

## **Welcome to our Impact Report 2015/16**

This has been an important year, and thanks to the support we receive we've been able to invest in cutting-edge research and improve the care and support available to people with cystic fibrosis. Discover the impact we're having on the lives of people with the condition, and join us on our journey towards a life unlimited.

- Dr Keith Brownlee, Director of Impact.

**We're working hard to shape a life unlimited by cystic fibrosis**, by empowering young lives, supporting breaths for life, harnessing the power of knowledge, making ambitions possible and changing lives through transformational therapies.

### **Research**

We invest more money into research into cystic fibrosis than any other charity in the UK; in this year, we committed more than £3 million to research including four huge new projects, and 12 innovative awards that will receive an additional £1.5 million from external sources as a result of our investment.

We invested an additional £600,000 into the Gene Therapy Consortium to help it continue the development of its gene therapy programme for people with cystic fibrosis, which has demonstrated the potential of this therapy for slowing the decline of lung function that limits so many peoples' lives.

We're breaking down barriers for people with cystic fibrosis, including: diabetes, joint pain, digestive problems, helping increase the understanding of gene therapy, and physical exercise as a treatment.

### **Campaigning hard**

We demand the right decisions and help the CF community shout louder. Our Stopping the Clock campaign demands access to precision medicines: 20,000 of you signed our petition and more than 6,000 people emailed their MPs to support our campaign. The voice of the CF community cannot be ignored... as a result, the Government has indicated that it is prepared to discuss proposals that could enable patients to access Orkambi at a cost-effective price. We'll fight until everyone has access to the medications that help keep them out of hospital so they can achieve their dreams.

We also teamed up with Parliament for a first-of-its-kind virtual campaigning workshop for the CF community.

Clara, who has CF, says: "I want to be able to tell people about the things that I think are important, like Orkambi. It would be so awful if it doesn't get licensed."

### **UK CF Registry**

Our new Registry platform makes it even easier to transform data into results.

The secure, improved platform holding information on all consenting individuals with CF in the UK makes it easier to use this data in clinical trials, which are notoriously hard to carry out for CF treatments. We are working towards people being able to contribute to their own data and even receive invitations to suitable clinical trials.

### **Support for all**

We answered nearly 4,000 calls for help this year; by phone or email, we are available to people with cystic fibrosis and their families throughout the week.

Whether they need a shoulder to cry on, or some help from our new Welfare and Rights Advisor to apply for the benefits they deserve, we're always here. 4,000 people will need to be assessed for Personal Independence Payments by 2018, and she's there for each of them.

### **Youth empowerment**

Our new Youth Empowerment Officer is getting young people with CF involved in our vision.

By inviting young people to help guide our work, we can provide relevant support and guidance to them at the most important time of their lives. We kicked off our Youth Advisory Group in early 2016 as well as presenting seven young entrepreneurs with the Helen Barrett Bright Ideas Award and support to help them build their ambitions into something more.

Poppy, who has CF, says: "I hope but never expected to win the award. I am so pleased that I am now able to start a career after my transplant."

### **At your fingertips (Information and Support)**

Our new resource for newly diagnosed families has helped empower over 100 families to make the right decisions for them. 29 new CF Connect volunteers have been trained to help support people through their experience of cystic fibrosis. 248 Health & Wellbeing Grants provided £63,000 of support to people in need. Our new scheme in Northern Ireland supports social workers helping people with CF.

### **SmartCareCF**

Our innovative programme investigating the remote monitoring of symptoms by people with cystic fibrosis in their own homes each day is progressing through feasibility studies. We're creating the tools to empower people to do things on their own terms, in the way that best suits them.

Sammie, who has CF, says: "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're in control and you can see if you need to eat more, or sleep more."

### **Engaging the community**

UK Cystic Fibrosis Conference

543 attendees, including nearly 100 friends and family of people with cystic fibrosis attended UKCFC; topics included psychology, nutrition, activity and pharmacy. UKCFC content was seen on Twitter nearly 150,000 times, and we reached 57,000 people with our Facebook posts and videos.

In the news

Over the year 1,500 media articles helped us reach over 10 million people with our messages around cystic fibrosis. We also gained 2,000 new Twitter followers and 238,000 YouTube video views.

### **New website**

You talked... we listened! 50% of users wanted to view the website on a mobile device and there was demand for a better search function. We've delivered both, and there's more on the way!

### **Breathe – Life Unlimited**

This year, we unveiled 'Life Unlimited', our vision for a future where cystic fibrosis doesn't limit every aspect of the lives of people with the condition. Our message was illuminated in the bright lights of Piccadilly Circus and our music track and video, Breathe, gained significant media coverage. We won't stop until our message is heard loud and clear: we're fighting for a life unlimited.

### **Volunteers**

We recruited 82 volunteers, including 29 offering peer-to-peer support as part of CF Connect. Their commitment over the year was worth over £300,000 to the Trust!

### **Income and Expenditure**

Accessibility: to see how we make our income and where we spend it, you can find the details in our annual Financial Statements available for download on our website. Income from normal activities was £11,386,000 and our expenditure was £13,583,000.

**Thank you to everyone who has supported us and made the impact highlighted in this report possible! Listed below are a few people who have helped us on our way, but we are grateful to have too many supporters to mention them all by name!**

### **Sixty Five Roses Club (England and Scotland)**

Faulkner Family

- Janet and David Lavender
- Nick and Toni Callaghan
- Lord and Lady Sawyer
- Mr and Mrs D Merriman
- Richard Parkinson
- Barbara and Tony Kelley
- Jeremy Wood
- Jane Wood
- James and Catherine Greenstreet
- Tim Miller and Emma Hawkey
- Robert and Jane Aitken
- Charles Van Der Lande
- Keith and Janet Paley
- Jan and Moira De Kok
- Ann and Michael Gaunt
- Alyson and Gilbert Carswell
- Diana and Terence Kyle
- Mr and Mrs Colin Jones

- Rev Iain and Mrs Marjorie Paton
- The Gay and Keith Talbot Trust
- Dame Barbara Kelly
- Laura Main
- Rob Law

#### **Trusts and Foundations**

- The Masonic Charitable Foundation
- The Robert Luff Foundation
- The City Charitable Trust
- The Swire Charitable Trust
- The Joseph Levy Foundation
- The Joseph Levy Education Fund
- The Enid Linder Foundation
- The Marjorie and Edgar Knight Charitable Trust
- The D'Oyly Carte Charitable Trust
- The P F Charitable Trust
- The QBE Foundation
- The Boltini Trust
- The Welbeing Trust (Sussex)
- The Elizabeth and Prince Zaiger Trust
- The Pilkington Charities Fund
- The Light Fund
- The Constance Travis Charitable Trust
- The Cadogan Charity
- The Blyth Watson Charitable Trust
- The John Raymond Tijou Charitable Trust
- The Laura Case Trust
- The Stanley Grundy Foundation
- The Sir Samuel Scott of Yews Trust

#### **Corporate Partnerships**

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- The Artemis Charitable Foundation
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- Reading Textiles
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