

**Cystic
Fibrosis Trust**

**Unstoppable
together***

Impact report 2023/24
Uniting for a life *unlimited*



This year marked our 60th anniversary and it's been a privilege to reflect on the incredible progress we've seen over the past six decades. But there is still so much important work to be done. New treatments are making a real difference, but they don't work for everyone and are not a cure. CF still dominates and shortens far too many lives.

Together, we've achieved a lot over the past 12 months. From winning the fight for life-changing modulator drugs to be approved on the NHS, to announcing the funding of exciting research that will design new medicines for people with rarer CF mutations, the progress we've made has been remarkable.

None of it would have been possible without our amazing supporters. Thanks to you, we'll continue our work funding groundbreaking research, providing world-class information, campaigning for change, and supporting our community every step of the way. We won't stop until everyone can live a long and full life – a life where they are physically well, mentally well and fulfilled.

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

David Ramsden,
Chief Executive of Cystic Fibrosis Trust



David Ramsden

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2023/24 highlights



Our #CFTruths campaign continues to raise awareness with a reach of over **18 million** through media and OOH advertising.



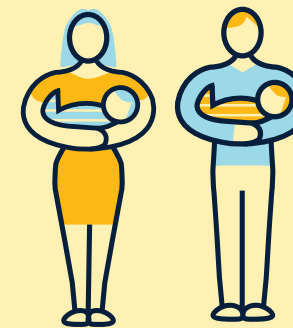
After years of fighting for life-saving drugs, modulators were permanently approved on the NHS.



We funded two new Strategic Research Centres (SRCs), one focusing on the impact of pregnancy on CF and another designing new medicines for those with rarer CF mutations.



We helped people with CF to access over **£1.9million** in benefits through our welfare and benefits advice service.



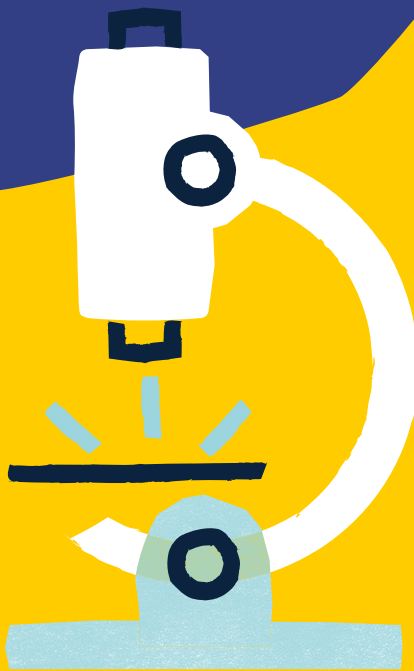
We partnered with Home-Start UK to support new parents with CF.



The Trust celebrated its 60th anniversary.

Research

In 2022, the CF community identified their top 10 research priorities – the things they felt would truly improve their lives. Since then, all of the research we fund has been carried out against a backdrop of these priorities.



Funding world-leading research

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.

In 2023/24, we funded two new Strategic Research Centres (SRCs):

- Dr Mike Gray at the University of Newcastle is leading an SRC focusing on designing compounds that could be CF medicines of the future for those with rare CFTR mutations who are not able to benefit from modulator medicines.
- Dr Imogen Felton and Professor Jane Davies of Royal Brompton Hospital and Imperial College London are running an SRC which looks into the impact of pregnancy, childbirth, and breastfeeding for those with CF.



Zoë Elliot, mum to twins with CF

"The commencement of a SRC to look at the impact of pregnancy and beyond shows how much life has changed for the better for people with CF. And for those who haven't been able to benefit from modulators, it is fantastic to see the Trust put funding into research that aims to provide them with the same life opportunities."

Zoë Elliott, mum to twins with CF

New scheme for early stages of research

This year, we created a new scheme called Development Awards (DAs), which allow researchers to undertake preparatory work, prior to applying for further funding.

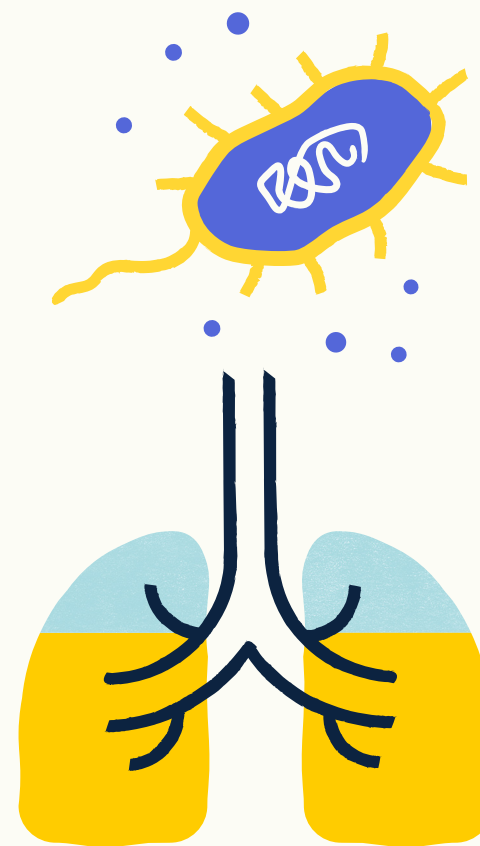
- Professor Nick Simmonds at Royal Brompton Hospital and Imperial College London is leading a DA to investigate alternative ways of diagnosing people with CF who have rarer mutations.
- Dr Freddy Frost from Liverpool Heart and Chest Hospital is running a DA looking at the heart health of people with CF.



Dr Freddy Frost



Professor Nick Simmonds



Uniting to diagnose lung infections

The CF AMR Syndicate, a partnership of the Cystic Fibrosis Trust, Medicines Catapult, and LifeArc, aims to develop new treatments for people with cystic fibrosis. This year, they published patient-centred Target Product Profiles (TPPs) for diagnostic tests for CF lung infections. They are now discussing how to use these TPPs to improve diagnostic options in clinics.

“Being invited to contribute to the development of the TPPs has provided much-needed reassurance that the demand for new or improved antibiotics for people with CF is still recognised as a critical requirement.”

Simon, who has CF

CTAP leads on groundbreaking research

The first phase 1 trial supported by our Clinical Trial Accelerator Platform (CTAP) early phase network opened late in 2023, testing a genetic therapy for adults who don't benefit from modulators. Two more phase 1 trials are due to open later in 2024.

Since CTAP's official launch in September 2017...



- **over 4,000** babies, children and adults have enrolled on to a CTAP study



- **over 70** CF studies have been supported by CTAP so far

- study set-up times have **decreased by 73%** across the CTAP network

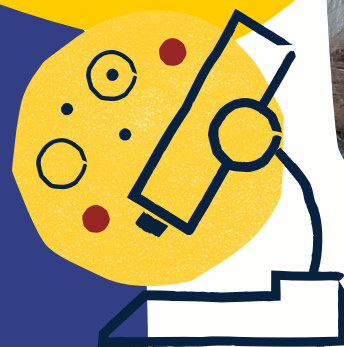
- more than three quarters of studies have exceeded **90% of their recruitment target**

- the average **retention rate** for CTAP studies is **98%**.

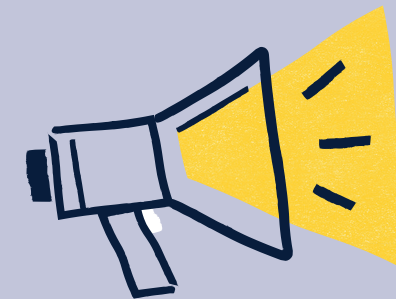


"I try to be a participant in as many trials as I can. The feeling of helping others with CF by putting myself forward for research makes me feel closer to our community, even if we cannot meet each other in person."

Sarah, who has CF



Sarah



Amplifying the CF community voice

Over the last year there have been a total of 24 research-related involvement activities, including 14 focus groups, covering everything from new diagnostics for lung infections through to looking at the mental health effects of Kaftrio.

At the UK CF Conference in October 2023, Professor Jane Davies gave a plenary presentation on 'Re-learning CF', informed by members of the Trust's involvement group.

Uniting researchers for a life unlimited

The October 2023 UK CF Conference showcased the Trust's research, attracting 146 attendees in London and 73 online. It highlighted the CF Innovation Hub and our partnerships with LifeArc and CF AMR Syndicate, as well as featuring lively presentations by early career researchers. Supported by CF community mentors, a follow-up online event allowed four of these researchers to present their work to the CF community.

The sixth annual UK Cystic Fibrosis Clinical Trials Conference, held in Leeds in March 2024, explored when and how the community's research priorities could be met by future clinical trials. Marking the Trust's 60th anniversary, it also reflected on six decades of CF research progress.

Working with CF centres for better care



Our patient experience surveys, run cyclically, help us collaborate with CF centres to identify successes and areas for improvement. The results of the children's survey released this year showed families rate care highly but noted gaps in psychological support and social work.

The adult services survey began in November 2023, with results expected soon.

We engaged over 150 CF professionals in virtual QI Share & Learn events and ran quality improvement sessions with several paediatric CF teams to support their projects.

And in March 2024, the Trust hosted a conference for CF professionals on key topics like patient-centred care, neurodiversity in CF, and treatment adherence.



Panel attendees at the new MDT Share & Learn conference



Our social media posts about the Creon shortages had a combined reach of **117,550** across Facebook and Instagram.

Creon shortages

There have been concerning ups and downs in the availability of Creon over the past year. We've been meeting regularly with Viatris, who make Creon, and the NHS to ensure everything is being done to fix the issues and prioritise our community, who depend on this medicine.

Cost of living

The cost of living in the UK is a worry for everyone – but especially for our community, who are already hit by the additional costs of living with CF. We've continued to offer financial support, advice and information to those with CF who are affected by the cost of living.



Carlie, who has CF and played Rita in our short film



Rita's story

Rita* first contacted our Helpline for support when her daughter, Asra*, who has CF, was three years old.

Rita said: "I lived in a house with 15 other people and there were sewage, flies, maggots, fleas and dead rats constantly in our living environment. Asra developed a skin condition due to the excess humidity and dampness in the room and a very dry cough... she was also always vomiting from tummy bugs she would pick up."

The Trust provided a package of support including an emergency grant, supporting letter for their re-housing application, and information and emotional support during this time. Rita was unable to access a social worker through Asra's CF team, which further prevented her from getting the help they needed. Later that year Rita told us she had suffered a mental health crisis and told us she had been thinking of taking her own life.

"I was heavily pregnant, and me and Asra were chased by a fox in the communal area from the broken window downstairs... it was so awful. When the landlord found out I was pregnant, he served me with a notice... he kept turning off the heating and hot water despite knowing I have a CF child."

After advocating for them when the council offered them alternative accommodation which was dirty and unsuitable, almost a year after she first contacted us, Rita was finally given a flat which was clean and suitable.

"Cystic Fibrosis Trust went out of their way to contact support services and the council... and provided support for me during the whole ordeal constantly calling me to see if I was ok. I would not be where I am today without the Trust. The grants that were offered to us during our crisis period and after moving to our new home has been lifesaving."



"I would not be where I am today without the Trust. The grants that were offered to us during our crisis period and after moving to our new home has been lifesaving."

Rita*



Laya and Robyn

"When we found out initially that these drugs weren't available in Northern Ireland it was like someone dangling a carrot in front of you and then taking it away. It is just so reassuring that Robyn can now access this – it's life changing."

Laya, whose daughter Robyn has CF

Modulator appraisal

In 2022, NICE began an appraisal of modulators, to assess if they were cost-effective enough. Initially they said they weren't, which was very challenging for our community. We were there to provide essential information at this time.

In June 2024, we were delighted that NICE, Vertex and the NHS were able to come to an agreement, and modulator drugs became permanently available on the NHS.

We know that not everyone can benefit from modulators, which is why we continue to invest in cutting-edge CF research for effective treatments for all. We won't stop until everyone with CF can live a life unlimited.

Our social media posts about the NICE appraisal had a combined reach of **327,440** across Facebook and Instagram.

Prescription charges

That many people with CF still have to pay for their prescriptions is high on the agenda of our community. We've worked hard to raise awareness of this issue in the media, taken a leading role in the Prescription Charges Coalition, and written to key ministers, making sure the voices of people with CF are heard.



James (left), James's dad, James's twin brother (who also has CF), and their mum



"Paying for my own prescription makes me feel unseen and invalidated as a student living with a life-changing illness. It's another cost on top of so many extra costs that CF brings to my life."

James, a Trust campaigner who has CF

UK CF Registry

The UK CF Registry is a pioneering database containing the health data of around **99% of people** with CF in the UK.

This year, the Registry:

- concluded three drug safety studies, generating total income of over **£1.7 million**
- received up to **£160,000** from NHS contracts for generating public reports and supporting the commissioning of CF services in England
- received **51** data requests and in March 2024, we received our **500th** data request.

We're seeing a steady increase in the number and complexity of data requests received, reflective of the increasing richness of the Registry data.

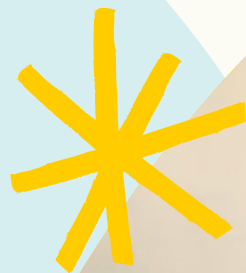


Dr Jamie Duckers

“The UK CF Registry is the envy of many disease conditions, and I believe it has been really important in helping to drive forward research and quality of care in the field of CF. We are grateful that over 99% of people with CF in the UK contribute to this powerful data resource which researchers from across the globe can apply to use in an anonymous or pseudonymous format.”

Dr Jamie Duckers

Uniting for the CF community



Financial support

We provide financial support to the CF community with a focus on helping people with CF stay well.

This year, we provided:

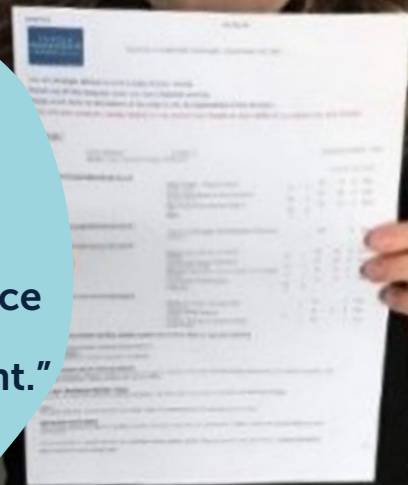
- **1,242** welfare grants, totalling over **£310,000**
- **324** Cost of Living Fund grants
- **61** Joseph Levy Education Fund grants
- **£20,000** in Helen Barrett Bright Ideas Awards
- and supported our community to secure **£1.9m** in benefits through income maximisation.

Information and resources

We offer free, balanced information on all aspects of life with CF so that you can use it along with the medical advice you receive from your CF team to make informed decisions about your lifestyle, treatment and care, however you're affected by cystic fibrosis.

"Without the help of the Joseph Levy Education Fund grant, my university experience would have been completely different."

Emily, who has CF



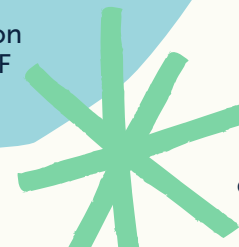
Emily, who has CF



Ambrose, who has CF

"A new diagnosis is incredibly overwhelming and tough, which is part of the reason Cystic Fibrosis Trust is so important to us."

Chris, whose son Ambrose has CF



This year we created new publications on...

- inhaled therapies
- hearing loss
- vaping
- inconclusive cf diagnosis (CFSPID)
- CF diabetes
- the sweat test.

Cystic Fibrosis Trust is part of the PIF TICK accreditation scheme, run by the Patient Information Forum (PIF). This means that you can be assured that what you're reading, watching or listening to is evidence-based, understandable, jargon-free, up-to-date and produced to the best possible standard.

**Trusted
Information
Creator**



Patient Information Forum



Young people

Building Brighter Futures, our programme for 6–14-year-olds with CF and their siblings saw 88 children attending 32 courses and one-off events, including baking sessions, resilience workshops and exploding science experiments!

Our Youth Advisory Group (YAG) of 14–25-year-olds with CF or loved ones with CF held 17 meetings.

Strong Beginnings, our support programme for parents of children with CF aged 0–6, ran peer support events, music sessions and parent/baby yoga. Almost 40 parents attended these sessions.

"I think it's really important that we're able to connect online with the people we relate to most, as we can't meet in person due to cross-infection and this can get incredibly isolating. So, it's great that we can just have a chat and a catch up as well as working on upcoming projects."

Tilly, who's a member of YAG and has CF

Tilly



Work Forwards

This year, we've provided detailed one-to-one support to 59 people and delivered a range of online group sessions on topics including transferable skills and rights and adjustments at work.

"I contacted the Work Forwards team to see how they could help and what advice they could offer. With the help of the team, I learned how to deal with my anxiety and not let my nerves control me."

Jonathon



Diverse and together

We work hard to raise awareness of CF and the issues that are important to our community.

CF News

Our monthly newsletter is sent to over **10,000** opted-in subscribers sharing the latest CF research breakthroughs, stories from our community and wider news from the Trust. Over the past year, the newsletter:

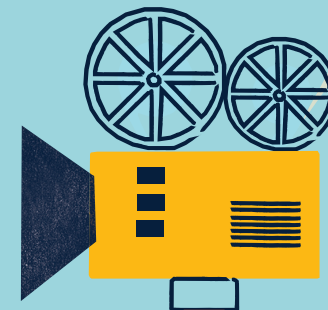
- averaged over **37%** unique open rate
- averaged over **1,000** click throughs to our website
- covered popular articles such as *CF Life* magazine, our awareness campaign and topics important to our community such as the NICE appraisal.

We had **1,453** pieces of media coverage over the last year with a huge potential editorial reach of 7.8 billion



“Cystic fibrosis is a 365 day a year, 24 hour treatment regime... it doesn't stop. You never get a day off.”

Jonathan, who featured in our #CFTruths campaign



#CFTruths

Our #CFTruths campaign had an incredible impact, thanks to out of home (OOH) advertising equivalent to **£450k** donated, which enabled us to reach over **7 million** people! Social media brought in **479,000** impressions, driving **4,000** clicks to our website. A Google Performance Max campaign added another **18,000** impressions, **1,800** website clicks, and over **700** conversions – including 10 online shop purchases totaling almost £350.

National media coverage in **The Mirror** and 11 regional outlets reached over 11 million people, spreading awareness far and wide. To top it off, our **You Don't See CF** campaign won bronze in the People's Choice Awards at the 2024 Smiley Charity Film Awards. Thank you for helping us share these powerful #CFTruths!



VOTE FOR
OUR FILM

Help us share our story



Our **You Don't See CF** campaign won bronze in the people's choice awards in the 2024 Smiley Charity Film Awards.



CForYourself

In Series 2 of the **CForYourself** podcast, listeners enjoyed a range of topics, from dating with CF to navigating menopause. The eight-episode series featured well-known voices like **Made in Chelsea** star James Dunmore and **Married at First Sight Australia**'s Lyndall Grace, adding celebrity insight to the conversations.

With **1,050 downloads**, the series' most popular episode, **#CFTruths: living with an invisible condition**, resonated deeply with the audience, shedding light on the challenges of living with an often-misunderstood condition.

Series 2 highlights

- **8 episodes**
- **1,050 downloads**
- **Most popular episode: #CFTruths: Living with an invisible condition**



Lucy Baxter, host of the CForYourself podcast

Socials

Over the past year, our social media presence has achieved remarkable results, with a combined reach of **6,919,658** across Facebook, Instagram, and TikTok, and **1,860,953** impressions on LinkedIn and X.

Video content has been especially engaging, generating over half a million views across all channels. These numbers highlight the growing impact of our online efforts in raising awareness and connecting with a diverse audience.



In the media

We had **1,453** pieces of coverage over the last year, with a huge potential editorial reach of **7.8 billion**.

Celebrities

Athlete Roger Black took on a new challenge when he battled the Beast on **The Chase**, as well as recording a heartfelt video cheering on Great Strides participants! James Dunmore and **Married at First Sight Australia's** Lyndall Grace joined us on the **CForYourself** podcast, sharing their stories with listeners. Lyndall also went live on Instagram, bringing the community together for a fun and interactive session, and James kept up his support by sharing our cause in Fabulous magazine.

Jenny Agutter lit up **Loose Women** with a special promo for Carols by Candlelight, and later delivered a moving reading at the event itself, alongside James Dunmore and the talented David Haig. Jenny also joined Vincent Franklin to create a lively Instagram Reel supporting our FeBrewery campaign.

And on Wear Yellow Day, we were thrilled to have presenter Richard Madeley, Interior Design Master Jack Kinsey, and comedian Nick Mohammed join a host of celebrities showing their support in vibrant yellow!



"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

James Dunmore ran London Marathon for the Trust in 2024

CF Week

CF Week was a huge success, raising an incredible **£78k** on Wear Yellow Day! With media coverage reaching **1.7 million** people, highlights included a James Dunmore interview in Fabulous and an awareness piece in **Take A Break**. BBC Access All helped amplify the **Your Life And CF** survey to over **4.6 million**, and our social media efforts reached **450,000+** with over **1 million** impressions. We received **£115,000** worth of 'out of home' (OOH) ads, reaching **800,000** people, and created impactful video and blog content from two research centre visits.

Eight celebrities, including Nick Mohammed, Lyndall Grace, and our ambassador Jenny Agutter, joined CF Week. Our community shared their #CFtruths, with people with CF guest editing CF News and taking over our Instagram stories. Politicians across the UK showed their support too, with **47** wearing Trust pins, **22** parliamentary mentions of CF, and Welsh First Minister Mark Drakeford publicly supporting CF Week. Thank you to everyone who helped make CF Week so impactful!

Thriving together

Our online community forum is a safe space for everyone connected to CF to seek information, access support, and chat with others who know what you're going through. This year, the community has had over **500** new sign ups, over **400** posts and **34,000** page views.



“It just brings you so much hope... there are people from all walks of CF life, and that’s just so promising and has put me at ease, made me feel hopeful and that it’s ok.”

Shanique, whose baby son Thiago has CF



Shanique's story

Shanique, whose baby son Thiago has CF, uses our forum to connect with older people with CF and other parents, which has reassured her about Thiago's future.



Empowering parents

This year, we partnered with Home-Start UK to support new parents with CF, recognising the rise in CF parents. A pilot project in Glasgow trained Home-Start volunteers in CF care, ensuring parents can access knowledgeable support. This collaboration shows how we can combine expertise to address evolving needs in the CF community.

CF Connect is our peer support service for parents of children with CF. This year, we trained a new group of parent volunteers, who'll provide invaluable support to other parents like them.

Helena's story

Recently we put Helena, a parent of a young baby with CF, in touch with one of our trained parent volunteers.

Helena had been through a difficult time, figuring out her new routine and keeping her baby well – she had questions about the future. Helena found solace in talking to one of our trained volunteers who had been there herself, and understood her worries.

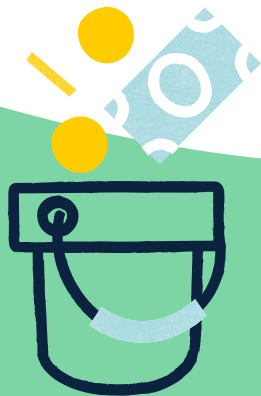
We provided a safe, non-judgemental space for Helena to get things off her chest and talk her concerns through.



Fundraising for the future

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. Thanks to you, we can make sure we're here for everyone with CF when they need us. We greatly appreciate everything you do for the CF community – we couldn't do it without you.

Our fundraising efforts brought in **£7.62 million** gross (£5.42 million net) this year! Here's how our incredible supporters made it happen.



“The Trust has been a huge part of my journey for as long as I can remember. I've been so glad to be able to raise money for them when competing in events such as London Marathon, as it's so important the Trust can continue their research.”

Jamie, who has CF



GAME
4 CYSTIC FIBROSIS

60
for
60



Community and events

We're so grateful to our incredible community and events fundraisers, who raised a fantastic **£2.27 million** to make sure we can keep working towards a life unlimited for everyone with CF.

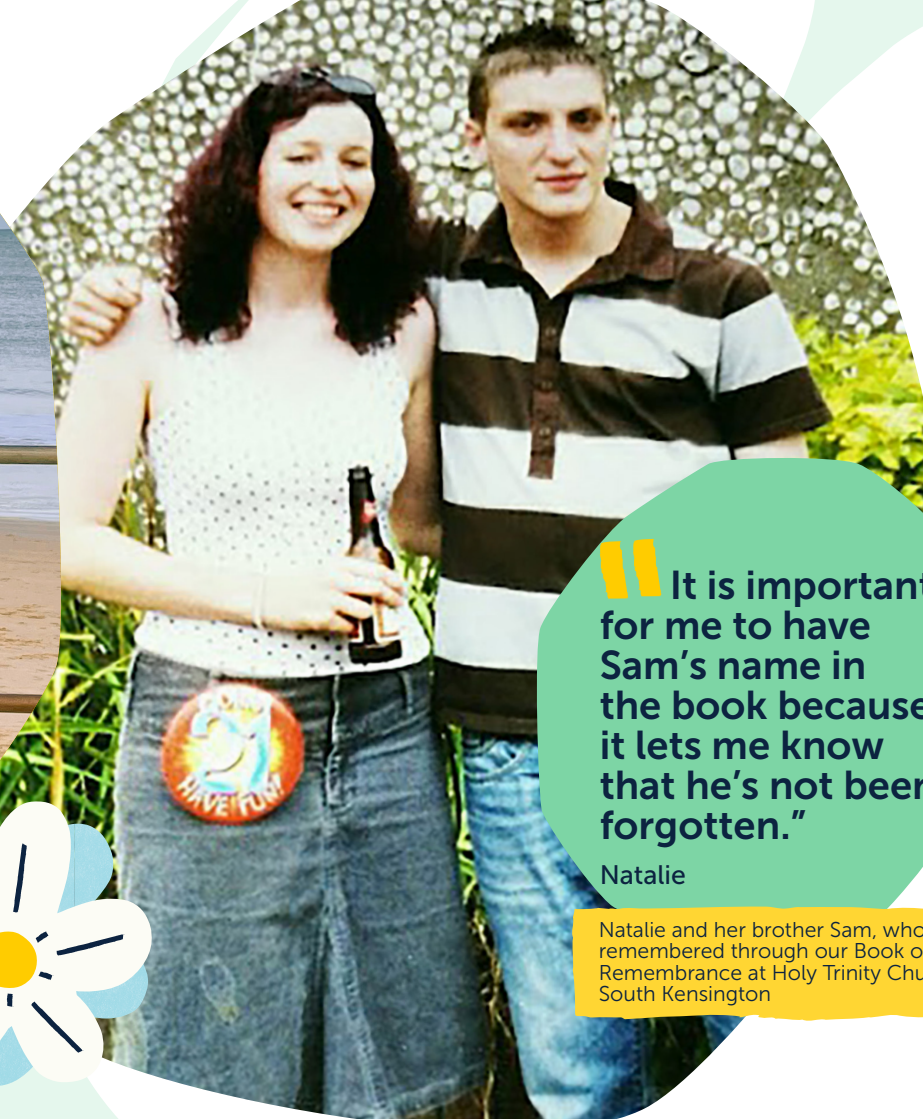
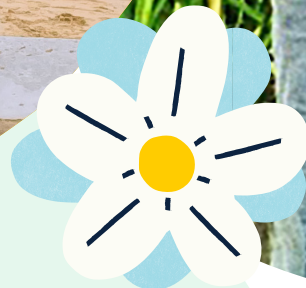
- Our fundraisers took on some incredible challenges, including London Marathon, London Landmarks Half Marathon, Edinburgh Marathon Festival, London to Brighton Cycle Ride, skydives, and overseas treks, to raise over **£1 million**.
- The CF community have been very busy fundraising through amazing events and activities such as Wear Yellow Day events, FeBrewary activities, balls, boxing matches, football matches, quiz nights, games nights, raising over **£1.08 million**.
- On Wear Yellow Day alone, our supporters raised over **£78,000**.
- Our dedicated branches and groups located all over the United Kingdom raised **£100,000**.

“Cystic Fibrosis Trust have been amazing and the research and developments that have come about as a result of the charity’s efforts has been incredible to see. Kaftrio has made a huge difference for me and my brother, but I know it’s not a cure and some people can’t benefit from it, so I’m determined to run for everyone in the CF community.”

Nell, who has CF



Nell



“It is important for me to have Sam’s name in the book because it lets me know that he’s not been forgotten.”

Natalie

Natalie and her brother Sam, who is remembered through our Book of Remembrance at Holy Trinity Church in South Kensington

Regular gifts

We’re grateful to our loyal donors, whose ongoing support contributed over £800,000 (including Gift Aid) in 2023/24, allowing us to plan effectively for the future. This year’s direct mail appeal and telemarketing campaign with Ethicall, our telephone fundraising agency, raised an additional £18,000.

Gifts in Wills

We were privileged to receive legacies from 88 people, and 42 supporters informed us of their commitment to leaving a legacy gift. We remain committed to promoting legacy giving through various channels and providing a free Will service to our supporters all year round.

In memory

We continue to honour and remember all those with cystic fibrosis who have lost their lives and thank everyone who donates in their memory. In 2023/24, more than **£320,000** was donated in memory of loved ones and they will always stay in our thoughts. Our Book of Remembrance, tribute funds and dedication wall remain special places where these individuals can be remembered.



Corporate partnerships

We're grateful for the continued support from our corporate partners this year, and we'd like to thank AJN Steelstock for continuing to back the Innovation Hub; Crane CPE for enabling funding opportunities through their Crane Widows and Children Fund; and The Bip Group, whose expertise strengthened the Helen Barrett Bright Ideas Awards. 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 were honoured to be named charity of the year by C-Stem, Orlo, McLemore Konschnik LLP, and SHS Drinks, and the benefitting charity for the Britannia Stakes race at Ascot thanks to the Betting and Gaming Council and their members.

Events like the UK CF Clinical Trials Conference, UKCFC and the Annual Registry Meeting are essential in highlighting our work, and we thank our dedicated sponsors for their ongoing support and enthusiasm.



"It was inspiring to see the passion in the room, and the depth and breadth of ongoing research which will help improve the lives of people with CF."

David Ramsden



Dr Lucy Allen speaking at the 2023 UKCFC

Philanthropy

We would like to thank the generous and committed support of trusts, foundations, the National Lottery Community Fund and BBC Children in Need who provide donations and multi-year grants. This is critical to the Trust's provision of services to our CF community and world-leading research.

In our 60th anniversary year, we're especially thankful for our long-term partners, the Robert Luff Foundation and the Joseph Levy Foundation, and we deeply appreciate the dedication of our Sixty Five Roses Club, who have **raised over £760,000** over the last decade.

As the CF community faces post-pandemic adjustments and the cost of living crisis rolls on, philanthropic support has allowed us to extend our Cost of Living Support Package programme which launched in 2022. This year we have supported 324 people with CF in low-income households with grants for energy bills, food and basic essentials over winter.

CF Innovation Hub on lung health at the University of Cambridge

This year concludes our groundbreaking CF Innovation Hub on lung health, launched in 2018 with the University of Cambridge and led by Professor Andres Floto. Thanks to our generous supporters, we raised £5 million for the Innovation Hub, which was then matched by the University of Cambridge. As this pioneering programme concludes, we extend our gratitude to all our funders who helped advance world-class understanding of CF lung infections.

Each donation, no matter how small, has made a real difference in helping us continue our work. Thank you.



Professor Andres Floto and his team working in the laboratory at the Cambridge LMB (Laboratory of Molecular Biology).

Areas we're working on in 2024/25

Research

The refreshed CF research priorities from 2022 continue to guide our strategy and funding, focusing on under-resourced areas like ageing with CF, CF diabetes, and the long-term effects of modulators.

We're building new networks and partnerships, including Medicines Discovery Catapult and LifeArc, to accelerate research on CF lung infections.

We remain committed to supporting more effective treatments, especially for those who cannot benefit from current modulators.



Sharon (right) receiving another fantastic fundraising donation to Cystic Fibrosis Trust

Supporting our community

We continue to adapt our services to meet changing needs while maintaining core support.

As issues important to our community continue to affect them, like the global Creon shortages and the national cost of living crisis, we'll continue to be there to make sure people with CF have the support they need to look after their health.

As a result of our pioneering collaboration with Home-Start, we're continuing to look at ways we can match people in our community with their peers who can support them.

We're also expanding support for neurodivergent individuals and those bereaved by CF.

Changing lives through data

We'll be sharing the results from our second adult services patient experience survey, along with personalised feedback for all the CF centres that took part. This autumn, we'll also be gathering new data on CF staffing levels and launching a survey for CF professionals to get their take on how care and workloads are changing. Plus, we're expanding our holistic follow-up offer to help CF centres dive into their data and plan targeted improvements, with adult services joining in next year.

Our Registry data will continue to support NICE in reviewing the impact of CF modulator therapies, and we'll be holding CF Live events to explain the data collection process and answering any questions. We're also looking to expand the types of data we collect to better support our community as CF care evolves.

"I know my fundraising has contributed to CF research over the years and that's really important to me because I've seen firsthand what a difference Kaftrio has made."

Sharon

Remembering Rachel

We would like to say a special thank you to Sir Ivan Lawrence KC, a long-term supporter of the Trust. In September 2023, Sir Ivan organised a very successful Gala Dinner in memory of his daughter Rachel.

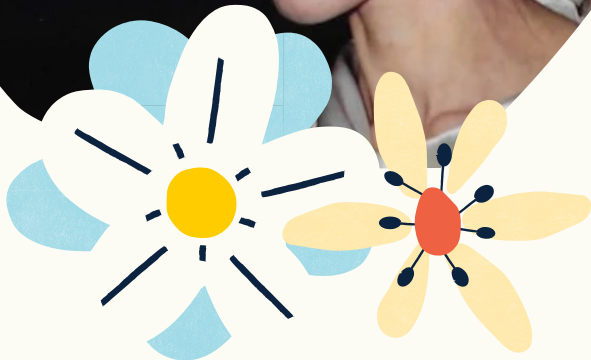
The event, held in London, was a celebration of Rachel's amazing vitality and all that she accomplished in her 45 years before sadly passing away in 2013. We're pleased to say that thanks to the incredible generosity of all those who attended, the event raised a wonderful £20,147, all in Rachel's memory.

What makes this event particularly special is that it brings the money raised by Sir Ivan and his friends and family in Rachel's memory to over £114,000.

Rachel, who followed in her father's footsteps to become a successful criminal barrister was an inspiration to many, including our very own Trustee, Michelle Shore, who has CF and is herself a successful lawyer, Michelle says...

"Rachel was admitted to the same hospital ward as me once when I was an inpatient. I was in the second year of my law degree and it made me think if Rachel has CF and can be a barrister, I can be a solicitor."

Thank you to all those who donated, attended and organised such a fantastic evening, and thank you, of course, to Sir Ivan Lawrence KC for continuing Rachel's incredible legacy. As Sir Ivan remarks, **"the nearly impossible can turn out to be achievable"**.



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.

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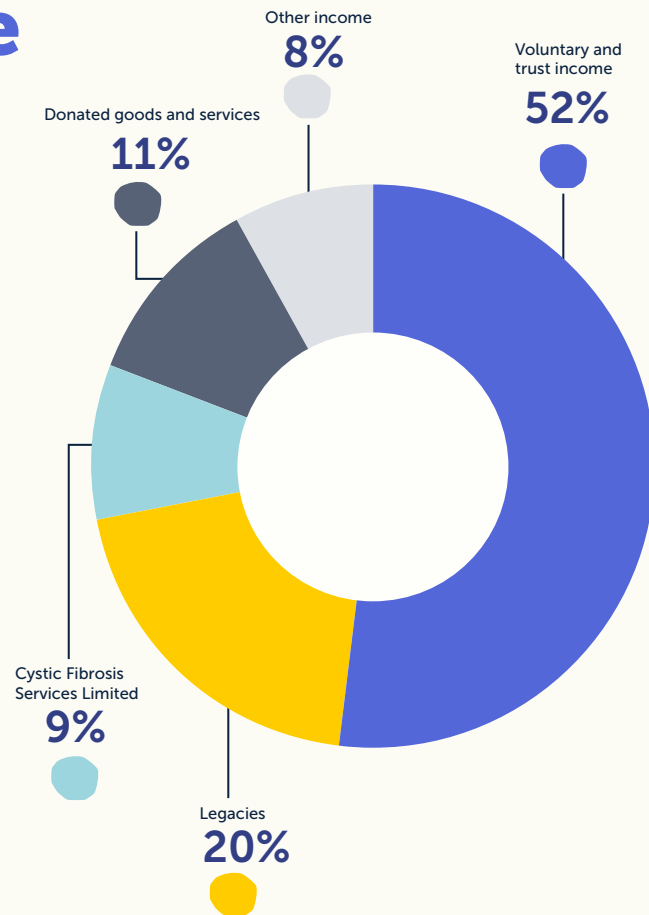


2023/24 income

The Trust's income from normal activities for the year to March 2024 was £14.7m.

This total income is unchanged from the previous year although the mix of income has changed significantly, with strong legacy income balancing lower income generated in other areas.

The cost of raising funds was £3.07m (2023: £3.32m) and includes direct fundraising costs of £2.73m (2023: £2.65m) and the costs of CFSL of £0.34m (2023: £0.67m). CFSL costs include UK CF Registry Support grants.

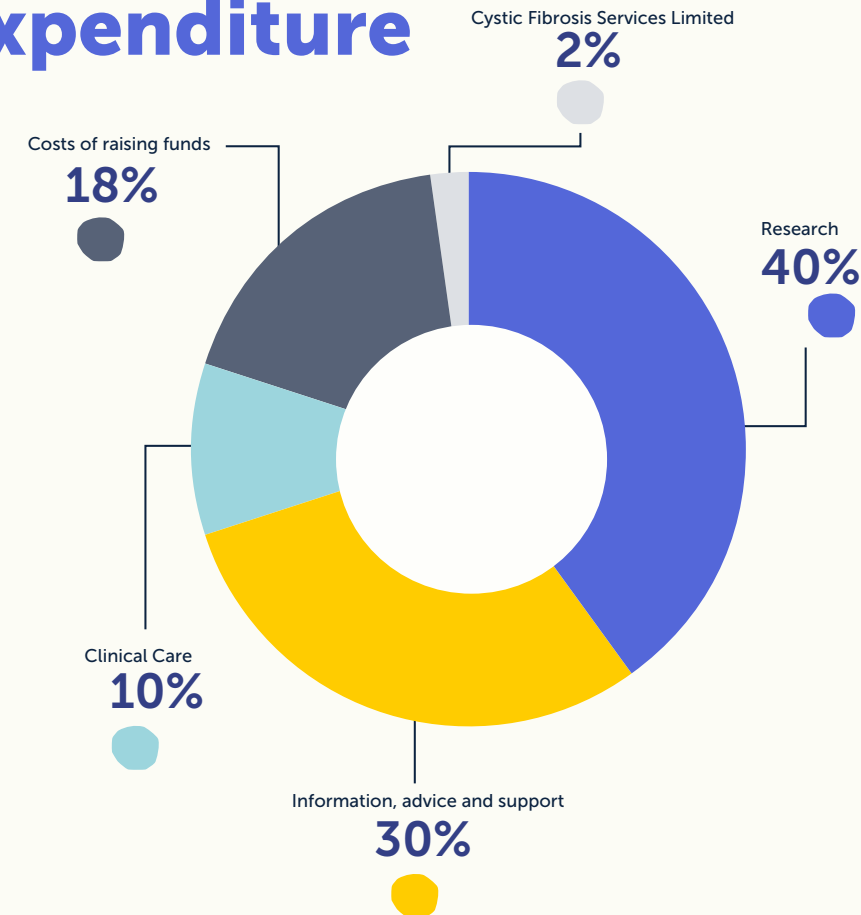


2023/24 expenditure

The Trust's total expenditure for the year was £15.1m, a £2.3m increase compared to the previous year.

Expenditure on charitable activities in the year was £12.0m (2023: £9.5m). This includes funding research, providing information and advice and support and supporting clinical care.

The increase in expenditure is mainly grants to support research.



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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