>
<b>Analysis of cash and cash equivalents:</b>	<b>£'000</b>	<b>£'000</b>
Cash on hand	3,366	2,941
Notice deposits (less than 3 months)	11,256	9,978
<b>Total cash and cash equivalents</b>	<b>14,622</b>	<b>12,919</b>

# Cystic Fibrosis Trust

## > Notes to the Financial Statements

For the year ended 31 March 2021

### 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) (second edition effective 1 January 2019) – (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 3. 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 surplus for the parent charity was £401,000 (2019/20 – deficit of £655,000).

The subsidiary's net surplus of £1,071,000 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.

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 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.

#### 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.

Endowed 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

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 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.

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 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.

#### q) Government grants

Government grants include Coronavirus Job Retention Scheme grants. These are recognised when the charity is entitled to the income, receipt is probable and the amount receivable can be reliably measured.

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 2a. Income from donations and legacies

	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	<b>Total 2021 £'000</b>	Unrestricted Funds 2020 £'000	Restricted Funds 2020 £'000	<b>Total 2020 £'000</b>
Branches, Groups & Community	1,546	8	<b>1,554</b>	3,599	15	<b>3,614</b>
Legacies	2,082	185	<b>2,267</b>	2,875	46	<b>2,921</b>
Individual donations	394	32	<b>426</b>	275	54	<b>330</b>
Corporate	269	107	<b>376</b>	222	-	<b>222</b>
Regular giving and appeals	1,285	39	<b>1,324</b>	1,167	42	<b>1,209</b>
Trusts	97	2,551	<b>2,648</b>	20	1,943	<b>1,963</b>
Appeal for Innovation Hub	-	658	<b>658</b>	-	438	<b>438</b>
Donations in kind	1,648	-	<b>1,648</b>	3,833	-	<b>3,833</b>
Gift Aid	345	-	<b>345</b>	538	-	<b>538</b>
Government grant income	304	-	<b>304</b>	-	-	<b>-</b>
NHS National Services England	81	-	<b>81</b>	81	-	<b>81</b>
NHS National Services Scotland	47	-	<b>47</b>	47	-	<b>47</b>
<b>Total income from donations and legacies</b>	<b>8,098</b>	<b>3,580</b>	<b>11,678</b>	<b>12,657</b>	<b>2,539</b>	<b>15,196</b>

Donations In Kind refer to non-monetary donations received from partner organisations. In 2020/21 £1,648,000 was donated in the form of digital and cinema advertising space and professional fees (2019/20: £3,833,000). 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.

#### 2b. Investment Income

	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	<b>Total 2021 £'000</b>	Unrestricted Funds 2020 £'000	Restricted Funds 2020 £'000	<b>Total 2020 £'000</b>
Income from listed investments	46	18	<b>64</b>	64	7	<b>71</b>
Bank interest	64	-	<b>64</b>	78	-	<b>78</b>
<b>Total investment income</b>	<b>110</b>	<b>18</b>	<b>128</b>	<b>142</b>	<b>7</b>	<b>149</b>

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 3a. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	Total 2021 £'000
<b>Raising funds</b>					
Fundraising	-	-	1,902	382	2,284
Trading and merchandising	-	1,376	61	-	1,437
<b>Charitable activities</b>					
Research	1,891	1,255	998	831	4,975
Clinical care	299	48	596	189	1,132
Information, advice & support	262	88	3,046	681	4,077
	2,452	2,768	6,603	2,083	13,905

#### Analysis of allocated Support Costs – current 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 & support	112	94	187	90	198	681
<b>Total costs</b>	341	286	573	273	609	2,083

Costs are allocated based on identifiable activities undertaken by central teams to support the wider organisation. The basis of allocation of support costs has been reviewed in the year. The prior year allocations have been restated in order to be consistent with the revised allocation basis.

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	Total 2020 £'000
<b>Raising funds</b>					
Fundraising	-	-	2,506	394	2,900
Trading and merchandising	-	602	61	-	664
<b>Charitable activities</b>					
Research	1,629	1,269	931	602	4,432
Clinical care	761	138	944	290	2,133
Information, advice & support	174	213	5,119	867	6,373
	2,564	2,223	9,561	2,154	16,502

The net restricted 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 – prior year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	Total 2020 £'000
Fundraising	78	52	101	56	108	394
Research	119	79	154	85	166	601
Clinical care	57	38	74	41	80	291
Information, advice & support	171	114	221	122	238	866
Governance	-	-	-	-	-	-
<b>Total costs</b>	424	283	551	302	591	2,153

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 3a. Expenditure (continued)

##### Net (expenditure)/income in the year:

	2021 £'000	2020 £'000
Auditors remuneration excluding VAT	22	21
Depreciation	23	18
Operating leases – building	244	244
Operating leases – other	6	6
Trustees' travel expenses	-	3

#### 3b. Grants

Grants were awarded during the year as follows:

	2021 £'000	2020 £'000
Grants to institutions	4,870	4,402
Grants to individuals	350	385
	<b>5,220</b>	<b>4,787</b>

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.

	2021 £'000	2020 £'000
Balance at start of year	12,299	12,502
Awarded in the year	5,220	4,765
Paid in year	(5,289)	(4,968)
<b>Balance at end of year</b>	<b>12,230</b>	<b>12,299</b>
Falling due within one year (note 9)	7,407	7,135
Falling due after more than one year (note 9)	4,823	5,165

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

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 3b. Grants (continued)

	2021 £'000	2020 £'000
University of Cambridge/Papworth Hospital	832	856
University of Liverpool	769	33
UCL Great Ormond Street	750	2
University of Bristol	749	2
Queen Elizabeth University Hospital	180	-
University Hospital Llandough	120	-
Imperial College London /Royal Brompton Hospital	56	163
Medicines Discovery Catapult	50	-
University of Copenhagen	27	-
CF Europe	21	21
Queen's University Belfast	17	3
MRC	3	-
Great North Children's Hospital	2	-
University of Birmingham	2	-
University of Edinburgh	2	-
University of Exeter	2	58
University of Newcastle/Newcastle Hospital	-	750
University of Sheffield	-	749
Kings College	-	157
Royal College of Surgeons in Ireland	-	97
Manchester University/Wythenshaw Hospital	-	95
Nottingham University	-	65
Royal Hospital for Children, Glasgow	-	50
Neem Biotech	-	30
ECFS	-	20
National heart and lung institute, London	-	20
Cardiff University		2
St George's University of London		2
Institute of Cancer Sciences, Glasgow		2
	<b>3,579</b>	<b>3,177</b>
Add: Trial Coordinator commitments made to CTAP centres (see note)	298	616
Add: Registry support grants made to various CF centres	1,376	602
Add: Other adjustments	19	7
Less: Release of grants made in previous years (see note)	(401)	-
<b>Total grants made to institutions</b>	<b>4,871</b>	<b>4,402</b>

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 third year of funding. In addition, a new cohort of 'Affiliate Centres' were awarded funding in the year.

Various grants totalling £401,000 were released during the prior 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 2021

#### 4. Staff costs

Staff costs comprise the following:

	2021 £'000	2020 £'000
Salaries	4,220	4,011
Redundancy and other termination payments	34	-
Temporary Staff	75	232
Social security costs	432	416
Other pension costs	254	235
	<b>5,015</b>	<b>4,895</b>

£34,000 in redundancy and other termination payments were paid to 2 (2019/20 – £Nil) staff members in the year following a review of the senior leadership team structure, which will result in a long-term recurring cost saving for the Trust.

#### Pension commitments:

The Charity operates a defined contributions pension scheme. The assets of the scheme are held separately from those of the Charity in an independently administered fund. The pension cost charge represents contributions payable by the Charity to the fund and amounted to £254,000 (2019/20 – £235,000).

#### Analysis of total average monthly headcount by category:

	2021 No.	2020 No.
Research	16	13
Clinical care	6	5
Information, advice & support	36	34
Fundraising	42	38
Management	2	4
Finance	7	6
IT and project management support	8	6
HR & OD	4	7
Facilities	1	2
<b>Total average monthly headcount</b>	<b>122</b>	<b>115</b>

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

	2021 No.	2020 No.
£60,001 – £70,000	9	2
£70,001 – £80,000	2	3
£80,001 – £90,000	1	-
£90,001 – £100,000	-	-
£110,001 – £120,000	1	1

Pension contributions to defined contribution pension schemes for these employees totalled £53,168 (2020/21 – £32,190).

Remuneration of key management personnel: The total remuneration paid to key management personnel, including pension and social security contributions, was £524,283 which relates to 7 individuals who served on the Senior Leadership Team during the year (2020/21 – £652,905 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. No expenses were settled on behalf of Trustees (2019/20 – £3,019 settled on behalf of 4) as all meetings were held remotely during the period.

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 5. Fixed assets

	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
<b>Cost</b>						
At 31 March 2020	630	834	243	403	183	2,293
Additions	-	36	-	-	-	36
<b>At 31 March 2021</b>	<b>630</b>	<b>870</b>	<b>243</b>	<b>403</b>	<b>183</b>	<b>2,329</b>
<b>Depreciation</b>						
At 31 March 2020	630	811	243	402	183	2,269
Charge for the year	-	23	-	-	-	23
<b>At 31 March 2021</b>	<b>630</b>	<b>834</b>	<b>243</b>	<b>402</b>	<b>183</b>	<b>2,292</b>
<b>Net book value at 31 March 2021</b>	<b>-</b>	<b>36</b>	<b>-</b>	<b>1</b>	<b>-</b>	<b>37</b>
Net book value at 31 March 2020	-	23	-	1	-	24

#### 6. Investments

Group and Charity	Total 2021 £'000	Total 2020 £'000
Market value as at 31 March 2020	5,670	6,031
Additions at cost	116	524
Disposals at opening book value	(1,376)	(524)
Net gains/(losses) on investments	782	(352)
	<b>5,192</b>	5,678
Change in cash	4	(9)
Market value as at 31 March 2021	<b>5,196</b>	5,670

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 6. Investments (continued)

Represented by:	Total 2021 £'000	Total 2020 £'000
Equities	3,921	2,952
Fixed Interest and multi-asset funds	495	468
Property	575	659
Cash	205	1,591
	<b>5,196</b>	<b>5,670</b>

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

The following assets were held at 31 March 2021. These make up more than 5% of total investments:

	Total 2021 £'000
The equity income trust for charities	670
Charities property fund	319
Property income trust for charities	256
Schroders responsible multi asset fund	2,398

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 2021 £'000	Group 2020 £'000	Charity 2021 £'000	Charity 2020 £'000
Trade debtors	1,085	305	-	-
Amount due from subsidiary undertaking	-	-	121	238
Prepayments and accrued income	2,151	2,263	2,151	2,263
Other debtors	65	51	65	51
	<b>3,301</b>	<b>2,619</b>	<b>2,337</b>	<b>2,552</b>

#### 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 2021

#### 9. Grants Payable

	2021 £'000	2020 £'000
Grant creditor at 31 March 2020	12,299	12,503
Grants paid during the year	(3,914)	(4,366)
Grants approved before 31 March 2021 and payable within one year	2,347	2,413
Grants approved before 31 March 2021 and payable after one year	1,498	1,749
<b>Grant creditor at 31 March 2021</b>	<b>12,230</b>	<b>12,299</b>

#### Represented by

Grants due within one year at 31 March 2021	7,407	7,135
Grants due > 12 months	4,823	5,165
	<b>12,230</b>	<b>12,300</b>

#### 10. Creditors

	Group 2021 £'000	Group 2020 £'000	Charity 2021 £'000	Charity 2020 £'000
Trade creditors	408	195	408	194
Other creditors	120	129	120	129
Accruals and deferred income	882	382	876	376
	<b>1,410</b>	<b>705</b>	<b>1,404</b>	<b>699</b>

#### 11. Financial Instruments (Assets and Liabilities)

	Group 2021 £'000	Group 2020 £'000	Charity 2021 £'000	Charity 2020 £'000
Financial assets measured at amortised cost (note a)	15,724	13,241	15,724	13,241
Financial assets measured at fair value (note b)	5,196	5,309	5,196	5,309
Financial liabilities measured at amortised cost (note c)	(13,529)	(12,681)	(13,529)	(12,681)
<b>Net financial assets measured at amortised cost</b>	<b>7,391</b>	<b>5,869</b>	<b>7,391</b>	<b>5,869</b>

(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.

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 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:

	<b>Total 2021 £'000</b>	<b>Total 2020 £'000</b>
Sales and sundry income	<b>2,580</b>	1,078
Cost of sales and administration	<b>(1,437)</b>	(664)
Intercompany recharges	<b>(71)</b>	(86)
<b>Net contribution to parent charity</b>	<b>1,072</b>	<b>328</b>

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

	<b>Total 2021 £</b>	<b>Total 2020 £</b>
<b>Current assets</b>		
Debtors	<b>1,077,967</b>	305,005
Cash at bank	<b>120,205</b>	269,234
	<b>1,198,172</b>	<b>574,239</b>
<b>Creditors:</b> amounts falling due within one year	<b>(127,506)</b>	(245,834)
<b>Net current assets</b>	<b>1,070,666</b>	328,404
<b>Net assets</b>	<b>1,070,666</b>	328,404
<b>Capital and reserves</b>		
Called up share capital	<b>2</b>	2
Profit and loss account	<b>1,070,664</b>	328,402
<b>Shareholder's funds</b>	<b>1,070,666</b>	328,404

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

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

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 13. Leasing commitments

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

	2021 £'000	2020 £'000
Within one year	271	271
Between two and five years	813	1,084

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 four years of the lease are now committed.

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

	2021 £'000	2020 £'000
Within one year	6	6
Between two and five years	24	24

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 £27,729 (2019/20 – £10,285). In addition, 5 of the trustees (2019/20 – 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 2021

#### 16. Analysis of 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

#### Prior year funds

	Unrestricted	Endowment funds	Gene Therapy restricted	Other restricted	2020 £'000
	£'000	£'000	£'000	£'000	
Tangible fixed assets	7	-	-	-	7
Investments	4,772	898	-	-	5,670
Current assets	15,297	-	-	241	15,538
Internal obligations	-	-	-	-	-
Current liabilities	(7,840)	-	-	-	(7,840)
Liabilities due in more than one year	(5,178)	-	-	13	(5,165)
	7,058	898	-	254	8,210

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 17a. Current year fund movements

	Balance					Balance
	31 March 2020 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	31 March 2021 £'000
Fixed asset reserve	24	-	-	-	13	37
Appeal deficit: Innovation Hub at Cambridge	(1,079)	-	-	-	658	(421)
Strategic reserve	-	-	-	-	200	200
<b>Total designated reserves</b>	<b>(1,055)</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>871</b>	<b>(184)</b>
Operating reserve	3,366	-	-	-	82	3,448
Retained reserves	4,778	711	10,788	(11,058)	(206)	5,013
<b>Total general reserves</b>	<b>8,144</b>	<b>711</b>	<b>10,788</b>	<b>(11,058)</b>	<b>(124)</b>	<b>8,461</b>
<b>Total unrestricted funds</b>	<b>7,089</b>	<b>711</b>	<b>10,788</b>	<b>(11,058)</b>	<b>747</b>	<b>8,277</b>
<b>Restricted income funds:</b>						
<b>Appeal: Innovation Hub at Cambridge</b>	-	-	658	-	(658)	-
<b>Restricted funds related to research:</b>						
Gene therapy research	45	-	43	-	-	87
General medical research	-	-	179	(179)	-	-
Imperial 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)	-
UCL/Great Ormund St SRC – Therapeutic gene editing	-	-	379	(375)	-	4
Liverpool SRC – Antimicrobeal therapeutics PIPE-CF	-	-	375	(375)	-	-
Life expectancy project	(20)	-	-	(3)	-	(23)
Transition information resources	15	-	-	-	-	15
Other research related restricted funds	1	-	4	(13)	-	(7)
<b>Total funds related to research</b>	<b>41</b>	<b>-</b>	<b>1,074</b>	<b>(944)</b>	<b>(89)</b>	<b>83</b>

Continued on next page

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 17a. Current year fund movements (continued)

<b>Restricted funds related to Information and Support</b>						
E W Joseph/Homecare grants	36	-	7	(25)	-	17
Joseph Levy/Education Grants	13	-	19	(46)	-	(15)
Young Lives programme	6	-	61	(39)	-	28
Support services (including welfare grants)	81	-	224	(225)	-	80
CF Connect (youth and parents)	26	-	-	-	-	26
<b>Total funds related to Information and Support</b>	<b>162</b>	<b>-</b>	<b>311</b>	<b>(335)</b>	<b>-</b>	<b>137</b>
<b>Other funds – various categories:</b>						
Coombe Hill	8	-	-	-	-	8
Kings fund	-	-	-	-	-	-
SmartCare CF	(10)	-	-	-	-	(10)
Clinical Trials Accelerator Programme (CTAP)	-	-	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)	-	22
HDRUK grant award	(14)	-	9	-	-	(5)
Other older funds	32	-	69	(62)	-	37
<b>Total other funds</b>	<b>36</b>	<b>-</b>	<b>1,557</b>	<b>(1,562)</b>	<b>-</b>	<b>28</b>
<b>Total restricted reserves</b>	<b>239</b>	<b>-</b>	<b>3,599</b>	<b>(2,841)</b>	<b>(747)</b>	<b>248</b>
<b>Endowment funds:</b>						
Ena Bennie Endowment	443	52	-	(3)	-	491
EW Joseph Endowment	150	17	-	(1)	-	165
Joseph Levy Endowment	257	30	-	(2)	-	285
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other Endowment funds	27	1	-	-	-	28
<b>Total endowment funds</b>	<b>897</b>	<b>99</b>	<b>-</b>	<b>(6)</b>	<b>-</b>	<b>989</b>
<b>Total funds</b>	<b>8,225</b>	<b>810</b>	<b>14,387</b>	<b>(13,906)</b>	<b>-</b>	<b>9,514</b>

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 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 Cambridge University as part of the Innovation Hub flagship programme. To date we have received £1.58m 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.

A new designated fund was set up in the year, to fund any cost grant extensions that are requested by research grant recipients as a direct result of delays due to COVID-19 restrictions.

**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 £1.58m to date in funding towards the £2.0m commitment made to Cambridge University. 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.

**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

- **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.

Continued on next page

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 17a. Funds (continued)

##### ■ Other restricted funds:

**Coombe Hill** – funding education about cystic fibrosis.

**Kings College Hospital Award** – funding the development of the cystic fibrosis centre at Kings College Hospital. The funds have now been accessed in full and work is in progress to refurbish the CF Adult Unit at the Kings College Hospital.

**Paediatrics** – funding work in the paediatrics department at the Royal Brompton Hospital, including peer reviews.

**Vertex Everest Trip** – funding an awareness-raising and fundraising trip to climb Mount Everest by a person with 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 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.
- The balance of the Strategic Reserve was moved into Retained Reserves.
- 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 2021

#### 17b. Prior year fund movements

	Balance					Balance
	31 March 2019 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	31 March 2020 £'000
Fixed asset reserve	40	-	-	-	(16)	24
Appeal deficit: Innovation Hub at Cambridge	(1,306)	-	-	-	227	(1,079)
Strategic reserve	-	-	-	-	-	-
<b>Total designated reserves</b>	<b>(1,266)</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>211</b>	<b>(1,055)</b>
Operating reserve	3,393	-	-	-	(27)	3,366
Retained reserves	4,960	(219)	13,981	(14,058)	114	4,778
<b>Total general reserves</b>	<b>8,353</b>	<b>(219)</b>	<b>13,981</b>	<b>(14,058)</b>	<b>87</b>	<b>8,144</b>
<b>Total unrestricted funds</b>	<b>7,087</b>	<b>(219)</b>	<b>13,981</b>	<b>(14,058)</b>	<b>298</b>	<b>7,089</b>
<b>Restricted income funds</b>						
Appeal for Innovation Hub at Cambridge	-	-	477	(250)	(227)	-
<b>Restricted funds related to research:</b>						
Gene therapy research	-	-	45	-	-	45
General medical research	-	-	106	(105)	(1)	-
UCL SRC: Personalised engineered cell therapies	-	-	8	-	(8)	-
Sport England – Helping the active stay active	9	-	57	(57)	(9)	-
Imperial SRC: <i>Pseudomonas aeruginosa</i>	-	-	42	-	(42)	-
Targeting immuno therapy for fungal infections-SRC15	-	-	14	-	(14)	-
RNA interference of ENAC as therapy for CF VIA 12	-	-	15	-	(15)	-
Life expectancy project	5	-	-	(25)	-	(20)
Transition information resources	15	-	-	-	-	15
VIA general awards	-	-	-	-	-	-
Other research related restricted funds	9	-	-	(7)	(1)	1
<b>Total funds related to research</b>	<b>38</b>	<b>-</b>	<b>287</b>	<b>(194)</b>	<b>(90)</b>	<b>41</b>

Continued on next page

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 17b. Prior year fund movements (continued)

	Balance					Balance
	31 March 2019 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	31 March 2020 £'000
<b>Restricted funds related to Information &amp; Support:</b>						
E W Joseph/Homecare grants	62	-	2	(28)	-	36
Joseph Levy/Education Grants	(12)	-	82	(69)	12	13
Young lives programme	49	-	48	(91)	-	6
Support services (inc. welfare grants)	70	-	117	(107)	1	81
CF Connect (youth and parents)	26	-	-	-	-	26
<b>Total funds related to Information &amp; Support</b>	<b>195</b>	<b>-</b>	<b>249</b>	<b>(295)</b>	<b>13</b>	<b>162</b>
<b>Other funds – various categories:</b>						
Coombe Hill	40	-	-	(15)	(17)	8
Kings Fund	157	-	-	(157)	-	-
SmartCareCF	(10)	-	-	-	-	(10)
CTAP – Clinical Trials Accelerator Platform	-	-	856	(856)	-	-
Digital Health Research Programme	-	-	647	(647)	-	-
CF Registry	1	-	-	(6)	-	(5)
Patient Reported Experience Measures	-	-	3	(1)	-	2
Consensus documents	1	-	25	(2)	-	23
HDRUK Grant Award	-	-	-	(14)	-	(14)
Other older funds	(4)	-	2	2	31	31
<b>Total other funds</b>	<b>184</b>	<b>-</b>	<b>1,533</b>	<b>(1,696)</b>	<b>15</b>	<b>36</b>
<b>Total restricted reserves</b>	<b>417</b>	<b>-</b>	<b>2,546</b>	<b>(2,435)</b>	<b>(289)</b>	<b>239</b>
<b>Endowment funds:</b>						
Ena Bennie Endowment	522	(67)	-	(4)	(8)	443
EW Joseph Endowment	173	(22)	-	(1)	-	150
Joseph Levy Endowment	297	(38)	-	(2)	-	257
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other endowment funds	35	(7)	-	-	(1)	27
<b>Total endowment funds</b>	<b>1,047</b>	<b>(134)</b>	<b>-</b>	<b>(7)</b>	<b>(9)</b>	<b>897</b>
<b>Total funds</b>	<b>8,551</b>	<b>(353)</b>	<b>16,527</b>	<b>(16,500)</b>	<b>-</b>	<b>8,225</b>

## Cystic Fibrosis Trust

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

For the year ended 31 March 2021

#### 18. Prior year Consolidated Statement of Financial Activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2020 £'000	Total Funds 2019 £'000
<b>Income and endowments from:</b>						
Donations and legacies	2	12,657	2,539	-	15,196	16,054
Other trading activities	12	1,078	-	-	1,078	1,321
Investments	2b,6	142	7	-	149	273
<b>Other income:</b>						
Other income	2	104	-	-	104	121
<b>Total</b>		<b>13,981</b>	<b>2,546</b>	<b>-</b>	<b>16,527</b>	<b>17,769</b>
<b>Expenditure on:</b>						
Raising funds	3	3,545	15	3	3,563	3,517
<b>Charitable activities</b>						
Research		3,346	1,085	1	4,432	4,695
Clinical care	3	1,085	1,047	-	2,132	1,804
Information, advice & support		6,082	288	3	6,373	5,722
<b>Total charitable activities</b>		<b>10,513</b>	<b>2,420</b>	<b>4</b>	<b>12,937</b>	<b>12,221</b>
<b>Total resources expended</b>	3	<b>14,058</b>	<b>2,435</b>	<b>7</b>	<b>16,500</b>	<b>15,738</b>
<b>Net income/(expenditure) before investment gains/losses</b>		<b>(77)</b>	<b>111</b>	<b>(7)</b>	<b>27</b>	<b>2,031</b>
Realised investment gains/(losses)		38	-	-	38	4
Unrealised investment gains/(losses)		(257)	-	(134)	(391)	22
<b>Net investment gains/(losses)</b>		<b>(219)</b>	<b>-</b>	<b>(134)</b>	<b>(353)</b>	<b>22</b>
<b>Net (expenditure) income</b>		<b>(296)</b>	<b>111</b>	<b>(141)</b>	<b>(326)</b>	<b>2,053</b>
Transfers between funds	17a	298	(289)	(9)	-	-
<b>Net movement in funds</b>		<b>2</b>	<b>(178)</b>	<b>(150)</b>	<b>(326)</b>	<b>2,053</b>
<b>Reconciliation of funds:</b>						
Total funds brought forward		7,087	417	1,047	8,551	6,498
<b>Total funds carried forward</b>	17a	<b>7,089</b>	<b>239</b>	<b>897</b>	<b>8,225</b>	<b>8,551</b>

## Structure, governance and management

### > Patron

- HRH The Prince of Wales KG KT GCB OM
- 

### > Honorary President

- Dr James Littlewood OBE MO FRCP FRCPE DCH
- 

### > Trustees

#### Chairman

- Richard Hunt

- Professor Andrew Jones
  - Michael Winehouse<sup>1</sup>
  - Louise King<sup>1</sup>
  - Ffyona Dawber
  - Professor Rosalind Smyth
  - Sean Collins
  - Anne Byrne
  - Richard Hoey
  - David Titmuss
  - Michelle Shore<sup>1</sup>
  - Joanna Barret<sup>1</sup>
- 

### > Finance Committee

#### Chairman

- Sean Collins

- Anne Byrne
  - David Sawyer (Independent member)
  - Michelle Shore<sup>1</sup>
  - David Titmuss
  - Ed Rushton (Investments Committee)
  - Nick Wood (Investments Committee)
- 

### > People Committee

#### Chairperson

- Michelle Shore<sup>1</sup>
  - Ffyona Dawber
  - Louise King
  - Michael Winehouse
  - Joanna Barrett<sup>1</sup>
- 

### > Charity Management

- David Ramsden – Chief Executive
  - Louise Honeysett FCA – Director of Finance and Resources
  - Dr Keith Brownlee – Director of Medical Affairs
  - Anne Shinkwin – Director of Fundraising
  - Rebecca Cosgriff – Director of Data & Quality Improvement
  - Clare Corbett – Director of External Affairs
  - Dr Lucy Allen – Director of Research
- 

### > Company Secretary

- Louise Honeysett FCA – Director of Finance and Resources
- 

### > Principal and Registered Office

One Aldgate  
London  
EC3N 1RE

**T** 020 3795 1555

**E** enquiries@cysticfibrosis.org.uk

**W** 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

---

<sup>1</sup> Indicates either person with cystic fibrosis, carer or close relative of someone with cystic fibrosis.

### > **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, 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, David Ramsden, and his Senior Leadership Team (SLT).

The Chief Executive 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 the 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 12 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.

## Currently active VIA awards

VIA	Lead investigator	Institution	Amount	Title
VIA035	Dr Fred Piehl	Imperial College London	42500	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data
VIA036	Dr Fred Piehl	Imperial College London	42500	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data
VIA038	Dr Andres Floto	Cambridge University	45000	Post-Doctoral Research Associate Machine Learning
VIA039	Ms Laura Birch	Bristol University	25000	Dietary manipulation to improve glycaemic control in young people with cystic fibrosis and altered glucose handling: A feasibility study
VIA044	Professor Jane Davies	Imperial College London	90000	RAPID point-of-care infection detection and antibiotic-resistance TESTING enabled with laser-patterned microfluidic devices (RAPID-TEST)
VIA045	Professor Chris van der Gast	Manchester Metropolitan University	45950.5	Detection of CF lung pathogens using engineered bacteriophages
VIA047	Professor Jane Davies	Imperial College London/Cycle Pharma	30000	Preclinical testing to repurpose of Glatiramer Acetate (GA) for treatment of <i>Pseudomonas aeruginosa</i>
VIA051	Dr Tanmay Bharat	Action Medical Research	89917.5	Elucidating the structural role of filamentous bacteriophage in <i>Pseudomonas aeruginosa</i> biofilms for disrupting infection in cystic fibrosis airways
VIA052	Professor Jane Davies	Imperial College London	50000	Exploring the utility of novel ‘antimicrobial resistance breakers’ on strains of <i>Pseudomonas aeruginosa</i> obtained from patients with cystic fibrosis
VIA059	Dr Joseph Jacob	UCL	50000	Quantifying bronchiectasis severity in cystic fibrosis
VIA061	Prof Alan Smyth	University of Nottingham	35369	Gut Imaging for Function and Transit in CF – The GIFT Study
VIA062	Prof Miguel Camara	University of Nottingham	50000	Scholarship for the National Biofilms Innovation Centre (NBIC)
VIA063	Prof Stephen Hart	University College London	51545	Development of in vitro Transcribed mRNA Therapeutics for cystic fibrosis
VIA064	Dr Andrew Jones	University of Manchester	34000	Arthropathy in Adults with cystic fibrosis

## Currently active VIA awards

VIA	Lead investigator	Institution	Amount	Title
VIA065	Prof Mark Baird	Diagnostig Ltd	20000	Development of a rapid diagnosis of infection with non-tuberculous mycobacteria in immune-compromised patients
VIA 067	Dr Martin Welch	University of Cambridge	33000	Tackling CF Lung Infection in vitro: Assessing the Global Impact of Antibiotics on the CF Airway Microflora in a Laboratory Bioreactor
VIA 068	Professor Jane Davies	Imperial College London	98594.93	The idealised LCI (i-LCI): Tuning in on the 'silent years' of paediatric CF
VIA 069	Dr Robert Gray	Edinburgh University	47000	Cystic fibrosis lung repair
VIA 070	Dr Laura Nolan	Imperial College London	30000	Understanding interbacterial competition in the cystic fibrosis lung to identify opportunities for intervention
VIA 071	Dr Elise Lammertyn	ECFS	20607	Clinical Trials Network (ECFS-CTN)
VIA 072	Dr Charles Haworth	Papworth Hospital	36000	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis
VIA 073	Dr Viek Dua	University College London	50000	Modelling and machine learning to aid the design of CF therapy
VIA 076	Dr Luke Allsopp	Imperial College London	20000	In the thick of it: Competitive Microbial Interactions in Biofilms
VIA 077	Prof Chris van der Gast	Manchester Metropolitan University	47000	Organisation and function of the gut microbiota in cystic fibrosis
VIA 078	Prof Chris van der Gast	Manchester Metropolitan University	48000	Non-tuberculosis mycobacteria infection and the wider lung microbiota in cystic fibrosis
VIA 079	Professor Soraya Shirazi-Beechey	University of Liverpool	32600	Restoration of luminal fluidity and microbiota in the CF gut (CFGJ-SRC)
VIA 081	Dr Anand Shah	Imperial College London	38000	FREAL – Fungal Resistance Evolution and Acquisition in chronic Lung disease
VIA 082	Dr Elise Lammertyn	ECFS	21304	Clinical Trials Network (ECFS-CTN)
VIA 083	Dr Paul McNally	Our Lady's Children's Hospital	97297	"RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in people with CF)"
VIA 084	Christine Dubois	ECFS	20000	ECFS & CFE Post-Doctoral Research Fellowship

## Currently active VIA awards

VIA	Lead investigator	Institution	Amount	Title
VIA 085	Professor Jane Davies	Imperial College London	50000	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
VIA 086	Dr Christabella Ng	University of Nottingham	65000	Gut Imaging for Function & Transit in cystic fibrosis Study 3
VIA 087	Prof Andres Floto	University of Cambridge	3000	Screening natural antibiotics against <i>Mycobacterium abscessus</i>
VIA 088	Prof Kevin Southern	University of Liverpool	18931.7	A randomised registry-based open label study to assess change in respiratory function for people with cystic fibrosis (pwCF) with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of muco-active aerosolised therapies (the CF STORM study)
VIA 090	Prof Michael Givskov	University of Copenhagen	26500	'Co-therapy of a novel <i>Pseudomonas aeruginosa</i> biofilm disruptor with standard of care antibiotics'
VIA 091	Dr Elise Lammertyn	ECFS	20607	Clinical Trials Network (ECFS-CTN)
VIA 092	Dr James Reihill	Queen's University Belfast	15000	The ubiquitylation system as a therapeutic target in CF
VIA 093	Dr Anand Shah	Imperial College London	15000	Development and validation of the use of videogames and virtual reality to enable autonomous remote monitoring of ototoxicity in high-risk population groups
VIA 094	Prof Pietro Cicuta	University of Cambridge	40000	Technologies for an in-vitro carbon copy of lung disease
VIA 095	Dr Beverly Isherwood	Medicines Discovery Catapult	49500	CF AMR Biorepository

## Committed VIA Awards 2020/21

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment	Source of External Funds	External Leveraged Funds
087	Prof Andres Floto	University of Cambridge	Screening natural antibiotics against <i>Mycobacterium abscessus</i>	£3,000	Demuris, University of Cambridge	£21,350
088	Prof Kevin Southern	University of Liverpool	CF STORM	£18,932	NIHR HTA	£1,492,268
089	Unsuccessful supporting bid – grant cancelled					
090	Prof Michael Givskov	University of Copenhagen	Co-therapy of a novel <i>Pseudomonas aeruginosa</i> biofilm disruptor with standard of care antibiotics	£26,500	Innovation Fund Denmark	£180,905
091	n/a	ECFS	Clinical Trials Network (ECFS-CTN)	£21,215	ECFS, CFE	£120,000
092 (pending successful review)	Dr James Reihill	Queen's University Belfast	The ubiquitylation system as a therapeutic target in CF	£15,000	Almac Discovery, UKRI Innovation Scholars Secondment	£300,000
093	Drs Anand Shah & Lorenzo Picinali	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	£14,374	RNID	£14,374
094 (pending successful review)	Dr Pietro Cicuta	University of Cambridge	Technologies for an in-vitro carbon copy of lung disease	£40,000	EPSRC	£300,000
095	Dr Beverly Isherwood	Medicines Discovery Catapult	Support for the CF Syndicate in AMR biorepository pilot	£49,500	Medicines Discovery Catapult	£49,500
<b>Total CF Trust Committed</b>				£188,521	<b>Total Potential Leverage</b>	£2,478,397

## Summer Studentships

Supervisor	Host Institution	Student & Project
<b>Dr Bettina Schock</b>	Queen's University Belfast	Miss Orla Fanthorpe – DREAM regulation of CF airways inflammation
<b>Dr Helen Weavers</b>	University of Bristol	Miss Isobel Davis – Developing a novel in vivo model of cystic fibrosis to explore cross-talk between airway damage, chronic inflammation and infection
<b>Dr Robert Gray</b>	University of Edinburgh	Miss Loren Hunt – Overexpression of CF antigen (Calprotectin) in the airways of people with CF
<b>Prof Adilia Warris</b>	University of Exeter	Mr Henry Phillips – Combatting CF-related Aspergillus infections with a combined treatment of antifungals and CFTR modulators
<b>Dr Malcolm Brodlie</b>	Newcastle University	Mr Robbie Bain – Characterisation of SARS-CoV-2 in people with cystic fibrosis



**[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)**

© Cystic Fibrosis Trust 2021. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 2nd Floor, One Aldgate, London EC3N 1RE.