

Cystic Fibrosis Trust

Impact Report 2020/21



Fighting for a
Life Unlimited

Cystic fibrosis (CF) is a devastating condition that affects over 10,655 people in the UK. It's caused by a faulty gene that causes the lungs to fill with thick mucus, making it hard to breathe and clear harmful bacteria. People with CF are also susceptible to catching dangerous bacteria, meaning that they can never meet each other in person.

While there is no cure for CF, there are treatments, including Kaftrio, which was made accessible for those eligible in England and Wales in 2020. However, Kaftrio is not suitable for everyone with CF, and we will continue to fight for those who are ineligible to ensure everyone affected by CF can live their lives unlimited by the condition.

This means funding ground-breaking research, fighting for access to lifesaving drugs for everyone who could benefit from them, providing vital information and support, and promoting the highest quality of clinical care.

In this report you will hear about our work over the past year, from April 2020 to March 2021, and find out how your incredible support has had a positive impact on people with CF throughout a hugely challenging time.

*Thank you from everyone
at the Trust.*



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“Your support has never been more important than over the last 12 months.

The continuing COVID-19 pandemic meant that for much of the year, people with CF were ‘shielding’, many faced financial hardship and disruption to care, alongside anxiety and concern for themselves and their loved ones.

The community has shown great resilience through such difficult times, and the Trust has continued to respond by offering direct support wherever possible, and a range of specific information and guidance. We also ensured we continued our important advocacy work, and supported research for the longer-term needs of people with CF.

The continued roll-out of Kaftrio has been life-changing for many. However, we know that it doesn’t work for everyone, it’s not a cure and many other health and support needs remain.

We will not stop until every person with CF can live a life unlimited – physically and mentally well and fulfilled in the life they’ve chosen.

I hope you’re truly proud of what you continue to make possible. Thank you.”

– David Ramsden, Chief Executive

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, and the financial burden, through to the effectiveness of vaccines on those post-transplant, we have worked tirelessly to provide timely information and support to those with CF and their families.

Shielding

People with CF were identified as extremely clinically vulnerable to COVID-19 by the Government and instructed to shield immediately. The shielding process was set up for 12 weeks, but 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 to manage their condition and stay healthy.

Demand for our services

The demand for our services rocketed at an unprecedented rate, at a time when the Trust was facing a substantial drop in fundraising income due to cancellations of many of our key fundraising events.

Coronavirus Hub

We provided regular updates through our dedicated Coronavirus Hub on our website and via our social media channels.

UK CF Medical Association (CFMA)

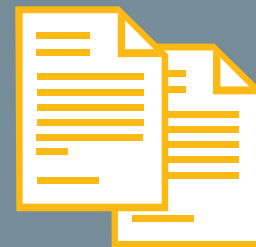
Thanks to the support of the UK CFMA we were able to provide regularly updated guidance from clinical experts to help the CF community stay safe and make informed choices during the pandemic.

Over the past year, we:

had over

100,000

visits per day, at its peak, to our broad Q&A content



answered

822

Helpline enquiries relating to COVID-19



provided essential welfare rights information, viewed over

20,000

times on our website



saw more than

35,000

views to our shielding advice pages

and our section on our collaboration with the UKCFMA received over

50,000+

views at the peak of the pandemic



Campaigning hard

We campaign tirelessly to make sure the voice of our community is heard loud and clear.

Since the start of the COVID-19 pandemic we have worked to ensure appropriate support for the shielding population across the UK, with focus on access to financial support, food and essential services and support for education and employment.

By advocating for clear and timely communications from the Government, particularly around shielding guidance, we worked quickly to interpret and share the latest guidance with our community to keep them safe. Keeping people with CF at the heart of what we do, we continued to raise the concerns of the CF community with policy makers.

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

Our work paid off:

- We secured improved priority access to supermarket deliveries for those who were shielding.
- We got home spirometers delivered to over 4,000 people with CF so that they could monitor their condition safely at home during the pandemic.
- We helped to move those who were most clinically extremely vulnerable higher up the COVID-19 vaccine priority list, resulting in faster access to the vaccine for adults with CF.



Thank you for supporting our emergency appeal

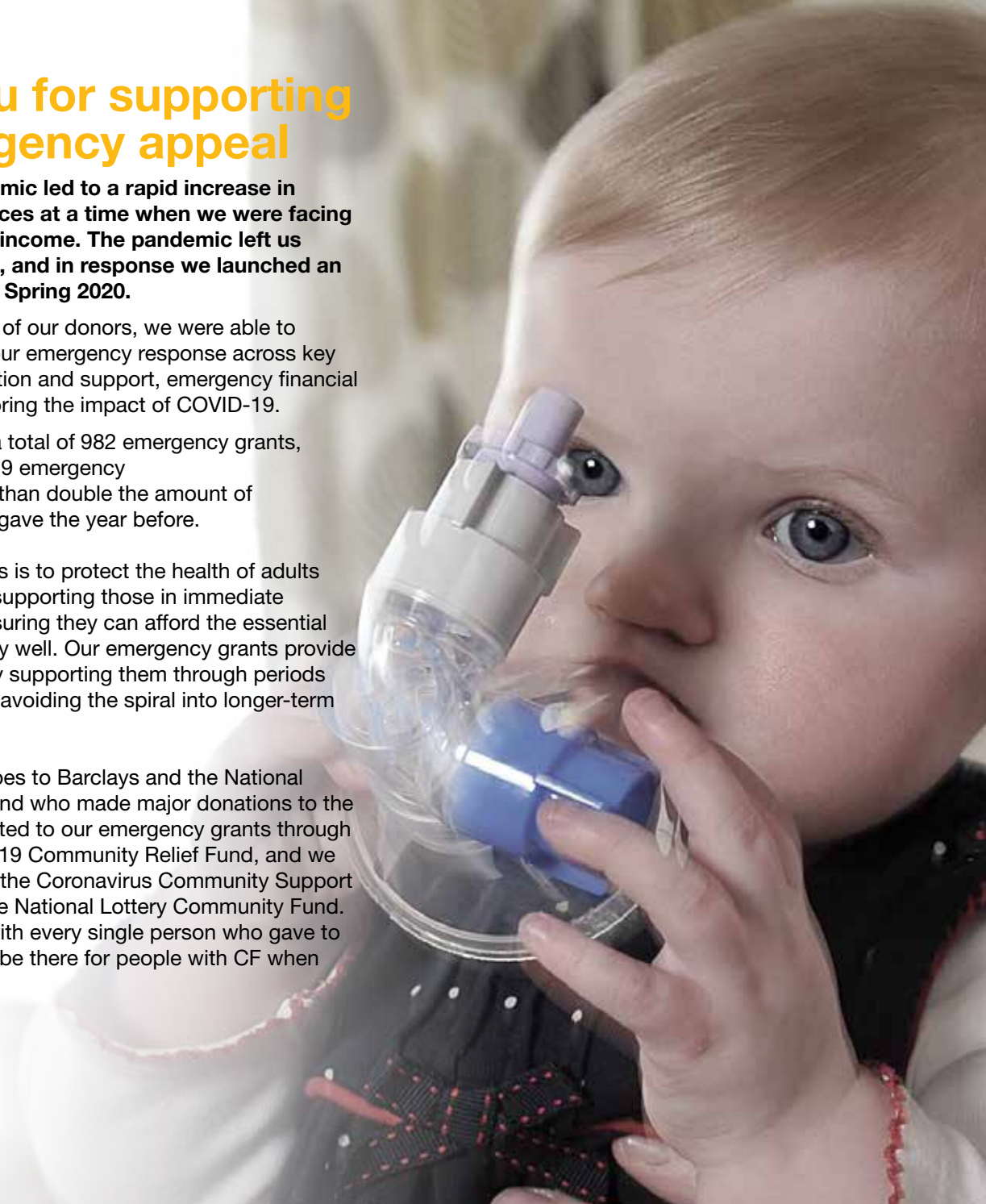
The COVID-19 pandemic led to a rapid increase in demand for our services at a time when we were facing a substantial drop in income. The pandemic left us facing tough choices, and in response we launched an emergency appeal in Spring 2020.

Thanks to the support of our donors, we were able to increase the scale of our emergency response across key areas such as information and support, emergency financial assistance and monitoring the impact of COVID-19.

We were able to give a total of 982 emergency grants, including our COVID-19 emergency exercise grants, more than double the amount of emergency grants we gave the year before.

The focus of our grants is to protect the health of adults and children with CF, supporting those in immediate financial crisis and ensuring they can afford the essential items they need to stay well. 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.

A special thank you goes to Barclays and the National Lottery Community Fund who made major donations to the appeal. Barclays donated to our emergency grants through their 100X100 COVID-19 Community Relief Fund, and we received funding from the Coronavirus Community Support Fund distributed by the National Lottery Community Fund. Their support, along with every single person who gave to our appeal, helped us be there for people with CF when they needed us most.



COVID-19 and the UK CF Registry

Although the Government identified people with cystic fibrosis as extremely clinically vulnerable to COVID-19, we entered the pandemic with very little clinical evidence into how COVID-19 would impact the CF community.

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.

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. We remain at the forefront of monitoring the impact of COVID-19 in people with CF.



The impact of Kaftrio on the CF community

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

Kaftrio, the first triple combination therapy for the treatment of CF, is a modulator therapy currently licensed for use in the UK for those over 12, who have 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 breakthrough followed years of relentless campaigning alongside the CF community, supporters, and parliamentarians to fight for access to new medicines. Our campaign included parliamentary debates, protests, and a health committee inquiry.

However, Kaftrio is not suitable for everyone, and so our work continues to find 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 we will continue to invest in research to find treatments for those who can’t. We will not stop.”

We will continue to fund research with the goal of finding treatments for all, so that no one is left behind.

Find out more at cysticfibrosis.org.uk/the-work-we-do/campaigning-hard/life-saving-drugs

“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.” – Lucy



Innovation Hub

The UK Cystic Fibrosis Innovation Hub is a ground-breaking partnership between Cystic Fibrosis Trust and the University of Cambridge, bringing together the UK's leading experts in lung health to prevent lung damage in cystic fibrosis.

It's concentrating on three areas of research to improve lung health: to develop better antibiotics and anti-inflammatories, to predict when exacerbations are likely to happen and what causes them, and to look at ways to repair existing lung damage.

Since being established in 2018, significant progress has been made during the first phase of the Hub:

- Novel antibiotic compounds have been developed that have activity against *M. abscessus* in vitro
- New Artificial-Intelligence 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 antimicrobial resistance 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.

The Trust has committed to raising £5 million over five years for the Innovation Hub, which the University of Cambridge has agreed to match pound for pound.



Find out the latest updates at
cysticfibrosis.org.uk/innovationhub



Robert Luff Foundation

The Robert Luff Foundation is a medical research charity and a longstanding partner of Cystic Fibrosis Trust for over 25 years, with donations totalling almost £4million.

In 2018, the Robert Luff Foundation chose to partner with the Cystic Fibrosis Trust to become one of two cornerstone supporters of the UK's first Innovation Hub and Centre of Excellence for cystic fibrosis research.

We caught up with Richard Price, Trustee and Secretary of the Foundation, to find out more about why the Trust has been so close to their hearts for a quarter of a century.

“Cystic Fibrosis Trust was a charity very close to the heart of Robert Luff, and so it has always been central to the purpose of the Foundation. Robert’s niece, Linda, had three children, two of whom were born with the condition.

Linda was married to Sir Robert Johnson QC, who was a Trustee of the Cystic Fibrosis Trust from its inception in 1964, and served as a board member, vice-chair and fundraiser for many years, before assuming the role of chair in about 2006/7. The Trust is therefore very special to the Foundation.

“We’re a volunteer-based organisation, so there are no paid members of staff. We review applications once a year when the Trustees consider the overall position of the Foundation. We distribute over £1million a year in grants to medical research charities and are lucky to have Mr Luff’s great niece, Melanie, and great nephew, Matthew, on the Board.



“We continue to support the charities Mr Luff chose, but we want to be sure our investments are well-placed. When considering any proposal, we also consider a charity’s reputation and their previous success in delivering high quality research outcomes. We require regular reports from our grantees to tell us about the progress they’ve made and the impact that the project is having on its intended beneficiaries.

“We’re very pleased to be able to continue to support the Cystic Fibrosis Innovation Hub in partnership with the University of Cambridge. The Trustees are really impressed with the work of the Hub over the last three years, and how it brings together people of all disciplines for the benefit of CF research. We are very happy to support such an exciting project, and really want to see it succeed.”



Richard Price

Clinical Trials Accelerator Platform

With more advances in cystic fibrosis (CF) care and treatment than ever before, and a host of new treatments in the pipeline, this has been an exciting time for the CF community. The Trust's Trials Accelerator was set up to create a UK-wide initiative that brings together CF centres to increase the number of CF trials running in the UK and the opportunities for people living with CF to participate in clinical trials.

Since launching in 2017, we have increased the number of CF centres who can run trials, funded a national team of 20 CF Trial Coordinators and created a wealth of information about taking part in clinical trials on our Clinical Trials Hub. We collaborate with pharmaceutical companies and researchers to showcase the UK as a desirable country in which to invest in CF clinical trials, bringing even more trials to the UK CF community than ever before.

Key achievements:

27

centres that collectively cover over 80% of UK CF community



871

people screened for clinical trials (246 of these screenings took place in the last year)



34

CF trials have been open for recruitment (seven over the course of the year)



726

people with CF have enrolled to a clinical trial (224 of these enrolments took place in the last year)



The 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 (Cystic Fibrosis Foundation) 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.

To find out more, visit cysticfibrosis.org.uk/clinicaltrials

Providing vital information and support

Cystic fibrosis is a complex condition that makes it harder to live a healthy, happy and productive life. We provide trusted, accessible and reliable information and support in all areas, allowing the CF community to get the help they need to live well with their condition.



This year we awarded over 1,393 welfare grants, totalling

£263,000

314

people supported by our Specialist Welfare Advisor, helping people access at least £1.6 million in benefits



£26,000

provided in grants to support people who are experiencing particularly poor health or a personal crisis so that they can be safe and comfortable at home



4,400

enquiries responded to by our Helpline team. Over 800 of these queries related to COVID-19

We secured a further three years of funding from BBC Children in Need for our Building Brighter Futures youth activity programme



£43,000+

spent 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

Helen Barrett

Bright Ideas Awards

For some people with cystic fibrosis, working for themselves can offer the flexibility and work-life balance that allows them to focus on both their health and their career. Helen Barrett was one such person: she dreamed of owning her own business and refused to let her CF hold her back, setting up a successful gym with her partner that is still thriving today.

Sadly, Helen died in 2010 aged 32, but her legacy continues to support other people with CF who wish to follow in her footsteps and set up their own business. The Helen Barrett Bright Ideas Awards offer grants and support to people aged 18 and over living with CF who want to pursue their dream of running their own business.

Despite the pandemic, the Trust received a record number of applications for this year's Awards. Two of the recipients were Jonathan Whittaker, whose company designs and develops swimming pool products, and artist Ellie Wilkinson, who paints limited edition fine art prints inspired by mythology from around the globe.



Jonathan



Ellie

“It was amazing to meet other people in the same circumstances as me and get help with business advice.” – Ellie

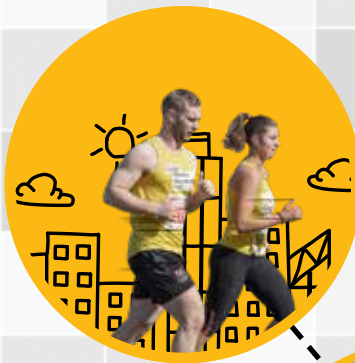
Ellie used the grant she received to cover the set-up costs involved with selling fine art prints, purchasing a fine art scanner and setting up her own website - while also teaching herself CSS coding in the process! Jonathan was able to sell more products and use the money to place orders with manufacturers, securing lower costs and keeping his products flowing.

Fundraising

2020/21 was a very challenging year for fundraising, with many external events and activities cancelled due to COVID-19 restrictions. This impact was seen across the whole charity sector, but we quickly adapted our plans, making our events virtual where possible and launching new activities.

Thanks to the continued commitment of our incredible supporters, donors and partners, the Trust raised £5.6 million net income. While this was a 24% reduction in our income compared to the previous year, we were overwhelmed by the response to our Emergency COVID-19 Appeal. We raised a phenomenal amount, ensuring that we could continue to support people with CF during this incredibly challenging time.

£260,000 raised from virtual events



£75,000 raised from Wear Yellow Day and our virtual Big Yellow party



£125,000 raised from participants of the 2.6 challenge



£17,000 raised from the launch of our FeBREWary campaign



£61,000 raised from Carols by Candlelight which was held online for the first time



HRH The Prince of Wales continues as Cystic Fibrosis Trust Patron

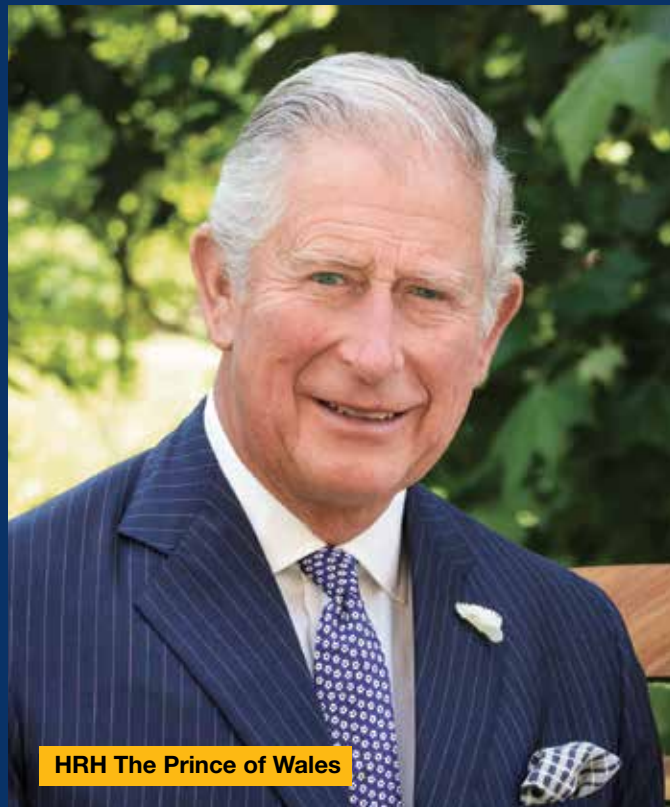
In November 2020 HRH The Prince of Wales confirmed that he will continue his Patronage of Cystic Fibrosis Trust for a further term.

HRH The Prince of Wales first became our Patron in 2014, having taken over from Princess Alexandra, who worked with the Trust for over 50 years. He hosted the Trust's 50th anniversary event at Clarence House that same year, commenting:

“Having for so long felt deeply about the suffering of cystic fibrosis patients, I am delighted to take on patronage of Cystic Fibrosis Trust from Princess Alexandra in this, the Trust's 50th year. By funding ground-breaking research, improving the quality of care and providing invaluable advice and support, the Trust carries out extraordinary work on behalf of people with cystic fibrosis in the United Kingdom.

The progress that has been made to improve the lives of people with this condition is a wonderful tribute to the determination of the cystic fibrosis (CF) community and their families. As well as to the clinicians and health professionals, scientists and all those who support the Trust and its important work.”

Since then, HRH The Prince of Wales has attended Trust events and in 2018, members of the CF community and supporters of Cystic Fibrosis Trust were delighted to be among the guests at The Prince of Wales' 70th Birthday Patronage Celebration.



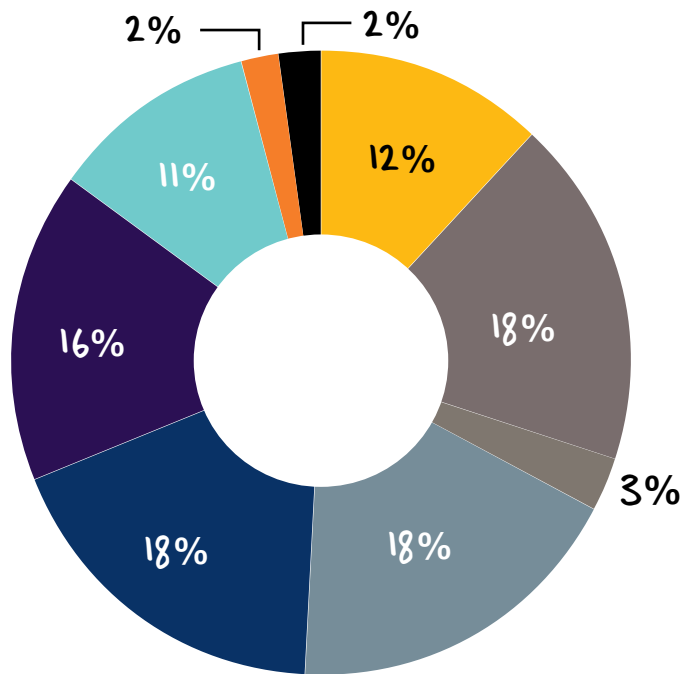
Richard Hunt CBE, Chair of Trustees at the Trust, welcomed the news of the continuation of the Patronage, saying:

“The Patronage of HRH The Prince of Wales is hugely significant to the Trust, helping, as it has, to raise awareness and the profile of a sometimes not well known and an often-misunderstood condition. We are delighted with His Royal Highness' commitment as the Trust enters a new chapter aiming for further progress in the treatment of cystic fibrosis and support for all those who live with its challenges.”

The Trust is proud and delighted to continue to work with HRH The Prince of Wales for many more years to come.

Income

The events of the past year have had a significant impact on fundraising, and the Trust has seen a 24% drop in donations and legacies compared to last year.

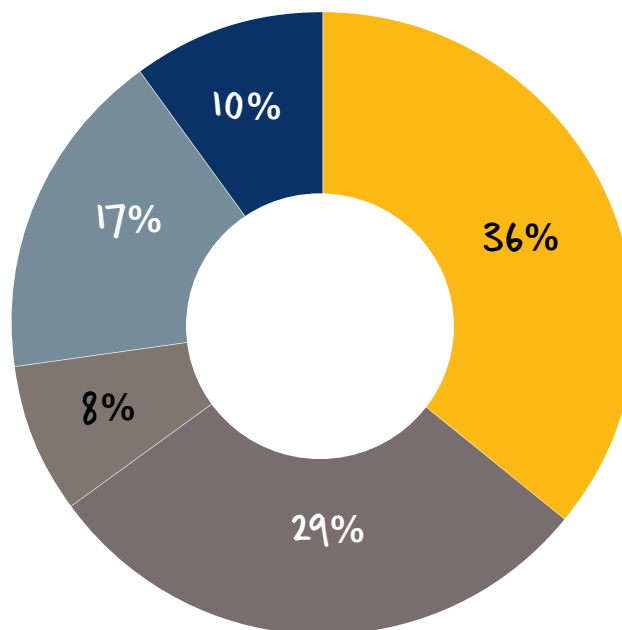


2020/21 income by income stream

- Branches, groups & community
- Regular and individual giving and appeals
- Corporate partnerships
- Trusts and Foundations
- Cystic Fibrosis Services Limited
- Legacies
- Donated goods and services
- Government grants
- Other income

| Income from normal activities: | | £'000 |
|---|--|--------|
| Branches, groups and community | | 1,672 |
| Regular and individual giving and appeals | | 2,626 |
| Corporate partnerships | | 377 |
| Trusts and Foundations | | 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 |
| Total income from normal activities | | 14,386 |

Total spend was 16% lower than last year, which was driven by COVID-19 related restrictions and delays.



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 |
| Charitable activities total | 10,185 |
| Costs of raising funds | 2,284 |
| Cystic Fibrosis Services Limited | 1,437 |
| Total expenditure | 13,906 |

Full details of our accounts can be found in our Annual Report and Financial Statements at cysticfibrosis.org.uk/annualreview

Sixty Five Roses Club

Join our Sixty Five Roses Club for exclusive access to a quarterly newsletter, bespoke events and the opportunity to meet like-minded individuals helping us unite for a life unlimited. A generous pledge to gift a minimum of £1,000 a year, for a minimum of three years, will guarantee your membership to the Sixty Five Roses Club. These donations will help to fund vital projects.

Email sixtyfive@cysticfibrosis.org.uk for more information.

After face-to-face events were curtailed by COVID-19, the Club hosted two virtual events last year. Hosted by our CEO, and joined by experts and guest speakers, the events explored different areas of Trust funded research.

Committed Club member, Jane Faulkner, not only raised money for the Trust by running the London Marathon, she also did it wearing a giant fabric rose structure with 64 smaller roses pinned on, breaking the Guinness World Record for fastest time (female) dressed as a 3D plant!



"We have been involved in this wonderful charity ever since my son was diagnosed with CF and have seen how they tirelessly raise awareness of the condition, campaigning for access to the newest treatments and funding cutting edge research." – Jane

Thank you

A special thank you to all our incredible donors, supporters, fundraisers, challenge and event participants and generous volunteers. We would not be able to achieve our work without your support.

Collaborating globally is vital to ensure we are providing the best possible support to the CF community. We engage internationally in a number of ways and would particularly like to acknowledge partnership funding from the Cystic Fibrosis Foundation.

Individuals and families

- Dujardin Family ■ Mr and Mrs K Talbot
- Mr A C MacAlpine ■ Dr U Cartellieri ■ Mr S Gaiger
- Mrs N Carr ■ Mr P Whight ■ Mrs E Barnes
- Mr K Khalil and Ms S Boyle
- Andrew Saul and Catherine Iliff
- Mr and Mrs A Douglas ■ Dr J Winn

Corporates

- AJN Steelstock ■ Barclays ■ Gaiger Bros Ltd
- Lloyd's ■ Sony Europe B.V ■ Talent84
- Amazon Smile ■ Gilead Sciences Europe Ltd
- Whisky Auctioneer Ltd ■ Bridgepoint Hardship Fund

Trusts and Foundations

- Garfield Weston Foundation ■ Robert Luff Foundation
- The Coronavirus Community Support Fund, distributed by The National Lottery Community Fund
- CF Foundation ■ BBC Children in Need
- Joseph Levy Foundation ■ The Stoneygate Trust
- Sport England ■ Rosetrees Trust
- Sir Samuel Scott of Yews Trust

Gifts in Wills

We are incredibly grateful to all our generous supporters who kindly remembered those with CF by including a gift in their Will. These special gifts make a huge difference to our work, ensuring every person with CF in the UK can live a long and fulfilling life. The family and loved ones of the following estate agreed for us to acknowledge their kind gift.

- Mr Peter George Bundy

Online Book of Remembrance

Our Online Book of Remembrance is a special place to remember those we love, who are never forgotten, with respect and affection.

You can view the Online Book of Remembrance on our website: cysticfibrosis.org.uk/bookofremembrance



Cystic Fibrosis Trust

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