

Cystic
Fibrosis Trust

Let's write for a life unlimited

Impact report 2022/23

Uniting for a life unlimited



"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 their education with the prospect of many years of employment. However, we know that not everyone with CF can yet benefit from the latest 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 2022/23...



1,202 people with CF enrolled on to a CTAP clinical trial, helping to develop new medicines for everyone with CF. This is nearly four times greater than last year.



We co-funded a new Strategic Research Centre (SRC) to understand in detail what happens to bicarbonate transport in CF, with the hope that the lab-based studies could lead to ideas about new ways to treat CF in the future – tailored to individuals, based on the form of CF they have.



We helped people with CF to access over **£900,000** in benefits through our welfare and benefits advice service.



We responded to **4,799** enquiries making this the busiest year on record. We continued to provide support to our community through the cost of living crisis.



We provided **342** grants over the winter period to support those on low incomes to afford food and essentials, as well as launching a new time-limited cost of living fund.



We reached over **10 million** people through out-of-home advertising in the second year of our **#CFTruths** campaign.

Impact of the cost of living crisis on the CF community

The impact of rising living costs was felt across the CF community, particularly over the winter months – with more people struggling to buy the basic essentials they needed to manage their health and stay well, or unable to make ends meet when faced with the cost of a broken home appliance or the loss of income that comes with a hospital admission.

We provided responsive, wide-ranging support, helping people with CF and their families access the basics they needed through our grants offer. We then worked to identify all the financial support available to claimants, supporting them to understand their rights and, importantly, being there to listen and offer emotional support when times were tough.

In response to the cost of living crisis, we launched a new time-limited cost of living fund, providing **342** grants of **£225** over the winter period to support those on low incomes to afford food and essentials.

85% of people who received a cost of living grant told us that without the grant, they would have struggled to buy enough food over the winter.



"It's so important that every single one of us gets behind the campaigning work of the Trust because ten thousand of our voices are so much stronger, powerful, and louder than just one."

Carlie, who has CF





CEO David Ramsden and Cystic Fibrosis Trust staff members at 10 Downing Street



Cost of living with CF

The Trust submitted evidence to a parliamentary inquiry on the cost of living, specifically highlighting the need to address how the uprating of social security benefits did not keep pace with inflation and that those who relied on this support were effectively worse off due to the challenges of living with a lifelong condition. Repeated lobbying of ministers and parliamentarians across the year prompted parliamentary questions and contributions to debates held by elected representatives across all four nations.

In early 2023, this culminated with a specific debate in the House of Commons on the financial cost of living with CF. We were pleased to see this advocacy work, and our partnership working through wider third-sector coalitions, saw the Chancellor of the Exchequer confirm that uprating would occur in line with inflation rather than the proposed lower rate. This debate on the cost of living with CF prompted further discussion in England around prescription charges. On behalf of the CF community, our CEO, David Ramsden, handed in a petition signed by **1,300** people to 10 Downing Street, calling for CF to be added to the list of conditions exempt from paying prescription charges.

Cost of CF campaign

In spring 2022, we surveyed the CF community to truly understand the additional cost of living with cystic fibrosis. Our report revealed that **87%** of people with CF were worried about the cost of living and that **1 in 3** had missed a hospital appointment due to the cost.

In January 2023, we published research in partnership with the University of Bristol, which found that a typical family with CF will lose **£564** per month – or nearly **£6,800** per year – because of the condition. We used this evidence base to call on governments across the UK to act.

Strategic Research Centres

Strategic Research Centres (SRCs) are virtual centres of excellence which bring together researchers from within and outside of the field of CF, supporting scientists and other specialists around the world to work together to address specific issues arising from cystic fibrosis. Since 2013, Cystic Fibrosis Trust has funded 25 SRCs, assembling over 140 scientists and specialists from over 15 countries around the world to tackle everything from joint pain to gene editing.

Two new SRCs will launch this year; one to research detailed ways to monitor lung health of people with CF, and the other to research into the pharmacological repair of bicarbonate transport in cystic fibrosis.



Research into more detailed ways to monitor the lung health of people with CF

A new Strategic Research Centre approved for funding by Cystic Fibrosis Trust this year will investigate whether Magnetic Resonance Imaging (MRI) could be used to track changes in lung health over time. New MRI methods have been developed by Professor Jim Wild, the Principal Investigator of this SRC, who is based at the University of Sheffield. The programme is co-funded by the Trust and the CF Foundation in the United States.

Professor Wild will lead a collaborative, multidisciplinary programme of research to investigate how and whether these MRI methods can be incorporated into CF clinical practice. This will include developing easy-to-use software to process the MRI data and working out the best ways to support CF clinicians and the people with CF and families they care for in understanding the significance of this new information for people's lung health. If successfully adopted into CF care, these new MRI methods could give a much more detailed assessment of the lung health of people with CF and reduce their exposure to X-rays (as they may require fewer lung CT scans that require X-rays).



Dr Paola Vergani

Restoring the Fizz: Pharmacological repair of bicarbonate transport in cystic fibrosis

In October, a new SRC led by Dr Paola Vergani, based at UCL in London, will begin a programme of research to understand in detail what happens to bicarbonate transport in CF. They will investigate it in different forms of CF (where people have rarer CF mutations) and in different tissues, particularly the liver. They hope that their lab-based studies could lead to ideas about new ways to treat CF in the future – tailored to individuals based on the form of CF they have – and could lead to drugs that treat CF in a different way than the current medicines. This research is co-funded by the Trust and the Cystic Fibrosis Foundation in the United States.



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 2022/23 the Registry team:

- supported the running of three drug safety studies, generating over **£1.7 million** in income. All three studies will be completed by the end of 2023
- will receive up to **£160,000** from NHS contracts for generating public reports and supporting the commissioning of CF services in England
- received **37** data requests between April 2022 and March 2023, of which **34** were reviewed by the Registry Research Committee, and **29** were approved
- continued to play a pivotal role in evaluating the effect of Orkambi, Symkevi and Kaftrio following interim access agreements across the UK
- submitted the final reports of the observational study of Orkambi and Symkevi at the end of 2022 and the final analysis of Kaftrio in summer 2023. These two reports will form an important part of the NICE appraisal of these medicines in 2023



- held the first face-to-face Registry Annual Meeting in November 2022, following pandemic restrictions. Around **90** Registry users from CF centres across all four UK nations attended the meeting in Birmingham
- published the UK CF Registry annual data report on 2021 data in September 2022. It was found that **7,384** people were reported as being on a CFTR modulator by December 2021
- submitted anonymised 2021 data to the European CF Society Patient Registry.

"It's very exciting to hear about potential clinical trials for genetic therapies. This gives me real hope that a 'wonder' drug could help her and give her more of a 'normal' life with no limitations."

Rachel, mum to Anna, who has CF

Clinical Trials Accelerator Platform

The Clinical Trials Accelerator Programme (CTAP), which is funded by the CF Foundation (CFF), provides invaluable support to sponsors (organisers of trials) with their delivery and a platform which enables the CF community to gain timely access to these trials. The Trust recently secured a further five years of funding, of over **\$6m**, from the CFF to maintain and further develop this network, which is a key part of the UK's CF research landscape. The CTAP network of **27 centres** from across the UK comprises a mix of research-focused clinicians and coordinators with a range of experience, knowledge and skills in CF care and running clinical trials. Collectively, the network covers approximately **90%** of the UK CF community.



Rachel (right) and daughter Anna

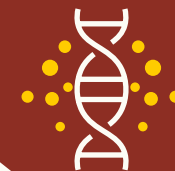
Since CTAP's official launch in September 2017:



3,585 people with CF have been screened for a trial within the CTAP network (2,207 in the last 12 months)



2,270 enrolled on a trial (1,306 adults and 964 babies & children) – 1,202 were enrolled in the last 12 months which is nearly 4 times greater than the previous year



50 CF trials have been supported by CTAP, with 15 studies open to recruitment in the last 12 months



Nicole, Martyn and Arlo, who has CF

“As a parent to a child with CF, it can feel like there are too many components that sit outside of your control. But being a part of QuestionCF has enabled us to feel like we’re doing something proactive. It’s refreshing to be part of a project that’s actually giving those in the community a voice and a chance to share their own perspective. It’s a really optimistic time to be part of the CF community, but there’s a lot that needs to be done to make sure that the needs of everyone with CF are met. Those that have access to modulators, and those that don’t.”

Nicole and Martyn, parents to Arlo, who has CF

Involving the CF community in shaping our research: The QuestionCF project

In 2016, the Trust was a partner in QuestionCF, a project to identify the research priorities of people with CF, as well as their families, carers and CF teams. Other partners in the project included the CF community and researchers at the University of Nottingham. The priorities were identified in the Priority Setting Partnership (PSP), facilitated by the James Lind Alliance (JLA) team at the National Institute for Health and Care Research (NIHR). The research priorities were published in January 2017. Since then, these priorities have helped us decide what research we fund; much of this research is ongoing, and you can read about some examples of the exciting work underway in a review article from December 2021.

We received over 1,600 responses to this first survey, from across the world, including Europe, Canada, North America, and Australia. The second survey, launched in the summer, asked participants to identify their top 10 priorities from a shortlist of 71 questions, and the final list of priorities was completed in an online workshop in November. Work is now ongoing to bring the research community and other potential funders together to accelerate research to address these priorities.

Find out the latest updates on the refreshed research priorities: cysticfibrosis.org.uk/researchpriorities

Providing vital information and support

- We launched the Home Essentials Fund and, between October and March, funded **113** vital appliances, including fridges needed to store medication and washing machines needed to keep clothes and homes clean and hygienic.
- We provided **57** Joseph Levy Education Fund grants, helping people with CF with the costs of higher or further education.
- We presented **10** Helen Barrett Bright Ideas Awards, supporting people with CF to take a step forward in self-employment, building confidence and giving an opportunity to shape a career that fits around their health.
- Our welfare team supported **377** people this year and secured benefits income of over **£900,000** for people affected by cystic fibrosis. 300 people received detailed, personalised one-to-one benefits advice, and 50 people were supported by our income maximisation service.
- Our Helpline responded to over **4,799** enquiries, making this the busiest year on record for our Helpline.

This year, we provided **1,190** grants totalling over **£310,000**, including over **400** emergency grants, funding basic essentials like food.



“Our team introduced us to the Trust at diagnosis, and we have learnt so much. It’s an amazing charity which is so supportive; they create huge awareness around CF, providing information and support to those living with CF and their friends and family. They are constantly striving to fund research for the CF community.”

Jason, dad to Luca, who has CF

The Joseph Levy Foundation

The Joseph Levy Foundation is a charitable grant-making Trust that has dedicated itself to tackling disadvantage in our society. Its vision is of a world where everyone has the opportunity to live a full and rewarding life – free from inequality and disadvantage. Since it was formed in 1965, the Foundation has been a longstanding, generous partner and friend of the Trust. We are proud that Joseph (Joe) Levy CBE BEM was a founding Trustee of the Cystic Fibrosis Trust and a great champion of the cystic fibrosis community. Jane Jason OBE is the current Chair of the Foundation. Under her dedicated leadership, Jane has generously advocated for the Trust alongside her fellow Trustees. **Jane talked to us about why supporting people with cystic fibrosis has been so important to her family over the last 60 years:**

“Supporting people with CF continues to be enormously important to the Foundation, and we thoroughly enjoy working with the Trust. It is so rewarding to see how the Foundation’s long-term support has made such a difference to people with CF in terms of practical support, medical advances and opening up educational opportunities.”



Jane



The Foundation supports three very important cystic fibrosis (CF) grant programmes:

The Joseph Levy Education Fund: The education fund was created through a gift from the Foundation, which has provided a permanent endowment: The Joseph Levy Memorial Fund for Education. This Fund seeks to break down the barriers for people with CF taking up higher and further education. Cystic fibrosis is a condition that comes with expense, and the Foundation has been instrumental in ensuring that this expense does not discount people with CF from being able to access education and brighter futures.

Rest & Relax grants: The Trust provides grants so that people with CF can take a holiday, trip or short break when they're going through a difficult time, supporting their mental and physical health. Thanks to the fantastic support of the Foundation, we can provide Rest & Relax grants to children as well as adults with CF.

Welfare grants: The Foundation has been a longstanding and committed supporter of our Welfare Grants Programme.

Being diverse and together as a community and an organisation

This year, we've continued to find new ways to engage with people affected by CF. From continuing to grow our presence on TikTok, to our active youth programme and the launch of our new podcast, we have focused on reaching everyone affected by CF and connecting with people in the best way that works for them. We've also sourced a greater range of voices in the stories we tell on our website, the media stories we place, and in our fundraising packs. High-profile campaigns like CF Week and #CFTruths have been shaped and influenced by people with CF and their families via our active involvement groups.



CF Week

This year:

- we raised over **£105,000**, with over **£53,000** being raised by CF Mamas' Wear Yellow Day Challenge through **74** incredible fundraisers
- we had **290** signs ups with **66** school fundraisers
- media coverage during or immediately following the week had a potential audience of **1.7m**, including a feature in Women's Own, which has a **76k** circulation
- we received a donation of out-of-home coverage worth over **£50,000** with a reach of over **3 million**
- we achieved over **20,000** views with our video content and over **387,000** impressions across our social platforms
- we engaged with politicians across the UK to share our resources to show their support.

"You don't see the hours coughing. Or the hours laughing. You don't see the mountain of pills I've taken. The hours of physio. You don't see me having to avoid meeting others with the same condition. The chance of catching an infection is simply too dangerous for us both. You'll just see me. See me grow. See me cough sometimes. See me try to live a life unlimited."

Kieron, who has CF and featured in our campaign posters and video



#CFTruths

Our awareness campaign aims to educate the public about CF, a condition which remains widely misunderstood. So far, the campaign has achieved:

- £200,000 donated support for out-of-home advertising with a reach of 10 million
- over 900,000 impressions across paid social media and display adverts
- over 700 clicks to the website through paid advertising
- over 115,000 impressions and over 41,000 views across social media
- a reach of over 11 million via media with a combination of national and regional news.

CForYourself podcast

Our podcast launched in June 2022 with host Lucy, who has CF. During each episode, Lucy and her guests talk openly and honestly about a whole range of topics, from exercise and employment to parenting and mental health. Each episode features a CF expert who shares their knowledge and advice for everyone affected by CF.

CForYourself is all about sharing honest insights into life with cystic fibrosis; the good, the bad and everything in between. It's been a huge success within our community and beyond. While most of our listeners are in the UK, we've also reached the CF community across the world, from Australia to the United States to Africa and beyond. The six episodes of season one have been downloaded over 1,000 times.

"From the moment that I was asked to host this podcast, I knew that I wanted it to be really special and open and vulnerable so that people with CF or those helping people with CF can understand and relate to something."

Lucy Baxter, CForYourself podcast host



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 know everyone is feeling the financial pressure much more this year, and that makes your support so incredibly special to us. We greatly appreciate everything you do for the CF community – we couldn't do it without you.

Voluntary income at the Trust has been significantly impacted by the cost of living crisis this year, which has been challenging as we continue to build back after COVID-19. In 2022/23, **£6.46 million** gross income was raised compared to £7.4 million in 2021/22, and **£4.31 million** net income. The difference was due to a decrease in income from community, events and individuals as a result of the cost of living crisis, alongside a significant reduction in Gifts in Wills income. Overall, this represents a 42% reduction in net income compared to pre-pandemic income in 2019/20.

Some of our fantastic
Wear Yellow Day fundraisers



Community and event fundraising

This year, our focus has been to continue to offer a portfolio of activities and campaigns to grow our income back to pre-pandemic levels.

- Our Team CF runners took on an array of races across the country, including Belfast City Marathon, Cardiff Half Marathon, Edinburgh Running Festival, London Landmarks, Royal Parks and London Marathon. The amazing runners who took part in these events raised a combined total of **£480,000**.
- Our loyal branches and groups across the country raised a fantastic **£124,000**.
- Our annual Wear Yellow Day continues to go from strength to strength and raised **£110,000** with growing numbers of our incredible CF Mamas and schools.
- The 20th anniversary of Carols by Candlelight raised **£60,000**.

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 just over **£834,000** in 2022/23, including Gift Aid. This year, we carried out a telemarketing campaign through Ethicall, our professional telephone fundraising agency. Ethicall have a respect and dignity policy that turns marketing calls into thank you calls if they suspect the person that they are speaking to is vulnerable. These campaigns (a regular giving upgrade and a direct debit recruitment campaign) resulted in an additional annual income of £15,000.

Gifts in Wills

In 2022/23, we received 93 legacies from supporters who generously included a gift to the Trust in their Will, as well as 48 supporters who told us they have pledged a gift. We are incredibly grateful to those who have thought of us in this special way or are considering doing so, and we continue to raise people's awareness of legacy giving.

In memory

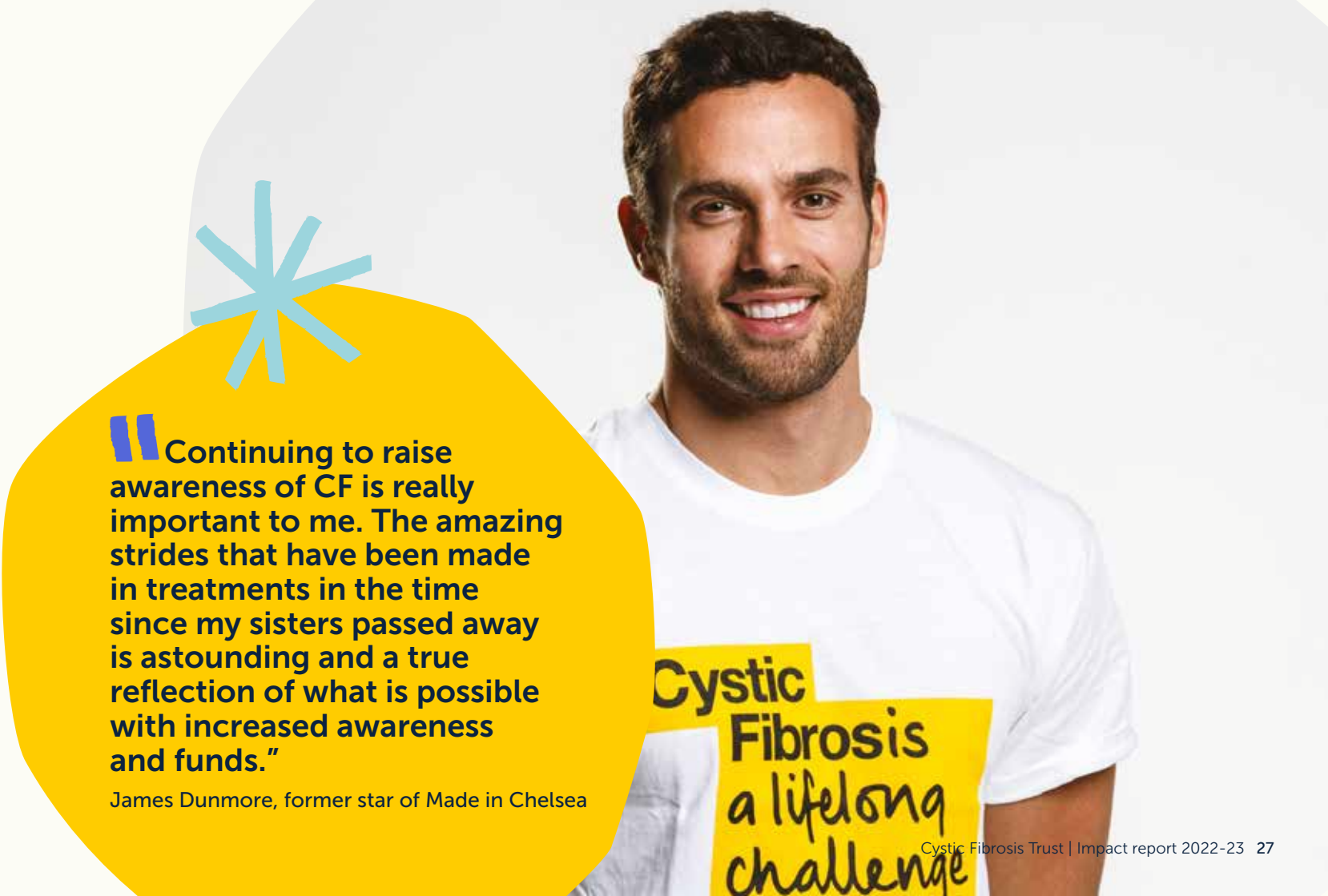
We continue to remember with respect and affection those who have lost their lives because of cystic fibrosis, and we thank all our supporters who fundraise in memory of their loved ones. In 2022/23, more than **£259,000** was donated in memory of those who are no longer with us, and many will continue to be remembered through our Book of Remembrance, tribute funds, and in the hearts of all who were close to them.

Corporate partnerships

Over the last year, the corporate partnerships team have continued to strengthen relationships with existing partners and build new partnerships to raise funds and awareness for Cystic Fibrosis Trust.

We were delighted to be chosen as LaingBuisson's Charity of the Year 2022 through a nomination from an employee who has cystic fibrosis. For Wear Yellow Day, a team from LaingBuisson walked 32 miles from their office in Berkhamsted to London. They completed it in 12 hours and walked 75,000 steps! In addition, the LaingBuisson Awards raised nearly £8,000 on the night from a silent auction and donations. We value the ongoing support from our advertising partners, such as Clear Channel, promoting our awareness campaigns through gift-in-kind outdoor advertising and campaign advice. We would also like to thank Bip, who we have been working with since 2019 (as Chaucer), and have donated advice as well as joining the assessment panel for the Helen Barrett Bright Ideas Awards and running workshops for our 60th Anniversary.

We were grateful for fundraising through AmazonSmile, which has raised over **£45,000** for the Trust in the five years before its closure in February 2023. Thank you again to our sponsors for the UK CF Clinical Trials Conference, the CF Registry Annual Meeting, and UKCFC, who we look forward to working with again this year.



“Continuing to raise awareness of CF is really important to me. The amazing strides that have been made in treatments in the time since my sisters passed away is astounding and a true reflection of what is possible with increased awareness and funds.”

James Dunmore, former star of Made in Chelsea

Philanthropy

The support we receive from charitable trusts, foundations and individual supporters has been more important this year than ever. To respond to the pressure of the cost of living crisis we launched our support package in October 2022 which was made possible by the support of generous donors. Thanks to those who contributed to our cost of living appeal, we were able to provide grants to 341 of the most vulnerable households this winter. We have been supported by generous individuals who are longstanding supporters of our work.

We are so grateful for the continued support of our Sixty Five Roses Club, which celebrated its 10th anniversary in 2022. The past decade has seen incredible advancements in CF care and treatments, changing what it means to live with the condition today. Members of our Sixty Five Roses Giving Club have been on this journey every step of the way; raising over **£700,000** over the last decade in support of our mission to ensure everybody with CF can live a life unlimited. We are able to continue our critical work and plan effectively thanks to the support of trusts and foundations who provide multi-year donations and grants, particularly committed partners such as the Joseph Levy Foundation, BBC Children in Need and Rosetrees Trust. We are grateful for our new partnership with the National Lottery Community Fund, enabling us to set up our employment programme, Work Forwards.

Support has grown for our Innovation Hub, which has raised **£3.4m** to date with income received and pledges. We are particularly grateful to AJN Steelstock, Robert Luff Foundation and Garfield Weston Foundation for their continued support, among many others.



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.

Corporates

- AJN Steelstock
- AmazonSmile
- Chiesi Limited
- Gilead Sciences Ltd
- Vertex Pharmaceuticals

Individuals and families

- Dr U Cartellieri
- Miss Maureen Heath
- Mr G Branston
- Mr S Edell
- Sir A Witty

Trusts and Foundations

- 65 Roses Trust
- BBC Children In Need
- Garfield Weston Foundation
- Joseph Levy Foundation
- National Lottery Community Fund
- Robert Luff Foundation
- Rosetrees Trust
- Sir Samuel Scott of Yews Trust
- Sport England
- The Boltini Trust
- The Eveson Trust
- The Gay and Keith Talbot Trust
- The Stoneygate Trust

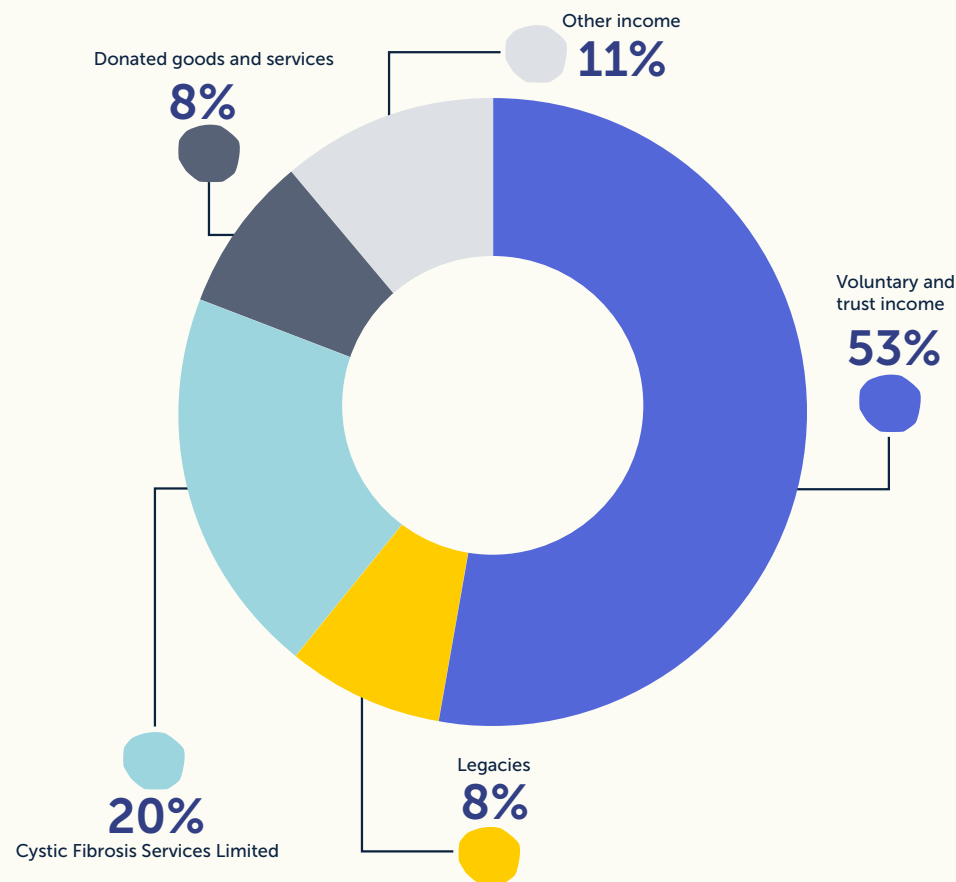
Gifts in Wills

- Mr Alfred Andrew Illingworth
- Mr Colin Victor Albert Prior
- Mr John Riggs
- Mr Marshall Irons
- Mr Robert & Mrs Ruth Thompson
- Mrs Kathleen Winifred Paige

2022/23 income

The Trust's income from normal activities for the year to March 2023 was £14.7m, a reduction of £1.0m (6%) compared to the previous year.

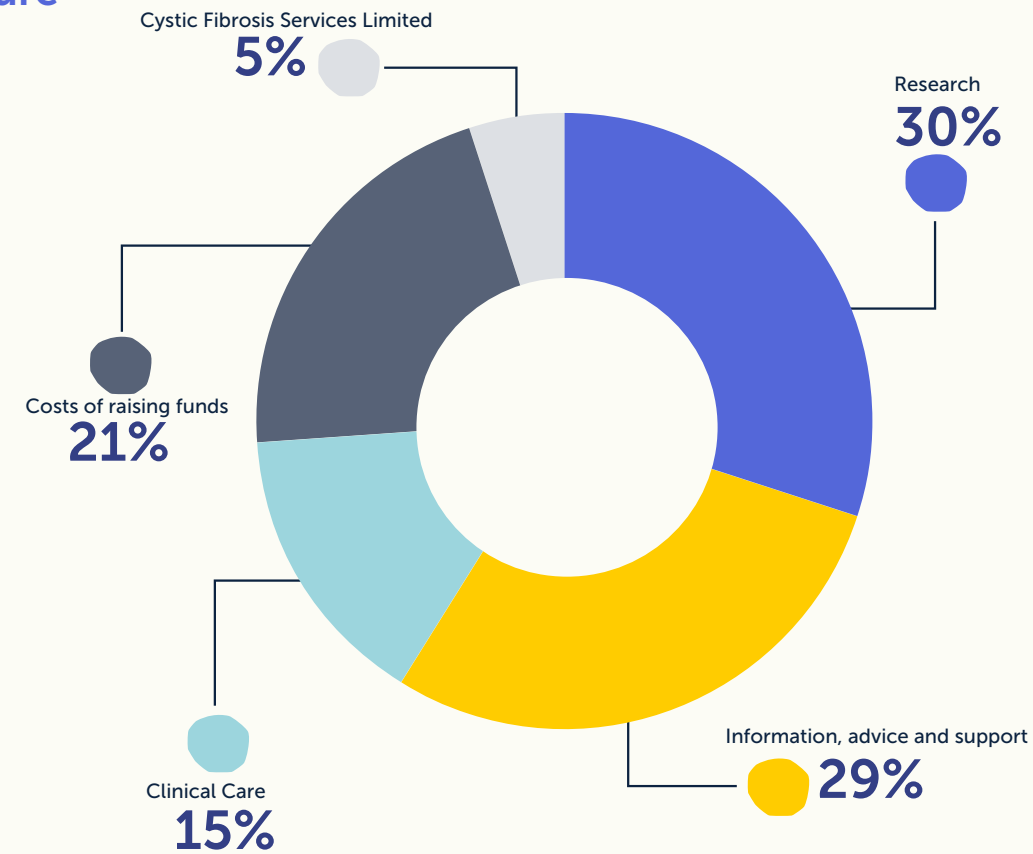
Voluntary and trust income of £7.8m (2022: £7.8m) includes regular giving programmes and appeals, from branches, groups and communities, corporate partnerships and trusts. In common with many charities, the ongoing cost of living crisis means that generating income remains challenging.



2022/23 expenditure

The Trust's total expenditure for the year was £12.8m, a £3.2m (20%) reduction compared to the previous year.

Expenditure on charitable activities in the year was £9.4m (2022: £11.8m). This includes funding research, providing information and advice and support and supporting clinical care. The reduction in expenditure is mainly as a result of focusing on research projects most likely to address our priorities; £3.3m of grants were awarded in 2023, compared to £5.5m in the year to March 2022.



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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