

**Cystic
Fibrosis Trust**

Let's write for a life unlimited

Impact report 2021/22



Uniting for a life unlimited

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. You are born with CF and cannot catch it later in life. One in 25 of us carries the faulty gene that causes it, usually without knowing. More than 10,800 people in the UK live with the condition, having to undergo a brutal daily regimen of physiotherapy and take up to 60 tablets a day just to stay healthy. Despite these treatments, many people with CF will go on to require a double lung transplant. The median age at which someone with CF dies is just 36 years old.

Our community is uniting towards the ultimate goal of effective treatment for all. We're at the forefront of innovation and progress. Boundaries will be broken by groundbreaking research and incredible discoveries that change lives for the better. To get there, we will use facts and information to empower us, we will inspire our community. We will campaign with passion. And support each other – improving care and building better mental resilience and physical health.

In this report, you'll learn all about our work from March 2021 to April 2022 and find out how your incredible support has made such a positive impact on people with CF and their families through another challenging year.

Thank you for uniting for a life unlimited with us.

On the cover – Youth Advisory Group (YAG) member Yasmin and her brother Kareem, who has CF



Supporter Alice and her family and friends

“At the Trust, we want everyone with cystic fibrosis to be physically well, mentally well and able to reach their full potential in a world that understands their needs and supports them in overcoming challenges.

We are in a time where there will be more people living with CF in the UK than ever before. For many people with CF, lives are getting longer and healthier. More young people will be completing education with the prospect of many years of employment. However, we know that not everyone with CF can benefit from these life changing treatments, and they are not a cure.

This means that we are facing a future where the community's health, treatment and support needs will become more diverse and complex. As the only UK-wide organisation dedicated to supporting and advocating for people with CF, we know that the Trust has a vital role to play in driving forward positive change – and we won't stop until everyone with cystic fibrosis can live without limits.

Thank you for uniting with us for a life unlimited for everyone with CF.”

David Ramsden, Chief Executive



David Ramsden

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Thanks to you, in 2021/22...



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



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



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



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



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



We saw a **120%** increase in cystic fibrosis-related searches online after the launch of our public awareness campaign #CFTruths.

The impact of COVID-19 on the CF community

In 2021/22 COVID-19 continued to challenge our community, with new variants circulating and cases rising. We focused on encouraging our community to get the COVID-19 vaccines and boosters, as well as informing them about new treatments available for people who are part of the clinically vulnerable group.

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

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



82% of people found our COVID-19 hub useful or very useful

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



Vicky and her husband Erik

"I try to cherish every day, and that's why the COVID-19 pandemic and shielding was so hard. It's had a huge impact on myself and Erik. I've tried my whole life to not let cystic fibrosis define me, and then COVID-19 came along and it felt like it was doing exactly that."

Vicky, received a double lung transplant over 20 years ago

Campaigning hard

We campaign hard to drive positive change for people with cystic fibrosis. Due to factors like COVID-19 and the conflict in Ukraine, the cost of living has been rising and the Trust has experienced an increase in demand for advice and support from across the community.

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



Research into better ways to treat CF lung infections

To live long and fulfilled lives everyone with CF needs access to effective medicines to treat CF lung infections, both for those able and unable to benefit from CFTR modulators such as Kaftrio.

New medicines to treat these infections are urgently needed due to antimicrobial resistance (AMR). This is where medicines such as antibiotics stop working as infection-causing bugs adapt themselves to avoid the effects of the treatment.

The Trust is supporting world-class research at the UK CF Innovation Hub to treat serious CF lung infections caused by *M. abscessus*. To develop novel ways to treat it, researchers at the University of Cambridge led by Professor Floto have made groundbreaking progress in understanding more about the causes of the infection.

“The aims of our research are to understand the biology of *M. abscessus*, how it works, how it causes disease and how it is passed on, but also to develop antibiotics to try and kill it,”

said Professor Andres Floto, Director of UK CF Innovation Hub at the University of Cambridge.

Professor Andres Floto

New medicines for CF infections need to be developed in a different way to medicines for other infections because of the environment within the lungs of people with CF.

The CF AMR Syndicate, a partnership between Cystic Fibrosis Trust, Medicine Discovery Catapult (MDC) and LifeArc, have developed a ‘toolkit’ of resources to overcome some of these difficulties and accelerate the development of new medicines.

“The idea is to make treating new CF infections, an exciting, attractive and easier area of research to work in – whether you are working in the ‘discovery’ end of the new medicines pipeline, or whether you are a biotech company seeking advice on the best ways to test a new medicine that would meet regulatory approval,”

said Dr Paula Sommer, Head of Research at Cystic Fibrosis Trust.

Dr Paula Sommer



Professor James Shaw

Investing in researchers

To continue to advance our knowledge and understanding of cystic fibrosis and develop more effective ways of treating the underlying condition, its symptoms and complications, we need to attract, retain and support scientists and clinicians working in cystic fibrosis research. One of the ways we do this is through our Strategic Research Centres (SRCs).

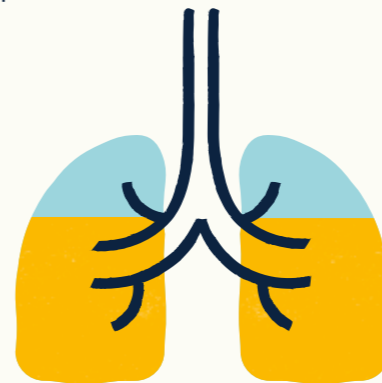
“Strategic Research Centres are a really wonderful mechanism of funding, bringing together scientists, particularly early career researchers for fantastically integrated science. They provide a forum for open exchange of ideas and collaborative working. The results are greater than the sum of the parts,”

said Professor James Shaw, CF-related diabetes SRC Principal Investigator.

An SRC award includes funding to train and support four or five early career researchers to work in the programme. The network within the SRC programme gives them peer support and the opportunity for exchange visits within the SRC to learn new skills and get to know other researchers working in different areas. Since 2013 we’ve funded 113 early career researchers.

Lucia Nicosia is studying for her PhD in Dr Patrick Harrison’s lab at University College Cork in Ireland. They’re part of the Trust’s ‘Therapeutic gene editing’ SRC led by Professor Stephen Hart.

“I’m going to visit two different labs within the SRC within a month. I’m going to France to test if my experiments work in cells that are a closer match for the lung cells in people with CF. A few weeks later I’ll then visit a lab in London, where I can test if my genetic editing makes a working copy of the CF protein. Our research is giving people with CF hope, and I think that’s just incredible,”
explained Lucia.



Dr Patrick Harrison and Lucia Nicosia



“The Trust has supported me at some important milestones in my career – from funding my PhD training, to receiving funding to train a PhD student myself. I’m now the lead researcher on a Strategic Research Centre award co-funded by the Trust and the CF Foundation in the United States.”

Dr Jo Fothergill, Reader in Microbiology, University of Liverpool.

We won’t stop developing the UK’s capacity to deliver CF research.

Refreshing the Research Priorities for CF

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

We know a lot has changed for people with CF in the years since the first research project. Many now have access to CFTR modulators, and due to the pandemic, many people's care will have changed. So this year, we felt it was time to review the research priorities and find out what matters most to the community right now.

A priority refresh project was set up – **QuestionCF** for short – and we are working with researchers at the University of Nottingham, people from the CF community, and the James Lind Alliance team at the National Institute for Health and Care Research (NIHR) to review these priorities and help shape the direction of future research.

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



"As a CF parent it can feel like you're a bit helpless and there's too many components that sit outside of your control. But being a part of QuestionCF has enabled us to feel like we're doing something proactive that we know will benefit so many people with CF."

Nicole, mum to Arlo, who has CF



Nicole and son Arlo



Katy

The impact of Kaftrio on the CF community

2022 saw the approval of Kaftrio for 6–11 year olds across the UK, following many years of campaigning by the Trust and the CF community. More than 1,500 children stand to benefit from this 'triple-combination therapy', which could limit the damage CF does in the critical early years. The Trust has worked closely with CF teams to support roll-out and ensure everyone who can benefit from the treatment can access it as quickly as possible.

For Stacey, mum to Katy, 8, who has CF, it was life-changing news:

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

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

Kaftrio is not a cure and not everyone with CF can benefit, and we won't stop until everyone with CF has access to the support and treatments they need.



The UK CF Registry

The UK CF Registry is a world-class database that includes data on over 99% of people with CF in the UK, who have consented to their data being submitted by their CF team. Anonymised Registry data is vital in supporting research, service improvement and information materials.

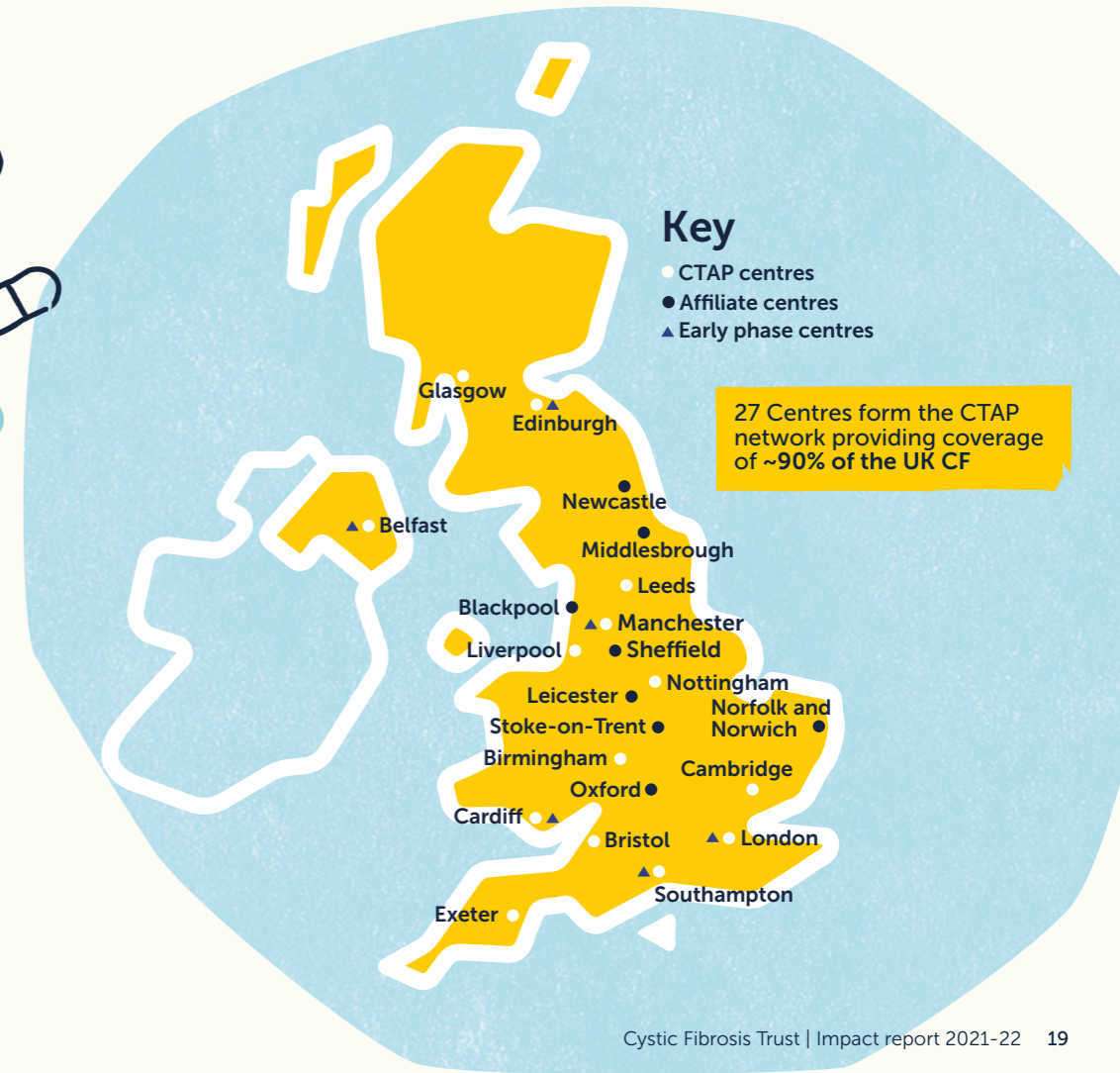
In 2021/22 the Registry team:

- supported the running of three drug safety studies and completed a fourth study
- supported the NHS to generate public reports and help with the commissioning of CF services in England
- approved 44 requests for data, bringing the overall total up to 457
- through working with the NHS and pharmaceutical companies, were able to generate over £1.8million, enabling us to provide grants to support centres in their data entry and fund other key aspects of our work
- launched CF Storm, the Registry-based clinical trial designed to find out whether people with CF can safely withdraw mucolytic therapy and reduce treatment burden of people with CF
- published our annual data report on 2020 data, including data on COVID-19 infections and the impact of the pandemic
- submitted anonymised 2020 data to the European CF Society Patient Registry.



Clinical Trials Accelerator Platform (CTAP)

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



Impact of CTAP

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



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



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



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

New five-year strategy

Over the last year, we have seen significant changes in the clinical and research landscape due to access to new modulator therapies, and also changes in the delivery of clinical care in response to the pandemic. Responding to these changes, a new five-year CTAP strategy was developed in collaboration with the CTAP governance board, CTAP centres and, most importantly, representatives from the CF patient community. CTAP's vision for the next five years is: To sustain the UK's position as a world leader in delivering a broad and innovative portfolio of clinical research in cystic fibrosis, accelerating the development of new and improved treatments for cystic fibrosis whilst acting as an exemplar for condition-specific clinical trial networks.

Community involvement

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

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

Engaging with Cystic Fibrosis Trust has been a blessing. Through their support, I have had the courage to speak up and share my story. The Trust has been the missing advocate for me... it gives me the opportunity for my voice to be heard on a range of topics that will shape future support for people with CF..."

Shad, who has CF



Shad

Providing vital information and support

Provided **940** grants totalling over **£292,000** helping to protect the health of people with CF by supporting those in urgent need to buy the basics they need to stay well



Supported **250** people on low incomes with a grant to fund household essentials such as food and energy



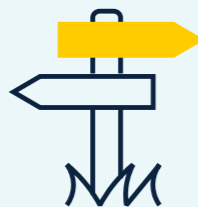
Provided over **£21,000** in homecare grants to support people with particularly poor health or in a personal crisis so they can be comfortable and safe at home



87 grants awarded through the Joseph Levy Education Fund, totalling just under **£47,000** to support people with CF into higher education or vocational training



Supported **305** people to navigate the benefits system



In 2021/22 we helped people to access at least **£1.025 million** in benefits



Supported **93** people to increase their household finances by an average of **£4,269** per household



Our Helpline responded to over **4,200** enquiries



Reaching all people with CF

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



CF Week 2021: a great success!

- raised over **£135,000**
- high-profile media coverage including BBC Breakfast and ITV's Lorraine
- out-of-home marketing campaign on 48 Clear Channel digital billboards
- an increase of 18.5% year on year on relevant CF Week website pages





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

Caitlin

#CFTruths

We launched #CFTruths, a public awareness campaign devised by Caitlin, who has CF and developed pro bono with Ogilvy Health. The campaign sought to raise awareness of CF amongst the general public and provide a space for our community to tell their own truth.

The campaign is still live, but since launch in March 2022:

- a **120%** increase in cystic fibrosis related keyword search terms to our website
- a potential reach of over **300,000** people with strong media coverage
- been visible on over **1,000** Clear Channel digital advertising billboards (media value over £200,000)
- reached almost **500,000** people through paid social media



Caitlin



Fundraising

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

The Trust continues to build back after the reduction in income due to COVID-19. In 2021/22, £7.4 million gross income was raised and £5.54 million net income, which is slightly higher than income raised in 2020/21 but lower than pre-pandemic net income by 25%.



Supporters holding collection buckets in Ballymoney

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

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

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

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

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

Regular gifts

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

Community and event fundraising

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

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



Corporate partnerships

The Trust continues to work in partnership with companies to raise funds and awareness of cystic fibrosis. We also work in partnership with companies to maximise the valuable benefits they can give through pro bono and gift-in-kind support.

This year we were delighted to have the support of Ogilvy, a leading marketing agency whose generous pro bono support enabled us to launch our brand-new campaign #CFTruths. We are incredibly grateful for the ongoing support from our advertising partners Clear Channel, Talon and Goodstuff, who provide gift-in-kind outdoor advertising and campaign advice.

We would also like to thank Chaucer, a strategy consultancy who supported us with pro bono advice across a range of projects.

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

This year also saw sponsorship from the pharmaceutical industry for the UK CF Clinical Trials Conference, the CF Registry Annual Meeting, and UKCFC.



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

Alice Collins, early career researcher whose brother has CF

Alice



Legacies

We received 92 legacies in 2021/22 from supporters who generously included a gift to the Trust in their Will, as well as 49 supporters who told us they have pledged a gift. We are incredibly grateful to those who have thought of us in this special way or are considering doing so.

In memory

We continue to remember with respect and affection those who have lost their lives because of cystic fibrosis and we thank all our supporters who fundraise in memory of their loved ones. In 2021/22, we received more than £249,000 in memory of those who are no longer with us, and many will continue to be remembered through our Book of Remembrance, tribute funds, and in the hearts of all who were close to them.

Philanthropy

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

This year we have continued our partnerships with the Joseph Levy Foundation, which supports our Information and Support work; BBC Children in Need, which supports our CF Youth programme; Sport England which supports people with CF to stay active when life changes; and the National Lottery Awards for All, which supports the development of our Helpline. In addition, we have worked with generous individuals who are longstanding supporters of our work, and our loyal Sixty-Five Roses Club members have also continued their amazing support, despite another challenging year.

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

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



Beatriz and son Yoel

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

Beatriz, mum to Yoel, who has CF



Dr Mary Goodchild

Gifts in Wills

Imagine what you could change for the next generation with a gift in your Will.

We are so grateful to all of those supporters who continue to choose to remember the Trust by leaving a gift in their Will, and to those who have already pledged to do so. These special gifts could help us to shape a better future for people with cystic fibrosis.

This year, we received a legacy from the late Dr Mary Goodchild, which helped to partly fund one of our SRC's. Dr Goodchild worked as a senior registrar at the Heath Hospital, Cardiff, specialising in the care of children who had CF, as well as making many contributions to CF research during her career. Dr Goodchild's gift will continue to help those with CF and their families for many years to come.

If you would like to know more about how you can support the Trust in this way, contact us at giftsinwills@cysticfibrosis.org.uk

"Mary dedicated her life to helping improve the lives of those affected by CF, through the work she carried out during her clinical and research career as a doctor. Leaving a gift in her Will was Mary's way of continuing to support the Trust's research after her death"

David, whose Godmother left a gift in her Will

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

Corporates

- AJN Steelstock
- AmazonSmile
- Chaucer
- Clear Channel
- Goodstuff
- Ogilvy Health
- Talon
- Vertex Pharmaceuticals

Individuals and families

- Mr P Bain
- Dr U Cartellieri
- Mr S Hale
- Dr J Winn

Trusts and Foundations

- 65 Roses Trust
- BBC Children in Need
- Chesthelp
- The Eveson Trust
- Garfield Weston Foundation
- The Gay and Keith Talbot Trust
- Joseph Levy Foundation
- Robert Luff Foundation
- Rosetrees Trust
- Sir Samuel Scott of Yews Trust
- The Stoneygate Trust

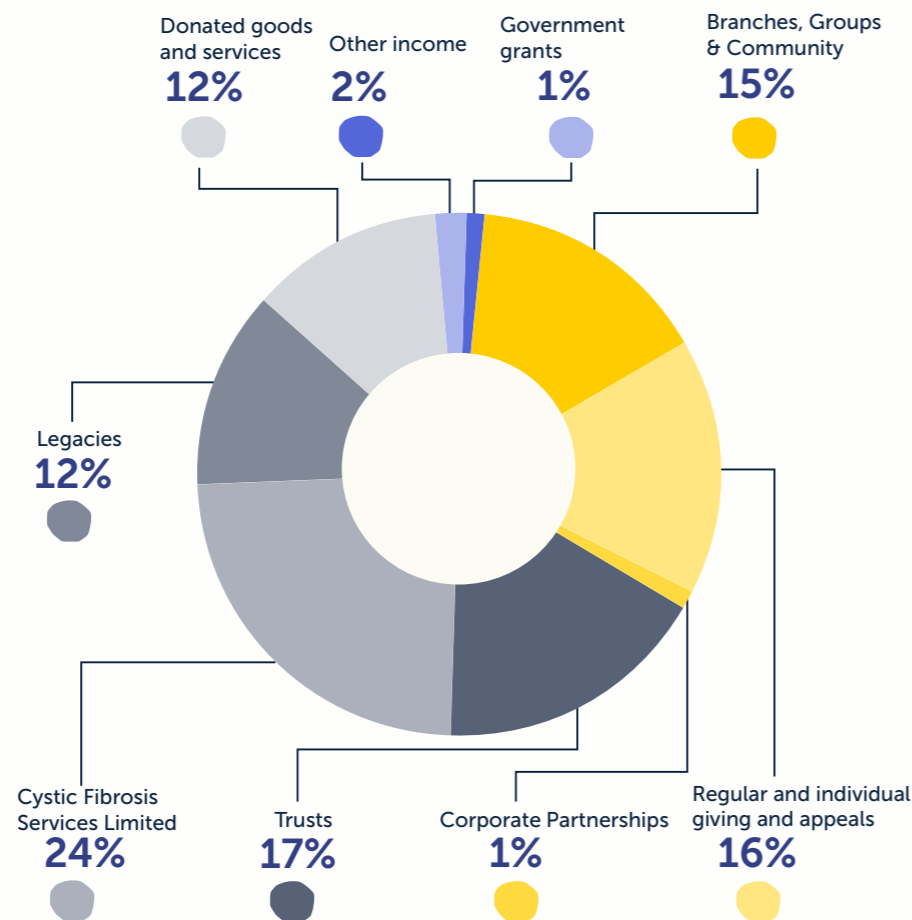
Gifts in Wills

- Mr John William Aylott
- Mr William Blyth
- Mr & Mrs Cordiner
- Mrs Alana Duncan
- Dr Mary Catherine Goodchild
- Ms Sheila Mary Palmer
- Mrs Lilian Jane Pickford
- Ms Vivienne Solley
- Mr Dennis Victor
- Mr & Mrs Wilkinson
- Mrs Eleanor Mary Williams

2021/22 income

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

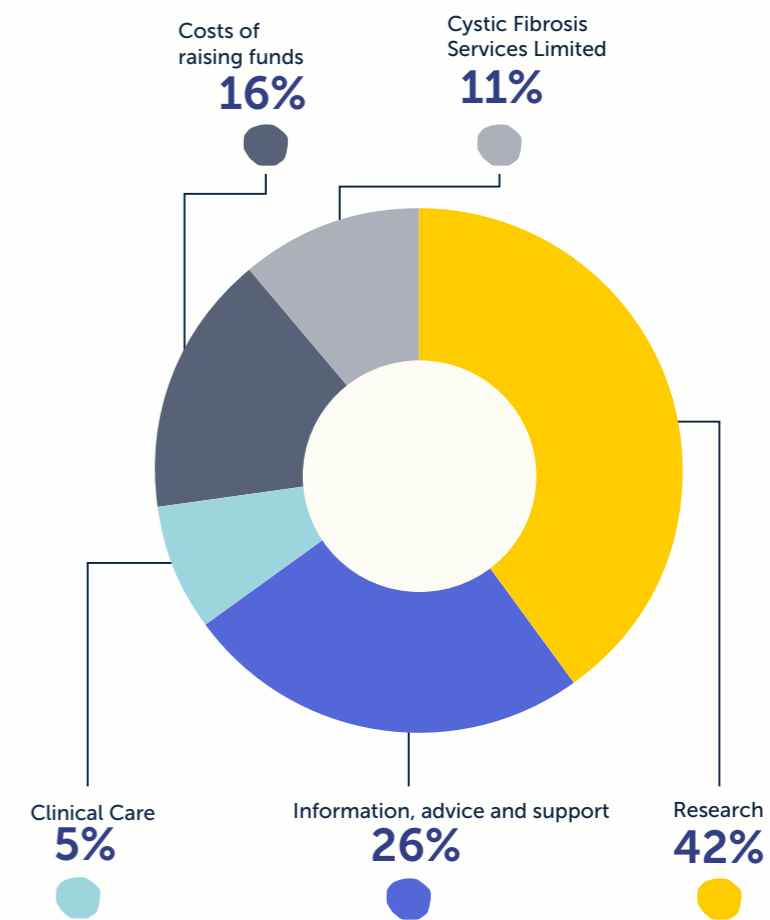
75% of the Trust's total income is made up of donations and legacies, totalling £11.2 million, (2020/21 – £11.7 million). This percentage is 6% lower than in the previous year, although our Community and Events income was significantly higher than in 2020/21, we saw a reduction in legacy, corporate partnerships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



2021/22 expenditure

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

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



Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity
uniting people to stop cystic fibrosis.
Our community will improve care,
speak out, support each other and
fund vital research as we race towards
effective treatments for all.

We won't stop until everyone can live
without the limits of cystic fibrosis.

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Uniting for a life *unlimited*