



## MUM WHO LOST THREE CHILDREN TO CYSTIC FIBROSIS CAMPAIGNS IN MEMORY

# Why I'll never give up my fight for CF patients

**AN INSPIRATIONAL Cork woman who has lost three children to Cystic Fibrosis has said she will not give up campaigning for resources until she can fulfil her son's dying wish.**

Cathy Carlton from Ballincollig, lost three of her four children to the complex and pernicious disease, Cystic Fibrosis (CF).

Her son, Danny, was the third of her children to die from the disease, only days before his 25th birthday. When he was dying, he pleaded with his mum to continue to campaign for resources for adults with CF.

Cystic Fibrosis is Ireland's most common, life-threatening inherited disease. Although this country has the highest incidence of the disease per capita in the world, we fall well below the acceptable standard when it comes to the provision of care.

Cathy was heartbroken when her first child, Lydia, who was born in 1968, was diagnosed with CF. Born in the UK, she spent six months in hospital and her parents were given a very poor prognosis from the outset. However, Lydia lived until she was ten-and-a-half years old.

To Cathy and her husband's joy, their second child, John, born in 1973, was free of the disease.

The couple moved back to Ireland later that year and, in 1974, their third child, Danny, was born.

Sadly, Danny also inherited the life-threatening disease and spent five months in hospital.

"I was so frustrated when I came back from England. When we were living there, the consultant who was treating Lydia had her own CF nurse and the facilities were far better. When I came back to Ireland, there was no such thing as a CF nurse.

"I could not understand how this was just across the water and yet they did have back up services for CF. The CF patients were treated in

*In the fourth of our series on living with cystic fibrosis, health correspondent Edel O'Connell talks to CF Association stalwart Cathy Carlton.*



this little corridor in St Finbarr's Hospital. It was quite primitive," said Cathy.

Tragically, on October 5, 1978, Cathy's first-born child, Lydia, died as a result of the disease.

"I was pregnant at the time with my second daughter, Sarah, who was born on October 28. She was also diagnosed with CF and was rushed straight to Crumlin Hospital. She died just seven months later. It was so hard as I still had two small children at home.

Cathy recalls feeling terribly isolated: "I was still at a very early grieving stage after losing my eldest daughter.

"I had a friend in Dublin who was involved with the CF Association up there and she was my lifeline when I was in Crumlin, but beyond this I had no support outside of my family of course."

Three years later, Cathy was asked by the CF Association to become a liaison officer for the Cork branch which would mean meeting with parents and sick children and acting as a link between the hospital and the families of CF sufferers.

"I felt so isolated. I did not want anyone to feel the way I did. Losing two children and having another child with CF, there was just no support mechanism out there. I felt that somebody needed to speak out about the lack of services in Cork. There was nothing here in Cork other than the two consultants at the time," she said.

Cathy's dedication to the CF Association and her campaigning work has spanned over three decades.

"Getting involved and visiting sick children and helping parents as well as lobbying for services was also part of my grieving process. It was therapeutic," she said.

Sadly, tragedy struck again in October 1999, when Cathy lost her beloved son Danny to the disease at the age of 24.

Before Danny lost his battle for life, he made his mother promise

that she would keep campaigning for resources for people with CF.

"Danny had been in hospital three times the year he died. Before that, he had a very good quality of life but his lungs had deteriorated. He died 20 days before his 25th birthday in 1999. It was heartbreaking," said Cathy.

"He had been housed in a twin room in Cork University Hospital (CUH) and after that they put him in a large ward, which just was not suitable," she added.

The last straw for Danny and his mother was when he had to be housed in a treatment room with no en suite facilities.

"He had no privacy. Here was a man of 25 years who was tethered to an oxygen tank trying to clear his chest with physiotherapy and administer insulin. Everyone needs their dignity and everyone deserves it, not just CF patients," said Cathy.

When Danny was discharged from hospital, he pleaded with his mother to let him die at home.

"Don't ever bring me back to that hospital again" he said. That was his experience of CUH. It was nothing to do with the staff, he had nothing but praise for them: It was the lack of isolation rooms. The only way I managed to keep him at home was the support I got from the hospital and from the consultants who were always on the other end of the phone," she said.

Danny came home in June and he never went back to hospital.

"When he was dying, he said to me: 'Mum, please keep going and try to get resources in place for adults with CF'. That was the kind of inspirational person he was. That has spurred me on even more," said Cathy.

The provision of a specialist unit for CF patients has been a dream of Cathy's for more than 30 years. Cathy is calling on the people of Cork to get behind the Build4Life campaign which is attempting to raise €1 million for the creation of a

specialist unit at CUH. The campaign is being spearheaded by Kerry developer Joe Browne who has a child with CF.

Cathy said the association was

also calling on people who intended to run in the Cork City Marathon in June to choose the Build4Life foundation as their chosen charity.

"Danny was one of the unlucky ones who passed away but we have

such amazing young people with CF here in Cork with great jobs and great positivity.

"We want to keep it that way," added Cathy.



## Councillor hails Cork campaigners' determination

PLANS for a special unit for people with Cystic Fibrosis have been backed by Cllr John Buttimer. "As a member of the Health Service Executive (HSE) Regional Health Forum, the issue of individuals with CF has been raised at the January 2008 meeting and, more recently, at the March meeting when I tabled a question asking for an implementation plan for the statement of need that is being produced by Dr Barry Plant at Cork University Hospital (CUH).

"In making representations at the HSE Forum, I

have been very impressed with the work undertaken by the Cork branch of Cystic Fibrosis Ireland (CFI), Paul Higgins in particular, and the manner in which they are able to advocate and articulate their need for improved services.

"I fully support the current campaign of the CFI and Build4Life, especially in relation to the development of specialist services. Members of the health forum were so impressed by their work that Dr Plant and representatives of CFI Cork will be invited to make a presentation to the forum later in

2008, once the Statement of Need is finalised and published.

"While much of the focus of attention is on the delivery of a special unit with single occupancy rooms and a dedicated access to accident and emergency, it is important to remember that as well as the physical aspects attached to CF, there are also many social, educational and psychological issues which require intervention.

"Having spoken to members of CFI in Cork, it is also clear that not only does the individual with CF

have needs but their supporting family also has needs. Families that have to cope with an enduring illness face additional costs; financially and emotionally, that other families don't experience. I hope that the soon-to-be published statement of need will take cognisance of their needs for education, financial support and respite.

"I would like to wish the current campaign all the best and to congratulate all involved on the tremendous work they are doing," added Councillor John Buttimer.