Cystic Fibrosis why we're here

Impact report 2014/15

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"I'm so proud of what we've achieved in the fight against cystic fibrosis this year, but we won't stop until we have beaten it for good - and for that, we need your support." – Ed Owen, Chief Executive

Cystic Fibrosis Trust – Impact Report (2014/15)

Cystic fibrosis is a life-limiting genetic condition that slowly destroys the lungs and digestive system. Take a look at how we've been fighting to create a better future for everyone with cystic fibrosis.

If this report leaves you wanting to find out more about the Trust and how your donations contribute to our vital work, visit **www.cysticfibrosis.org.uk**.

Welcome!

"I'm Jess, and I want to thank you for your interest in the incredible work of the Cystic Fibrosis Trust. At the start of 2015, the Trust launched a new campaign for the whole CF community (page 10) - one that had significant outcomes for me and many others like me.

This is just one of the ways the Trust has had an impact on the lives of people with cystic fibrosis this year, as you'll see in this report.

I am looking forward to supporting the Trust as it takes on bigger and bolder challenges in the year to come." – Jess

This year, thanks to your support, we were able to invest £4 million in research into beating cystic fibrosis.

- Of this, more than £450,000 was invested into Venture and Innovation awards. For every £1 we provided, an additional £5 in external funding was added.
- We also gave two £750,000 grants to fund Strategic Research Centres, where world-leading scientists are fighting to find better ways of using data to improve clinical decisions and promoting the development of drugs to treat the most common cause of cystic fibrosis, the faulty F508del gene.
- In memory of Sir John Batten, we created a £10,000 fund to pay for five studentships for researchers investigating topics related to cystic fibrosis: MRSA, fluid secretion in the airways, F508del function, CF-related diabetes and airway inflammation.

Funding cutting-edge research is vital for creating a brighter future for people with cystic fibrosis, who often tell us it's their number one priority.

April

Nearly 5,000 join our Hope for More campaign for a national transplant register

With a generous donation from the Pears Foundation, we funded a study into using induced pluripotent stem cells from white blood cells to correct specific genetic mutations in cells in the airways. This world-class research, by Dr Ludovic Vallier (pictured above) and Professor Andres Floto, could help to find life-saving treatments for cystic fibrosis.

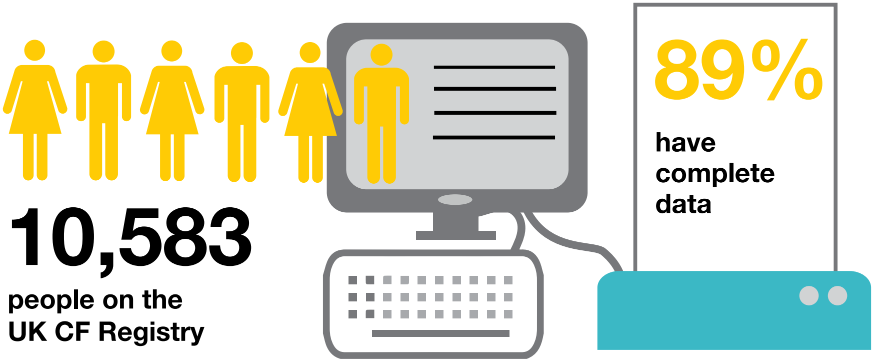
Stem cells offer significant potential as they replace damaged cells that would otherwise not be replenished. If successful, this research could pave the way for treatments to permanently fix the specific mutations being investigated.

May

We welcome HRH Prince Charles as our Patron at our Fiftieth Anniversary Gala

Driving up standards – Registry

The Cystic Fibrosis Trust Registry is a secure collection of data about people with CF in the UK, collected with consent and used to improve care and to monitor new treatments.



10,583

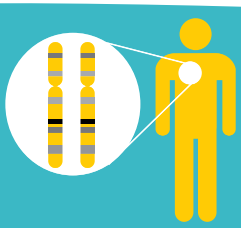
people on the UK CF Registry

89%

have complete data

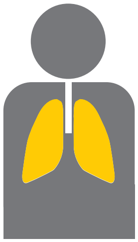
59.3%

of people with cystic fibrosis are aged 16 or older



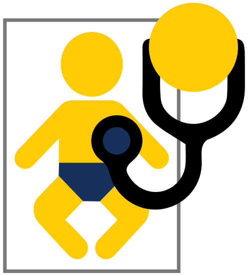
97.7%

of people with cystic fibrosis have their genotype recorded



72

transplants in 2014 compared with 57 the previous year



2 months

is the median age of diagnosis

40.1

is the median predicted age of survival

70.1%

of adults with cystic fibrosis are in employment or study

June

Trust partnership leads to Phase IIa clinical trials of Lynovex antibiotic treatment

Every £1 spent on peer reviews raises another £22 in funding for the facilities we review, making your donations work even harder to ensure higher standards of care for everyone with cystic fibrosis.

Our peer reviews benchmark specialist CF centres against the Trust's 'Standards of Care', resulting in extensive online reports that provide evidence for funding applications. By revisiting each facility within five years, we create accountability and encourage facilities to share best practice, driving up the standard of care experienced by every single service user and their families.

July

Trust and Jim Shannon MP get transplants to top of Westminster agenda in debate

Campaigning hard for our community

50 official parliamentary champions on board

31 members in a new all-party parliamentary group on CF

131 MPs added to our mailing list

16,000 supporting actions from the CF community

5 political events with dozens of parliamentarians

35 parliamentary questions asked = 103 recorded mentions of CF in parliaments across the UK

August

Trust campaigns for fair travel insurance for people with cystic fibrosis

We tirelessly campaigned for our community, addressing issues such as prescription charges for CF medicine and below-standard CF facilities at a London hospital.

Actions like these had some great outcomes for people with CF, such as the £2.3 million pledged by the Welsh Government to fund a new CF ward in Llandough, a pilot for a new policy on donor lung allocation across the UK and senior politicians calling for the Prime Minister to introduce soft opt-out for organ donation in the UK.

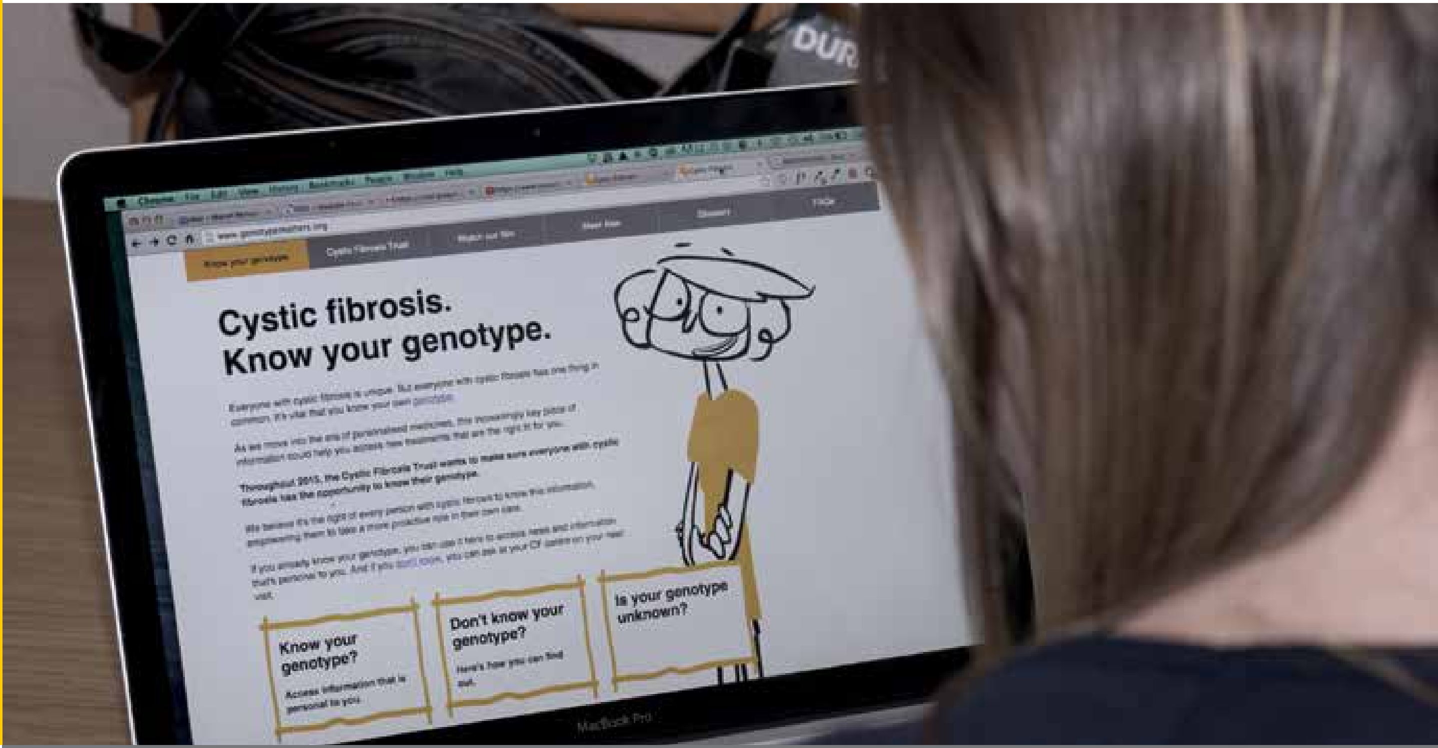
September

Our UK CF conference is live-streamed for the first time to make it accessible for all

~~ONE~~
~~SIZE~~
~~FITS~~
~~ALL~~

We know that cystic fibrosis is as unique as the individuals who are fighting it; that's why we launched our Genotype Matters campaign.

We campaigned to make sure that everyone with cystic fibrosis could find out their genotype, to ensure that they are getting the best treatment possible and to pave the way for them to take advantage of personalised care the second it becomes available.



Cystic fibrosis.
Know your genotype.

Know your genotype?
Access information that is personal to you.

Don't know your genotype?
Here's how you can find out.

Is your genotype unknown?

October

Trust event in Northern Ireland calls for change to organ donation legislation

Jess's Story

"Through taking part in the Trust's Genotype Matters campaign, I discovered that there was a drug in development that could radically improve my day-to-day life.

This drug was initially unavailable to people with my form of cystic fibrosis, despite evidence that it could reduce my time in hospital by 70%. That's why I jumped at the chance to get involved with the Trust's campaign to get access to this treatment – which was a great success – and I'm now doing much better on the new drug!

I hope that by sharing my story, it will shine a light on how the Trust's campaigns have a daily impact on people living with cystic fibrosis."

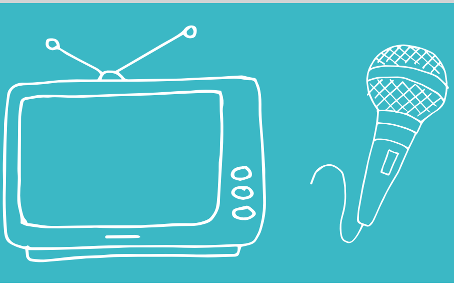
November

We campaigned for new facilities for people with CF at Kings College Hospital

We managed to secure nearly

£3.5 million

in print coverage for the Trust and more than 150 pieces of broadcast coverage.



Our #CFYelfie campaign inspired people to send in yellow-themed selfies to celebrate our 50th year, and was in the 'Top 50' social media campaigns by the Telegraph – over £2,500 was raised by hundreds of supporters.

December

We partner with the British Comedy Awards for an awareness campaign

Social Media highlights

13 April 2014
London Marathon 2014

Facebook likes
6,902

Twitter favourites
208

26 September 2014
One Republic 'I Lived' The music video by the US band, featuring cystic fibrosis.

Facebook engagements
4,093

Twitter engagements
1,209

Facebook shares
219

Retweets
175

14 November 2014
'A cystic fibrosis 'cure'? – Understanding this week's research news'

Our most read blog ever!

4,401 **views**

204 **comments**

17 December 2014
'The Breath Before' video

8,551
views on Youtube in its first 24 hours

268
links to the film were tweeted in that period

January

Our Time to Talk organ donation awareness campaign launches

Grants

More than 350 awarded, worth around

£122,000

Nearly **£50,000**

helped 66 families with funeral expenses at a difficult time

More than

£15,000

enabled 52 people to boost their health with a holiday

More than **£7,000**

supported 31 families during the transplant process

Helpline

Over **500** emails

Nearly **2,000** calls

More than **2,500**

calls for help answered

February

We announced funding for two new Strategic Research Centres

What is SmartCareCF?

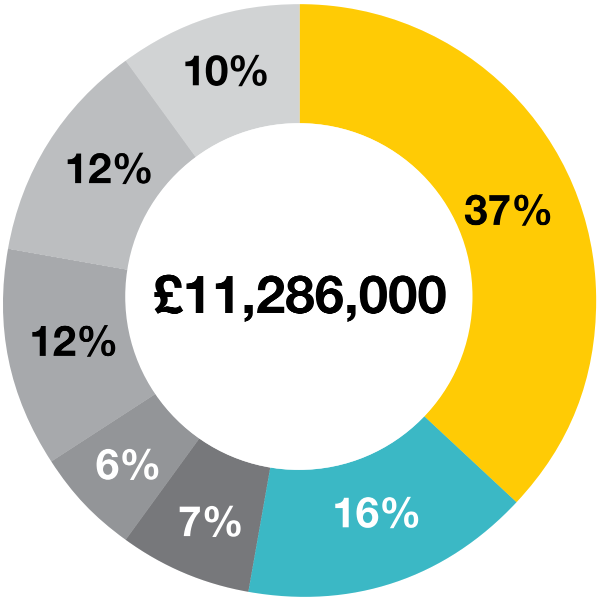
Working with people with cystic fibrosis and specialists from clinical, academic and industry backgrounds, we are investigating ways that people with CF can harness the power of mobile technology to manage their health and wellbeing efficiently.

Preparatory activities from multi-centre feasibility studies to creating a databank of evidence are paving the way for an exciting period for the SmartCareCF programme!

March

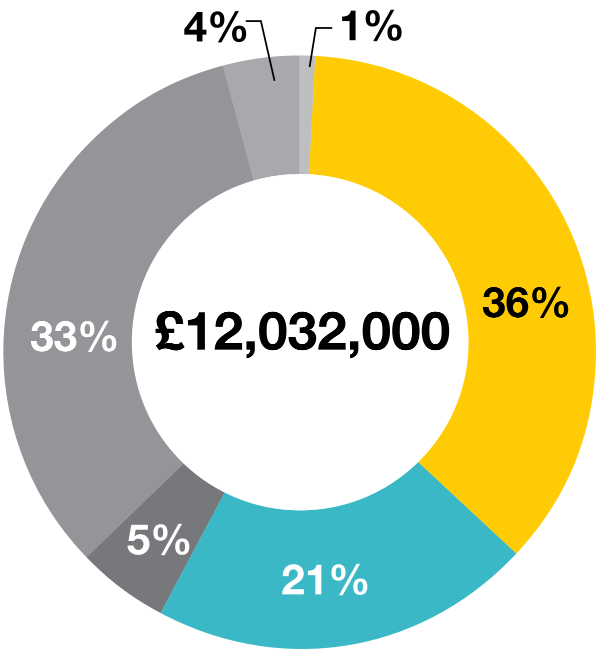
Trust announces funding for ground-breaking stem cell research for CF

2014/15 income from normal activities by income stream



Income from normal activities:	£'000
🟨 Branches, Groups & Community	£4,219
🟦 Individual gifts	£1,837
■ Corporate Partnerships	£797
■ Trusts	£632
■ Trading income from sales of goods and services, and use of Registry data	£1,376
■ Legacies	£1,361
■ Other income	£1,064
Total income from normal activities	**£11,286**
Net profit from sale of former premises	£827
Total income	**£12,113**

2014/15 expenditure by cost type



Expenditure:	£'000
🟨 Research	£4,281
🟦 Information, advice & support	£2,580
■ Clinical Care	£614
Charitable activities total	**£7,475**
■ Costs of generating voluntary Income	£3,962
■ Costs of running CF Registry	£523
■ Governance costs	£72
Total expenditure	**£12,032**

"It's been a busy year! Our mission to transform the lives of people with cystic fibrosis means we have invested in cutting-edge research into new treatments and campaigned tirelessly for better care.

Our helpline and welfare grants have been more popular than ever, helping people with cystic fibrosis overcome the challenges of their everyday life and make the most of the good times, too.

Our 50th year has been a time for acknowledging and reflecting on progress so far. People with cystic fibrosis are living longer than ever and research into treatments is thriving. But we won't rest on our laurels – we have bold and ambitious plans for the future, and I hope you will support us as we enter an exciting period of change at the Trust. Together, we will create a brighter future where people can live longer and happier lives, unlimited by cystic fibrosis." – **Ed Owen, CEO**

Thank you

We’d like to thank all of our supporters who have helped in the fight to beat cystic fibrosis for good, with a special thank you to Jess Didlick for bringing this report to life with her story.

In May 2014, we were honoured to announce His Royal Highness The Prince of Wales, KG, KT, GCB, OM as our Patron. In March 2015 we welcomed Hannah Begbie, Michael Winehouse and Louise King as Trustees.

A kind thank you to members of the Sixty Five Roses Club, some of whom are listed below, for their generous support.

Sixty Five Roses Club

Faulkner Family
Gay & Keith Talbot Trust
Colin and Victoria Jones
Richard Parkinson
Mr & Mrs K M Paley
Tom & Liz Sawyer
Terence Kyle
Tim Miller & Emma Hawkey
Mr Michael Gaunt
Mrs Ann Gaunt
Tony and Barbara Kelley
Charles van der Lande
John and Carol Law
James and Catherine Greenstreet
Janet and David Lavender

Sixty Five Roses Club Scotland

Dame Barbara Kelly
Alyson & Gil Carswell
Wilma Gorman

Thank you to all of our kind supporters – every single donation enables us to continue the fight to create a brighter future for people with cystic fibrosis. We'd also like to thank the Trusts and Organisations that we work with – we don't have space to mention them all here, but we'd particularly like to thank:

Trusts

The Marjorie and Edgar Knight Charitable Trust
Pilkington Charities Fund
The Constance Travis Charitable Trust
Enid Linder Foundation
Joseph Levy Foundation
Joseph Levy Memorial Fund for Education
Swire Charitable Trust
The Elizabeth and Prince Zaiger Trust
The Childwick Trust
Donald Forrester Trust
The Freemasons' Grand Charity
The February Foundation
Chiltern Charitable Trust
Pears Foundation
The City Charitable Trust
The Robert Luff Foundation

Strategic Partnerships

Nationwide Group Operations
East London Textiles
Vertex Pharmaceuticals
Hard Rock Café
National Grid
UK Parliamentary Football Club
Gilead
Network Rail
Paperchase
UK Air Cargo Club
NHSBT
Atlantic Philanthropies
Reading Textiles

A warm thank you to the following people, who have each generously left us a gift in their will after making provision for their family and friends. Gifts in wills are an important source of income and allow us to know that we can continue fighting cystic fibrosis until we beat it for good.

Mrs Bertha Blinkhorn
Miss Elizabeth Brown Provan
Mrs Helen Barbara Standley
Mr Robert William Allen
Miss June Margaret Hills
Mr Alan Frank Shipman
Mrs Shirley Simpson
Mrs Margaret Yaxley
Sir John Charles Batten
Mr Arthur Harold Betts
Ms Joyce Winifred Ruth Ford

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Fibrosis Trust

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