

# Thank you to an exceptional Chief Executive

In 1996 Rosie Barnes took up her appointment as Chief Executive of the Cystic Fibrosis Trust, and she retired in August 2010. Over the past 14 years Rosie (as she is affectionately known by all) has been undoubtedly a most successful and effective Chief Executive. During her time at the CF Trust major changes occurred. The charity tripled in size as did the income. Rosie was also directly responsible for creating the UK CF Gene Therapy Consortium and led and inspired the very substantial fundraising effort to support it. This initiative is now recognized worldwide as a novel and very important new way for scientists to work together.

Although initially there were some concerns that clinical care would take second place, as it has turned out, nothing could be further from the truth. Rosie initiated and led the Peer Review program of CF Centres and Clinics which has vastly increased the quality and quantum of care delivered to CF patients across the UK. Using her experience in politics, she has led discussions with the NHS of how funding for patient care in the Health Service is to be reformed and has placed CF in the vanguard of this change program. A successful campaign led by Rosie in the Nineties eventually led to the introduction of national neonatal CF screening in 2007, so now every baby with CF born in the UK is diagnosed soon after birth.



Rosie Barnes and Dr Jim Littlewood OBE

An extraordinary ability to communicate and grasp a particular situation has resulted in Rosie becoming very knowledgeable on both the clinical aspects and scientific progress in Cystic Fibrosis. This and her natural empathy with and genuine liking for people with CF and their families has resulted in her being held in the highest regard by the whole CF community, be they patients, parents, professionals or other interested parties.

Rosie has been quite exceptional in her total commitment to effectively improving the lot of people with Cystic Fibrosis – always carried out with determination but with kindness and a sense of humour. It has been a great pleasure and privilege for me to work with her over the past 14 years. We are pleased that Rosie will not lose contact with the CF Trust as she is keen to continue to support the CF Trust in an ambassadorial role. We wish her all health and happiness in the future in her new role as retiree and grandma.

*Dr Jim Littlewood, Chairman, Cystic Fibrosis Trust*

“Reading through *CF Today* I often wondered if Rosie Barnes had a twin; she managed to be at so many events and meetings, usually at different ends of the country and seemingly so close in time, that it would be impossible for her to cover the territory required, and anyway how could anyone have that much energy? Rosie’s organisational skills are amazing, and she has so much energy she could sell back the surplus to the national grid. But it is her enthusiasm and enjoyment of all she does that has made being in her company such a pleasure. Working with her as a Trustee has been a wonderful experience; she has always guided with insight and inspiration. Rosie has a warm and sympathetic way about her that helped in the most difficult circumstances; and I will miss seeing that very particular twinkle in her eye that made one aware of the fun to be had.”



*Jenny Agutter, CF Trust Patron and Trustee*



“Although the Trust had become established as a major sponsor of research, progress seemed frustratingly slow, particularly for those of us with CF children. Into this situation came Rosie Barnes, an inspirational administrator and communicator – a born leader. She lifted us into a different league.

“She conceived and drove forward a plan that led to us speaking for the first time of “finding a cure”. Suddenly there was hope. Sadly these developments will be too late for some but the struggle will have been worth it.

“Thank you Rosie.”

*Sir Robert and Lady Linda Johnson*

“To paraphrase history, so what did Rosie do for us?

“Her key first change was to see that the difficult science underpinning gene therapy needed a large team to solve the issues. The three groups in the UK were working largely independently; with a characteristic mix of charm and firmness of hand, Rosie brought them together to form the UK CF Gene Therapy Consortium.



“Secondly, it is clear that such 'big science' does not come cheaply. Rosie's fundraising energy, enthusiasm and success are legendary, but importantly were coupled with an understanding that rigid bureaucratic vigilance of CF Trust funds would not allow the ambitious aims of the gene therapy programme to be met. Within the framework of rigorous external peer review, the Consortium was given the flexibility to direct funds as changing circumstances dictated, likely saving years in the delivery of a clinically relevant product.

“Above all, Rosie kept CF patients centre-stage. There were no decisions in favour of 'interesting science'; the gate-keeper has always been, and remains, how will any experiment speed translation to the clinic?

“So what did Rosie do for us? As my teenage children would say – 'durrgh, it's not very difficult.' She made gene therapy a real therapeutic option for patients with Cystic Fibrosis.”

*Professor Eric Alton, Chair, UK CF Gene Therapy Consortium*

## Rosie's Lasting Legacy

We are delighted that Rosie has agreed to become our legacy ambassador, and this autumn she is helping the CF Trust launch a new campaign, encouraging our supporters to leave a legacy to the CF Trust in their wills. You can read about Rosie's decision to leave the Trust a gift in her will in our new legacy leaflet.

Leaving a legacy to the CF Trust is a relatively simple way of supporting the Trust's work in the future, and making sure your family are cared for. Remember, you don't need to be wealthy to leave a gift in your will – every gift, no matter the size, makes a difference.

Increasing our legacy income is important. We need to ensure we have funds to continue to develop and improve the gene therapy products as effective treatment for CF in the lungs (read more about the progress of the gene therapy trial on page 13). To give you an indication of the costs involved in this programme, we have committed nearly £11 million over the next three years to the Gene Therapy Consortium.

We also need to improve the quality of life for those with CF, for example through research into CF-related diabetes and other non-lung complications. The Trust invests £1m on non-gene therapy research each year.

In the leaflet you will find information about why the Trust will continue to need legacies in the future and what they have helped us to achieve so far, why it's important to write or update your will and the benefits of leaving a legacy, and the information you will need to include a gift in your will.

Look out for our new legacy leaflet this autumn. In the meantime, if you would like any information, please contact Sue Whitehead, Legacy Marketing Manager on 020 8290 8051 or [swhitehead@cftrust.org.uk](mailto:swhitehead@cftrust.org.uk).



Rosie with her daughter and grandson