

Steve Williams` Obituary

We are all poorer since our loss of Steve, too early in a life devoted to helping those with, cystic fibrosis. However, he never let this define him, even though his parents were given a poor prognosis at age 18 months and again in his early 20s. He was a happy child who often tried to conceal his poor health through school. He knew little of his condition then but admitted to struggling with the diagnosis in adolescence and as a young man.

He graduated in Engineering Design at Leicester Polytechnical College, then enjoying a successful career as a talented innovative designer, being known particularly as an inventor, illustrator and artist. He designed medical equipment, including a clickhaler and other respiratory devices. Working for a design consultancy he had a hand in the design of Eurotunnel trains and much else until retirement in 2007. He excelled in this profession which gave him his independence and he told me, a sense of purpose, important when he was coping with his condition later.

In 1998, we raised funds towards a dedicated regional clinic for increasing numbers of survivors with cystic fibrosis at Birmingham Heartlands Hospital. Steven came forward to help, speaking about patients` needs at the Birmingham Town Hall mayoral launch of the appeal to build a centre of excellence. He was active over 4 years to help raise £2 million pounds, particularly with our patients` families, as he had a reputation for empathy, kindness and humility. Within our appeal he produced his own scheme, `Steven`s Appeal`, which raised £400,000 to help build and furnish 20 patient suites for individual care. Our success, leading to a royal opening in 2002, was in part due to his enthusiasm and popularity with patient families. Today the centre cares for over 400 such people and is one of the UK`s major centres. Over the years since, he remained an inspirational and popular speaker to patients and professionals.

In 2000 we formed a charitable trust, `Heartlands Adult Cystic Fibrosis Centre Appeal`, (charity no. 1074745) for the benefit of the centre. Steven became a trustee, serving from 2007, helping to raise funds and decide on priorities to purchase extras like laptops, TVs, gym equipment and holistic therapies, also to provide start-up salaries, research grants, staff training expenses and room

refurbishments. He took these duties seriously, having something of value to say on most matters and spoke up when difficult things needed to be said. We were fortunate to have the benefit of his artistic and computer skills with key advice on other matters, including rebranding the centre and helping with our website (address here).

Our first encounter with Steve, aged 22, was at in 1987, following a deterioration in his health. He appeared carrying a helmet, in full bright leathers, leaving a high-powered motorcycle in the carpark. He was your original cheeky chappy and we had a feisty first consultation and he soon learned to look after himself. By 1989 he had declined, leading to referral to Papworth Hospital Cambridge for transplant assessment. Shortly afterwards a joint heart-lung procedure was performed by pioneering surgeon, Mr John Wallwork. He endured with typical courage, making a good recovery, despite a poor prognosis at the time. Subsequently he developed renal failure requiring kidney transplantation at 5 and 12 years, the last donated by his father, both of which he endured with the usual fortitude and good humour. He always expressed great gratitude and thanks to the team at Papworth and to those in Birmingham who had cared for him through his life.

By any standards Steve lived a full fruitful life and was at the time of his death, in the 32nd year after the joint transplant, making him one of the longest survivors in the world. Following his care, he made himself available to others, setting an example, alleviating anxiety, giving comfort and inspiration to those with similar conditions.

Steven leaves his father Graham, brother Andy, sister-in-law Jean and niece Anna. Steven`s ambition was to live a life `just like his mates`, but also less ordinary. His achievements are due to dedication, the love of his family, his friends and ward 26, his second home.

Written by Dr D.E.Stableforth