

Cystic Fibrosis Trust



Impact Report 2015/16: At a glance review

"I want to be able to tell people about things that I think are important like Orkambi. It would be so awful if it doesn't get licensed." – Clara

We're very proud of the work we've done with your help; take a look at some of the ways your support has made a difference this year.

- We invested more than £5 million into cutting-edge research, including over £3 million of new commitments. **(Watch Ciara's short film about one of these projects at cysticfibrosis.org.uk/srcshaw. Page 3)**
- We provided the gene therapy consortium with £600,000 to develop its CF programme.
- Nearly 20,000 signed our Stopping the Clock petition for fair access to precision medicines. **(Clara shared her story to help us promote the campaign. Front cover)**
- We launched a new platform for our fantastic UK CF Registry.
- We offered advice and support in response to more than 4,000 enquiries to our helpline.
- We recruited a youth empowerment officer to ensure we're supporting young people effectively.
- The Helen Barratt Awards helped seven young people turn their hobbies into careers. **(Including talented artist Poppy. Page 2)**
- Our New Diagnosis pack has helped 100 families through those anxious first months.
- The flagship SmartCareCF project is progressing through feasibility studies **(Bringing hope for people like Sammie. Page 4)**
- Over 1,500 supporters, researchers and clinicians watched our UK CF Conference online.
- We launched 'Breathe', a music track and video that gained great media attention and brought CF to the attention of a whole new audience.

We're really going places, but to reach our destination and beat CF for good, we need people like you to keep on supporting us. By doing so, you are an essential part of our team, alongside researchers, clinicians and fundraisers shaping a brighter future.

We're determined to keep fighting for a life unlimited by cystic fibrosis; we hope you'll join us.

Dr Keith Brownlee,
Director of Impact, Cystic Fibrosis Trust

"I hoped but never expected to win the award. I am so pleased that I am now able to start a career after my transplant."

– **Poppy, Helen Barrett Award recipient**



Achievements and performance

>Investing in cutting-edge research and innovation

The Cystic Fibrosis Trust is one of the biggest funders of university research specifically for the benefit of people with cystic fibrosis (CF).

>Grant making policy

Governance for funding research at the Trust is overseen by two principle committees, the Research Strategy Implementation Board (SIB) and the Research Strategy Advisory Board (SAB). Applications for research grants undergo a rigorous external peer review process before being considered by SIB, which recommends applications for funding. We also evaluate all proposals in terms of the existing portfolio of research-funded projects and their distribution across the aims of the research strategy to ensure we maintain a balanced portfolio of high quality research activity.

>Strategic Research Centres

These virtual centres of excellence bring together researchers from within and outside the field of CF, enabling scientists around the world to work together to address specific issues facing people with cystic fibrosis.

Our SRCs aim to:

- Create clusters of world class researchers.
- Bring researchers from different fields or disciplines together, to tackle the complex problems in cystic fibrosis.
- Widen awareness of cystic fibrosis research outside the traditional biomedical disciplines and so attract high quality investigators from new research disciplines.
- Recruit the brightest and best young researchers to CF research. Each SRC provides funding for five or six young scientists, who will work alongside the experts. Investing in these scientists at this stage in their careers leads to long-lasting interest in the field.

Following an open call in February 2015, the Trust has committed £2.6 million during this financial year to four new Strategic Research Centres, reflecting the high quality of applications, with co-funding for one SRC from the host organisation, the University of Leeds. This brings the total commitment since 2013 to £6.3 million covering nine SRCs.

1. The CFRD (Cystic Fibrosis-Related Diabetes) SRC

Prof James Shaw, University of Newcastle

This study aims to unravel the primary mechanisms underlying CF-related diabetes (CFRD) by bringing together researchers from the fields of CF and diabetes based throughout the UK, Europe and USA. The study aims to establish how the genetic defects responsible for CF increase blood sugar levels, a first step in understanding the development of CFRD. By building on this initial investigation, the researchers hope to identify novel interventions for CF patients to help prevent the development of diabetes thereby reducing morbidity and increasing life-expectancy.

2. Personalised Engineered Cell Therapies for Cystic Fibrosis

Prof Stephen Hart, UCL Institute of Child Health This project aims to prevent or repair lung damage caused by cystic fibrosis. The researchers will investigate two approaches to precisely repair the patient's own CF gene using an exciting new approach called 'gene editing'. Firstly, the gene editing molecules will be wrapped in a protective coating to form 'nanoparticles' which can be inhaled, correcting the CF gene in the lung. Secondly, they will take cells from the patient and treat them with gene editing in the laboratory. The patient's own corrected cells will then be delivered back into the lungs where, once there are enough cells, the lung should now be healthy. If one of these approaches is successful, it could lead to a huge improvement in lung disease that limits the lives of so many with cystic fibrosis.

3. Physical Activity, Exercise, Sport and Recreation Promotion for Adolescents with CF

Prof Craig Williams, University of Exeter

This project seeks to provide detailed information on how best to utilise activity for adolescents with cystic fibrosis. Many clinicians and their support teams, whilst valuing the role of physical activity to people with CF, are unsure how to promote it. Similarly, parents and adolescent patients are often overwhelmed with managing a busy treatment and education schedule to be able to fit sport, exercise or recreation into their lives. The researchers aim to bring together exercise specialists, psychologists, physiotherapists, engineers, clinicians, parents and adolescents to prescribe physical activity more effectively.

This SRC complements the new 'Activity Unlimited' programme of work also announced in 2015. A key component of the Trust's commitment to supporting 'breaths for life', Activity Unlimited is designed to help everyone with cystic fibrosis take control of their physical health and wellbeing through support and information on the wide range of activities that can help improve lung health.

4. Targeting Joint Disease in Cystic Fibrosis (CF): Identifying Therapeutic Targets in CF Arthropathy

Prof Michael McDermott, University of Leeds

Diseases of the joints (arthropathy) are amongst the most rapidly increasing complications of CF, but also the most overlooked. Symptoms of joint pain and disability affect more than one in ten people with CF, but effective forms of treatment are limited. The causes of CF arthropathy (CFA) are poorly understood, and there is no CF-specific method for describing and assessing joint symptoms or the effects of quality of life. The proposed research seeks to provide a systematic clinical and biological understanding of joint disease in CF, and will provide the basis for a drug trial of a novel agent for treatment of CFA.

"It's really great to see someone who is so passionate about trying to help someone like me. The work he's doing is incredibly important..."

– Ciara, who has cystic fibrosis-related diabetes, met Professor James Shaw, Principal Investigator on our Diabetes SRC



> Venture and Innovation Awards

One of the key strategic funding streams for research in 2015/16 is our Venture and Innovation Awards (VIAs) programme, which forms part of our five-year research strategy. VIAs leverage funding from external sources for transformational research projects, and enable us to respond quickly to new investment opportunities. VIA grants are awarded on a rolling basis by an internal committee which assesses the validity and value of individual projects against an agreed set of criteria. The award is contingent on the project undergoing the rigour of the peer review process of the partner organisation.

In 2015/16 we committed more than £700,000 in total to 11 VIA projects covering a wide variety of aspects of cystic fibrosis, including engaging those living with cystic fibrosis in helping shape the direction of future research.

In February 2016 we held a 'research sandpit' to explore the GI tract and CF, one of the most significant and yet often overlooked aspects of life with cystic fibrosis. Research sandpits bring together experts in a wide range of fields, including non-CF-related, to address specific issues to do with cystic fibrosis.

This year we also continued our commitment to supporting the next generation of scientists with £10,500 to support six summer studentships, as part of a co-funded scheme with the British Lung Foundation to give emerging PhD students experience working in world-class research.

Continued investment in SmartCareCF has seen the programme hit a number of key milestones. The adult feasibility study on remote monitoring, which is led by Papworth Hospital, opened for recruitment in August 2015, and will continue to collect data for analysis until April 2017. A parallel study into the feasibility of remote monitoring for paediatric patients has been planned this year.

Governance for funding research at the Trust is overseen by two principle committees, the Research Strategy Implementation Board (SIB) and the Research Strategy Advisory Board (SAB).

The Research SAB met in September 2015, after the UK Cystic Fibrosis Conference in Manchester, to complete a midterm review of the research strategy. In addition, SAB was asked to review proposals for changes to the strategy (particularly that of the VIA scheme) to ensure the existing research strategy is aligned to the new cooperate strategy to 2020.

> Collaborating with the clinical community to drive up standards of care

In August, the Trust announced the launch of the Excellence in Clinical Care & Innovation Awards – a new programme to support the very best ideas and innovation in CF clinical practice. The awards will provide funding for exciting quality improvement and clinical innovation projects. All UK CF centres are eligible to apply for awards ranging from £15,000 up to £75,000, to be met by matched funds from an alternative source.

This year we awarded two clinical fellowships, to Kings College Hospital (£75,000) and Belfast Health & Social Care Trust (£75,000). The Clinical Fellowship Programme is designed to encourage, develop and maintain high-quality leadership in the field of cystic fibrosis, helping develop and train the next generation of CF centre directors.

The Trust also contributed £75,000 towards a project in collaboration with the children's medical research charity Sparks to search for drugs that could benefit children with rare forms of the genetic mutation that causes cystic fibrosis. We made a contribution of £50,000 as co-funding for a study with Action Medical Research and Great Ormond Street Children's Hospital to develop a safe means of diagnosing cystic fibrosis during early pregnancy.

The Clinical Advisory Group met twice this year to advise on Cystic Fibrosis Trust publications, helpline enquiries and wider clinical issues. Chaired by Dr Keith Brownlee, Director of Impact, the group brings together representation from all the devolved nations, parent representatives and people with CF, as well as chairs of the Allied Health Professionals groups.

"Monitoring things means I can keep an eye on things I wouldn't have noticed before, so it's helped in quite a few ways... You are in control and you can see if you need to eat more, or sleep more."

– Sammie



In recent years, the Trust's Peer Review programme has been an essential part of our commitment to working with people with CF, commissioners and clinicians to ensure the best care for people with cystic fibrosis. Each CF centre is reviewed every five years, to help identify areas of best practice, assess the service against service specifications and review the outcomes and experiences of a service. The peer review programme in its current form came to an end in October 2015, to allow us to evaluate the process. We are currently undertaking an extensive consultation with all interested parties, to produce a more objective, outcome-driven process that is centred on people with CF, and which will be more frequent and flexible.

> **Reforming the Registry to harness the power of knowledge**

The UK CF Registry is a world-class database that includes over 99% of people with cystic fibrosis in the UK who have consented to their data being submitted by their CF care team. The Cystic Fibrosis Trust commissioned the development of a bespoke, adaptable and flexible registry platform, which launched in February 2016, to make it easier for teams at CF centres to enter data, and to unlock the potential for the Registry's next phase of development, which we committed to following a 2015 community survey. This includes enabling Registry-based clinical trials and developing a portal so that people with cystic fibrosis can view their clinical data as well as inputting their own information about their wellbeing. This has been an investment of £315,000 during 2015/16 with further investment scheduled for 2016/17.

The 2014 Annual Data Report was published in August 2015 with both a full report and 'at a glance' summary to offer a complete and an accessible snapshot of the UK CF population. The 2015 Annual Data Report will be published in August 2016 and will be similarly available on the Trust's website.

Through three pharmacovigilance and two NHS contracts, the Registry generated income of £1.2 million, all of which has been used either directly to support the Registry – including through grants to CF centres – or to fund research work dedicated to cystic fibrosis.

We are delighted to announce that this year saw Dr Siobhán Carr, who is a Consultant Paediatrician at the Royal Brompton Hospital, appointed as the new Chair of the Registry Steering Committee.

The Trust also held a national meeting in Nottingham for Registry users to learn, feed back, and share best practice. The meeting was attended by over 100 delegates, with 100% rating the event good, very good, or excellent.

> **Offering information and support for all**

2015/16 was a very exciting year for the Information and Support team, with additions increasing its capacity to deliver support for those who need it most, and a commitment to give support for people at every stage of the cystic fibrosis journey.

The recruitment of a Welfare and Rights Advisor enabled the team to offer specialist benefits and rights advice. This was boosted in Northern Ireland with the successful pilot of a benefits advice scheme, working with the Citizen's Advice Bureau.

The addition of a Youth Empowerment Officer (YEO) in February 2016 enables the Trust to achieve its goal of empowering young lives, and ensure that young people with cystic fibrosis have a voice in the work we do. By the end of March the YEO had developed and recruited the Trust's first Youth Advisory Group, which features people with cystic fibrosis aged 11–25 as well as siblings and friends.

In June 2015 we launched a new support pack and film aimed at parents of a child newly diagnosed with cystic fibrosis. These resources bring together stories and accounts from others who have been in that position, as well as practical advice and guidance.

We have sent out over 80 new parent packs since launch. We have also continued to expand our CF Connect scheme, putting new parents affected by CF in touch with trained parent volunteers who offer a listening ear, advice and support, in confidence.

This year we awarded 695 grants to individuals, totalling more than £230,000. This includes grant giving activity in partnership with the Joseph Levy Foundation, with 85 education related grants made from restricted funds.

Our health and wellbeing grants are awarded by an independent expert panel that meets every eight weeks, and includes a person with CF, a parent and a former CF social worker. Emergency grants are processed by the Support Service team on a weekly basis.

➔ In 2015/16 we awarded:

- 248 Health & Wellbeing grants, totalling over £63,000, to help people with the financial burden of managing and living with cystic fibrosis.
- 139 Emergency grants totalling over £19,000 to support people in moments of crisis
- 24 Transplant grants totalling £6,000 to support people going through the transplant process.
- 85 Funeral grants totalling £64,000 to help families who have lost a loved one.

Steve is just one of many grants recipients who have benefitted from our programme of support this year. Following the birth of his son in 2014, Steve was finding it more difficult to find the time to do as much exercise as he had been used to, and his lung function started to drop drastically. He had been working hard on getting out running, but with winter approaching he was concerned that he wouldn't be able to keep this up, so he contacted us to see if we could help him with a grant for a new rowing machine.

Steve said, “Without the rowing machine, I would have been so inactive over the winter. I’m really starting to feel the benefits of having it. My physiotherapy is noticeably different after I’ve had a row. Thank you to the Cystic Fibrosis Trust for giving me the opportunity to give my health a boost with this new rower.”

Through other programmes, we awarded:

- £28,000 through holiday grants
- £44,000 in education grants
- £7,000 of homecare grants

> Campaigning hard

Throughout 2015/16 the Trust continued to campaign on the issues most affecting people with cystic fibrosis, including access to medicines, transplantation and equal care. The CF community was also represented in the Westminster Parliament by an All-Party Parliamentary Group.

In November 2015 the Trust launched one of its biggest and most wide-ranging campaigns to date, ‘Stopping the Clock’, dedicated to ensuring that people with cystic fibrosis who could stand to benefit from life-changing precision medicines can access them on the NHS wherever they are in the UK.

Through this ongoing campaign we are amplifying the voice of our community and putting pressure on policy influencers and decision makers to work together for the good of those who are without access to these life-changing treatments.

- Almost 1,500 members of the CF community took part in our survey on attitudes to precision medicines, which informed our submission to the NICE consultation on the combination treatment Orkambi, which could benefit around half the UK CF population.
- More than 20,000 supporters signed our petition calling on the NHS across all four UK nations and drug manufacturers to take responsibility for ensuring access to precision medicines. The petition was handed in at Number 10 Downing Street. In December 2015 we worked with the Houses of Parliament’s Outreach Service to organise a unique digital parliamentary debate. The service spreads awareness of the work, processes and relevance of the institution of Parliament, encouraging greater engagement between the public and the House of Commons and House of Lords. Members of the community shared videos and took to twitter to share their stories with Ian Austin MP, who raised the debate and represented the voice of the community. Following this members of the UK Government met with the Trust’s policy team to discuss working together to ensure greater access to medicines.
- The campaign has so far generated more than 3,000 new active supporters to the Cystic Fibrosis Trust, allowing us to better engage and understand their views, ideas and issues.

George Freeman MP, Minister for Life Sciences, said

“The Government and I wholeheartedly support the Cystic Fibrosis Trusts’s campaign’s central aim of ensuring that as many people with CF as possible will have access to personalised medicines by 2020. That sets an inspiring and clear goal and I relish the attempt to deliver it.”

This is clearly a ringing endorsement of our campaign, and also offers a real hope for the future for people with CF.

> Raising awareness and more effectively engaging with our community

We are responding to the changing face of marketing and communications and moving the Trust into a more digital first approach.

June 2015 saw the return of CF Week, the Cystic Fibrosis Trust's annual week devoted to awareness and fundraising. The theme for 2015 was 'the power of us', and a focus on the strength and impact of the CF community themselves. People from across the community shared stories and experiences, and the Trust offered an in-depth look at some of its key projects.

In September we held the UK Cystic Fibrosis Conference, the UK's largest conference dedicated to a multidisciplinary CF agenda. Bringing together clinicians, health professionals and researchers from around the world, the UK CF Conference promotes innovation, dialogue and shared learning. This year the event expanded to two days: one for a multidisciplinary clinical, research and academic audience, and a second for clinical healthcare professionals as well as those with a personal or professional interest in cystic fibrosis.

For the first time we streamed the entire conference live and recorded it for our website, so that the whole CF community was able to follow it in real time or watch key sections back later.

2015/16 saw the roll-out of 'Life Unlimited' a bold new era for the Trust with an exciting programme arranged around five key bodies of work. A soft launch in October introduced Life Unlimited to our core audience, followed in February with a big public event, accompanied by a world exclusive music track and powerful campaign video.

With Life Unlimited, the Trust is setting out to reach a wider audience, to boost income to allow us to do more, and achieve greater impact than ever before for the cystic fibrosis community. The public launch was aimed at attracting the attention of the wider public who know little or nothing about cystic fibrosis and the Trust.

In the first week following the launch, the video had been viewed 389,000 times, including 63,565 times on YouTube, and added 220 new subscribers to the Trust's YouTube channel. The video and campaign secured a total of 62 pieces of media coverage, including both BuzzFeed and the Mail Online.

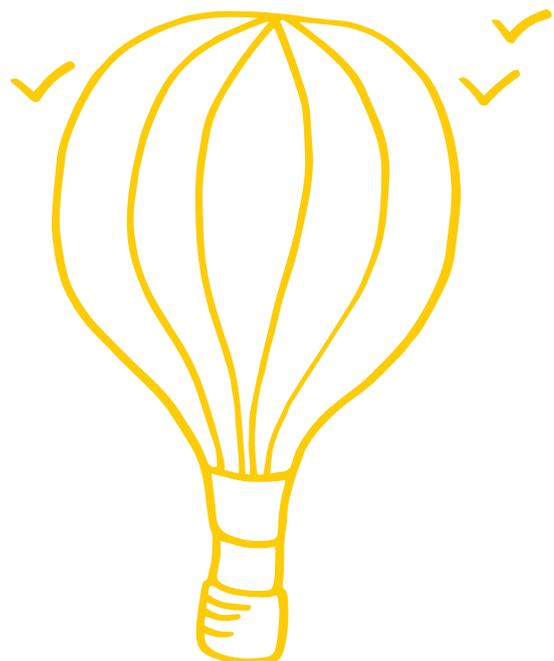
The launch benefitted from the support of a corporate partnership with ClearChannel, Digital Outdoor Advertising. As part of this outdoor campaign, the Life Unlimited advert appeared during rush hour at Piccadilly Circus, in London, and at 38 outdoor sites across the city, giving it an estimated audience reach of more than six million.

This year, the Trust launched a new website in order to deliver greater impact. Over a year in development, the new website will enable the Trust to better serve its supporters and a growing audience. With 59% of traffic to the site coming via either smartphone or tablet, it was imperative to develop a mobile-responsive site with a better search function and all-round user-experience. Phase 1 of the site went live in February, with continuing development for Phase 2 extending into 2016/17. In addition to being more intuitive, the new site will allow the Trust to personalise content according to user profiles, so that users will find the content they need quickly and easily.

> Developing an effective organisation

In 2015/16 the Trust continued to expand on its volunteer programme following the award of the Investing in Volunteers accreditation in 2014.

A huge thank you to all of our volunteers who give their time and skills to help us achieve our mission, including the additional 82 volunteers we recruited across the organisation in 2015/16, a 10% increase on 2014/15. We have also developed new volunteer opportunities in CF Connect, photography and our project placements from Queen Mary University. Volunteers work across the organisation, in areas including Content, Digital, People and Organisational Development, and Fundraising Support, and collectively give nearly 32,000 hours of their time to support the Trust, showing just how dedicated they are to helping to beat cystic fibrosis.



> Fundraising

The Cystic Fibrosis Trust receives no government funding, and we are very grateful for the ongoing support of the individual donors, organisations, charitable trusts, foundations, and corporate partners without whose generous support none of our life-changing work could take place.

This year, we were delighted to receive a number of gifts from high net worth individuals in support of both our core and project work, in line with plans to develop this area of income. We were also very pleased to develop warmly supportive relationships with new and existing members of the high value membership Sixty Five Roses Club at our annual flagship event in October 2015.

Income from charitable trusts and foundations continued to grow significantly in 2015/16 with income doubling in the last two years. This included two major grants totalling £500,000 from well-established grant makers the Garfield Weston Foundation and the Freemason's Grand Charity.

Corporate partnerships fundraising was given a boost in 2015/16 by securing major partnerships with HSBC Private Bank, Champneys, and Sainsbury's Central Retail Division. We were delighted to secure strategic partnerships with Simply Health and Yakult, and were selected as the charity of choice for the City-focused 'Swaps Ball' held at The Dorchester, London, which raised £92,000. The successful UK CF Conference 2015 received £67,000 in sponsorship from a range of industry partners and has laid the foundation for an increase in sponsorship income for the 2016 conference. We are also very grateful for the generous in kind support from Clear Channel in helping to promote the work of the Trust.

We received notification that 52 of our supporters passed away in 15/16 who had generously included a gift in their will for the Trust. We would like to express our gratitude for thinking of us in this way. Very many thanks are also due to the 53 very kind supporters who responded to our Gifts in Wills campaign with notification of a future legacy.

Fundraising and community activities are essential to the continuing work of the Cystic Fibrosis Trust, providing opportunities to raise awareness, engage supporters and build lasting relationships, as well as generating much-needed income. This year we supported 118 challenge events, such as marathons, bike rides and treks, in the UK and beyond, raising more than £ 2,271,000. Our Community, Branches & Groups Activity also raised an amazing £2,081,000, including gift aid.

We are also very grateful to the new and existing donors who support our work through regular monthly donations via direct debit, as this ongoing support is invaluable in enabling us to plan ahead. Equally the support of everyone who made a donation to our Christmas appeal, via our web site, or in response to our telephone appeals, or who bought a raffle ticket is very much appreciated.

The Trust would like to convey our sincere and heartfelt thanks to each and every person who supported the charity's work in any way over the past year. Your support is literally a lifeline for all the Trust's innovative research, campaigning, and information and helpline services. Without your help none of our life changing work could take place.



Plans for the future

In 2015, after an intense period of planning, trustees agreed a bold and ambitious five-year strategy to deliver a step-change in the impact of the charity on the lives of people with cystic fibrosis. 2015/16 has been the first year of the Life Unlimited strategy and has seen much progress on a range of fronts, with significant investment in world-class research, more focused support for those who need it most and development of flagship programmes like SmartCareCF and the UK CF Registry.

Crucial to embarking on such a significant journey was the process of listening to all parts of the CF community in the UK itself, understanding their needs, concerns and goals. This engagement remains vital in enabling the Trust to take a leadership position on behalf of our community, and to bring together the expertise and insight within it.

Putting people with CF first in everything we do is a central part of our strategy, and we are seeing much greater involvement of our core beneficiaries in the shaping and delivery of our activities, with significant benefits in ensuring the projects are having maximum impact.

The revolution in genomics and personalised medicine is creating extraordinary opportunities for people with cystic fibrosis. We are determined to seize them. Transforming our work to change the lives of those we are here for inevitably takes time and creates challenges. But we have made a good start and we are confident of further progress in the coming years.

With the community and public launches of the Life Unlimited era, the ground has been prepared for 2016/17 to see the start of a step-change for the Trust. This year we will develop and begin to roll out four flagship programmes, which will drive our work over the next five years. These world-class programmes will underpin our strategic priorities and bringing us closer to our goal of beating cystic fibrosis for good.

- Therapeutic Development Programme: to develop new therapies for all people with CF whatever their genotype and whatever the stage of their condition. This programme includes the Clinical Trials Accelerator Programme, which is design to promote equity of access to clinical trials across the UK and thereby increase opportunities for people with CF to be involved in trials
- SmartCareCF: to identify, test and enable the deployment of innovative digital technology solutions that can improve the health and wellbeing of people living with cystic fibrosis.
- Innovation Hubs: to help establish new academic centres of excellence creating a focused critical mass in clinical and basic sciences research.

- The UK Cystic Fibrosis Data Registry Phase II: the Registry will move to a new, more efficient platform that will unlock its potential to revolutionise the way clinical trials are carried out. We will also open the CF Registry to people with CF so they can track their health, input their own data, and increase their involvement in research.

Other key activities for 2016/17 include:

- Stopping the Clock – the campaign will continue, including engagement with the NHS in England and Scotland over Orkambi.
- CF Week in May, engaging the community with the impact of research and their role in helping shape the future.
- CF Yelfie Day on 1 July.
- The UK CF Conference in September, which this year will run to three days including a satellite event designed to engage our community with research.
- The announcement of up to three new Strategic Research Centres, as well as new VIAs and other programmes, and a new round of summer studentships.
- New Information & Support materials, aimed at parents of children with cystic fibrosis starting school, and a fertility pack for adults with CF considering starting a family.



Financial review

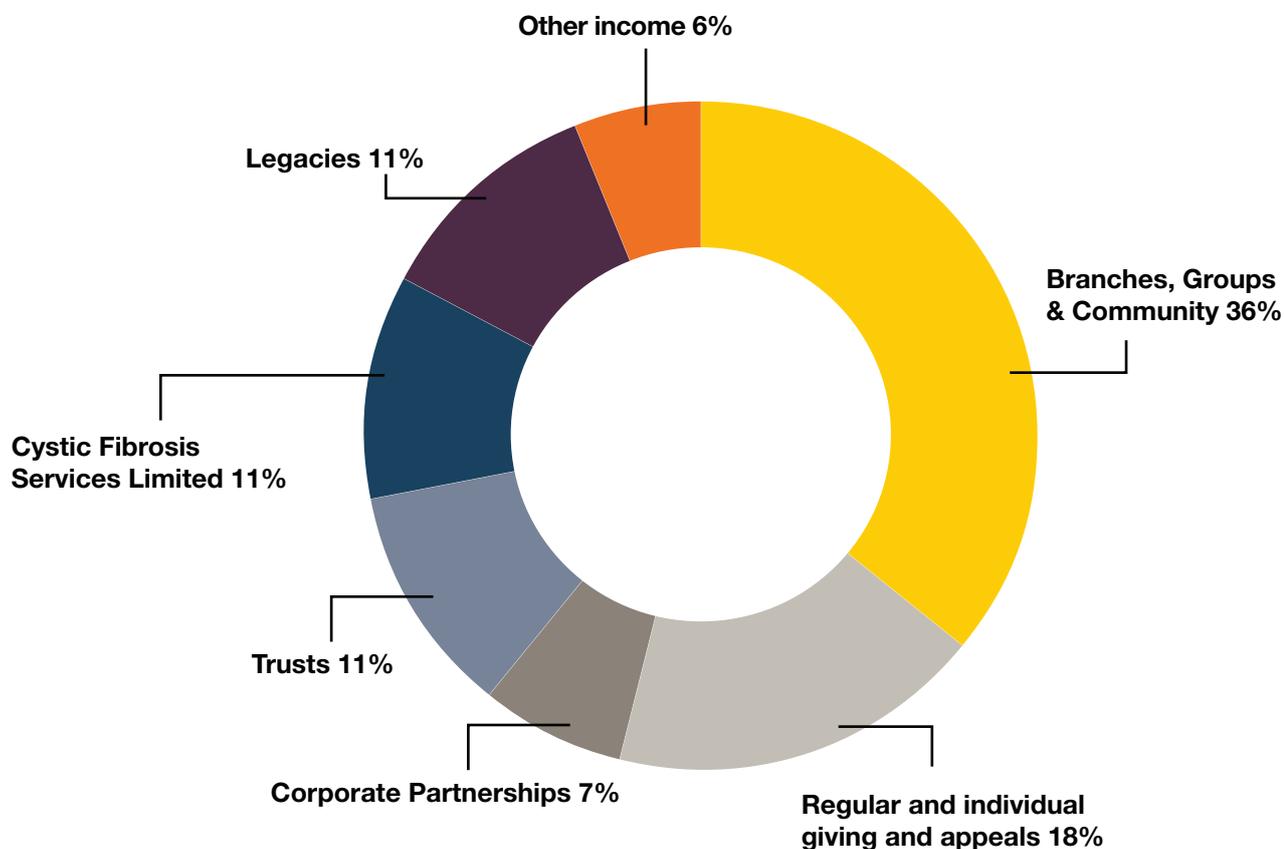
Income

The Trust's income from normal activities for the year to March 2016 was £11.4 million, an increase of 1% over the previous year. This does not include a one-off gain in the prior year of £827,000 due to the sale of the former office premises in Bromley.

84% of the Trust's income from normal activities was voluntary income, bringing in £9.6m, consistent with the prior year. Income raised by community fundraising and branches was £4.2m which represents 40% of this figure (a slight fall compared to 2014/15), confirming the continuing importance of the volunteer network to our fundraising efforts. While income from legacies and corporate partnerships was lower than in the prior year, income from Trusts and Foundations doubled – this significant growth is the result of a strategic focus on this area of fundraising.

Income raised through CFSL, the Trust's trading subsidiary, was at £1.3m (2014/15 - £1.4m). Three (2014/15 - 3) long term commercial contracts are in place for Phase IV pharmacovigilance studies based on the extraction of data from the Trust's UK CF Registry, and we are actively seeking further new business in this area, including shorter term contracts for specific projects.

> 2015/16 income by income stream



Income from normal activities:	£'000
Branches, Groups & Community	4,157
Regular and individual giving and appeals	2,073
Corporate Partnerships	772
Trusts	1,274
Cystic Fibrosis Services Limited	1,264
Legacies	1,217
Other income	629
Total income from normal activities	11,386

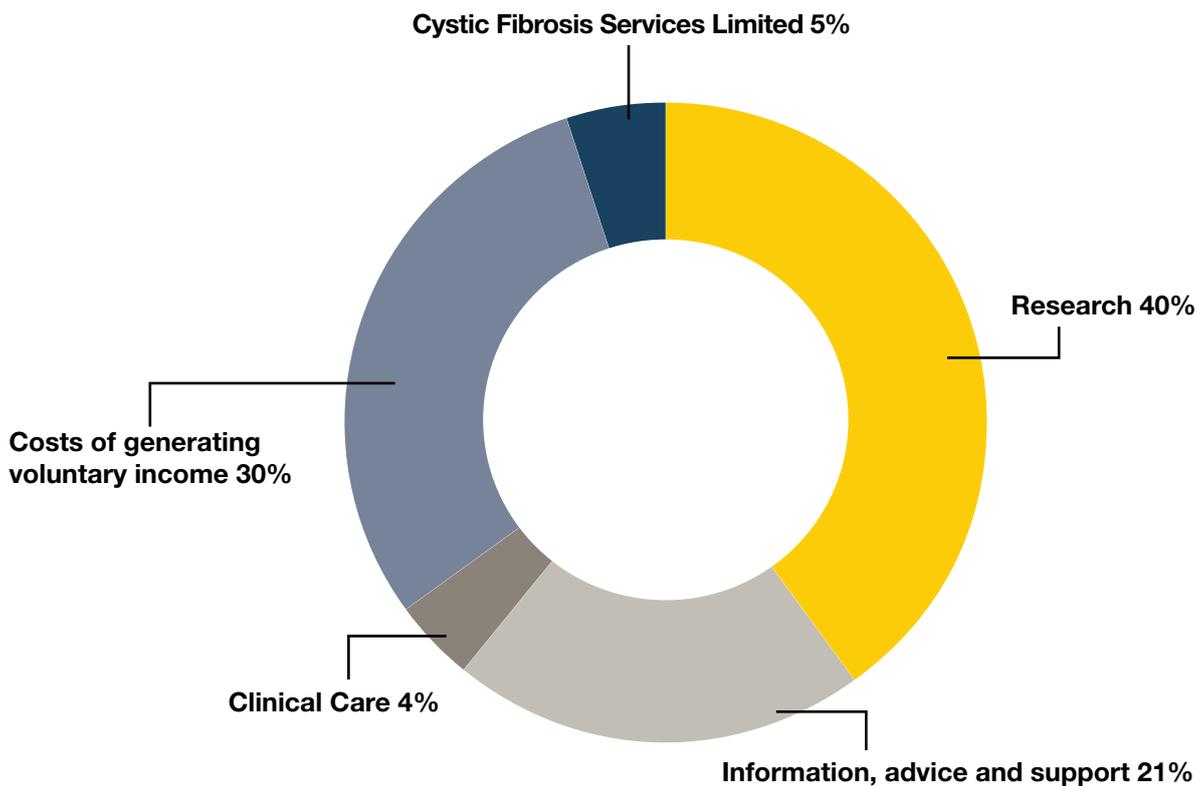
Expenditure

The Trust's total expenditure for the year was £13.6m, a 13% increase compared to the previous year. Almost all of this increase was in the area of charitable activity – £8.9m, representing 65% of total expenditure (2014/15 62%), was spent on programmes of research, information, advice and support and clinical care. The remainder was spent on fundraising and running the charity, reflecting investment in fundraising and information technology as part of setting the basis for future growth within the context of the five year strategic plan.

Total grant commitments in the year at £4m were 9% higher than in the prior year. Grants worth £3.8m (2014/15 £3.1m) were committed to a range of institutions, including £2.6m (2014/15 £1.5m) committed for four Strategic Research Centres.

Work on the Flagship Programmes of SmartcareCF, CF Registry Platform Development and Therapeutic Development have continued, with total spend on these programmes of £1.2m (2014/15 £0.5m).

> 2015/16 expenditure by cost type



Expenditure:	£'000
Research	5,461
Information, advice & support	2,931
Clinical Care	496
Charitable activities total	8,888
Costs of generating voluntary income	4,029
Cystic Fibrosis Services Limited	666
Total expenditure	13,583

Cystic Fibrosis Trust

cysticfibrosis.org.uk

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Fighting for a
Life Unlimited