

Parents' grief as daughter dies after hospital 'forced them to change her treatment'

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Francesca Blair-Robinson suffered from Congenital Vericella Syndrome, a rare medical condition

A little girl with a very rare medical condition died after a hospital threatened her parents with a police protection order if they did not comply with a new treatment plan, it has been claimed.

Francesca Blair-Robinson, 12, died five months after her father says he and her mother were forced to withdraw their opposition to new treatment.

Father Malcolm, who had taken the lead in his daughter's care, believes the change in treatment led to her death and that Francesca would be alive today if his hand wasn't forced with the threat of police intervention.

Last night the devoted father-of-six spoke out about the tragic circumstances of his daughter's death, calling for a change in the way vulnerable children are treated.

Speaking of the hospital's decision to pursue a 'much more aggressive' therapy plan he said: 'I had warned in writing that such a medical approach may prove fatal, based upon the fact that I had been Francesca's full-time carer for almost the whole of her life and had studied her medical condition and her response to treatment 24/7 for 11 years.

'I have conducted significant research into her case since her death and I am entirely satisfied that the treatment killed her and that neither I nor her mother nor Francesca herself would have agreed to this approach but for the intervention of child protection procedures.'

When Francesca was born with a rare congenital syndrome causing a catalogue of symptoms, including being very small and frail, it was feared she would not make it to the age of one.

Sent home to die she confounded expectations by surviving under the dedicated care and attention of her family.

Her novelist father, 69, became her full-time carer, devising a treatment plan by 'trial and error' but tailored to her needs that included antibiotics, a nebuliser, physiotherapy and a special diet.

Mr Blair-Robinson, who split from Francesca's American businesswoman mother in 2004, said: 'Working closely with doctors we not only saved her life but developed therapies through cautious use of drugs which gave Francesca a quality of life, a richness of experience and an inspirational nature that was little short of a modern day miracle.'

Although weak, the little girl was able to go to school for short periods, and have a home tutor for the rest of the time. She developed a network of friends on the internet and loved the countryside.

But after moving from Surrey to West Sussex in 2006 the doctors overseeing Francesca's care changed.



Malcolm Blair-Robinson is proposing a change in child protection law

When she collapsed in May 2007 medical staff at St Richard's Hospital, in Chichester, wanted to change the way she was treated. She made a swift recovery but doctors still advocated 'aggressive use of IV antibiotics' and oxygen therapy, claims Mr Blair-Robinson.

He said both he and his ex-wife objected, and within a week were summoned to a meeting where they were confronted without warning by a social worker, police officer and medical staff.

'Her mother and I were threatened that unless we withdrew our opposition to the hospital's medical plans, Francesca, a frail and vulnerable child with a very sharp intellect, would be made the subject of an immediate police protection order.'

Terrified the couple complied and the little girl was referred to Southampton General Hospital which set out the more 'aggressive' programme.

Within five months she had died of respiratory failure, a death that Mr Blair-Robinson would not have happened if he had been allowed to continue taking the lead in her care.

He believes there should have been a narrative record of her care in her medical notes and a better system of information sharing and is calling for an overhaul of the way the NHS handles complex cases of children with special health needs.

'She knew she was dying, insisted on doing her Christmas shopping early as she feared she would not reach the day herself and confided that she felt the doctors were killing her.'

He said he did not indeed to pursue legal action as he did not think it 'helpful'.

'Doctors do their best but they make mistakes, they are human,' he said. 'They are forgiven but changes need to be made.'

He is sending a copy of his proposed reforms to child protection process to Downing Street.

Of Francesca, who he believes could have survived into adulthood, he said: 'She was a completely magic person, everybody who came upon her was enchanted by her, she may have had a wonky body but she had a golden spirit.'

'So that the values of her life may be more widely shared, it seems fitting to propose reforms to our approach to helping the vulnerable.'

Francesca had congenital varicella syndrome, a condition that is related to the mother being infected with chickenpox early in pregnancy.