

Parents force NHS to fight for babies with rare genetic disorders

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A couple's fight to persuade an NHS hospital to resuscitate their daughter who was born with a rare genetic condition has set a precedent for other parents.

Rumer Gomez had Edwards' syndrome diagnosed in the womb at 23 weeks. The disorder is closely related to Down's syndrome and has traditionally been regarded by doctors as incompatible with life.

About 100 babies are born in the UK with the condition each year but only about eight will survive their first 12 months. The symptoms vary greatly from child to child but can include



Rumer Gomez had a rare genetic condition diagnosed in the womb

heart and lung problems, diaphragmatic hernias and severe developmental disabilities. The oldest survivors in Britain are two women in their twenties.

Women whose babies have the disorder diagnosed early in their pregnancy are usually encouraged to have an abortion, and Edwards' syndrome babies born alive are routinely placed in end-of-life care.

That may change after Helen Roper, a 35-year-old midwife, and Chris Gomez, 36, a signalman, persuaded a hospital in London to prolong their child's life. Rumer is thought to have been the first baby to be kept alive with artificial ventilation after being diag-

nosed with the syndrome in the womb. Another couple has already used the case to argue that a different hospital should try to keep their baby alive.

Rumer's parents did their own research and came across new scientific studies that suggested proper treatment can more than treble the chances of survival for babies with the disorder, also known as trisomy 18 because it is caused by cells that contain three copies of the 18th chromosome.

The traditional prognosis was so bad that the couple had begun planning to bury Rumer in their garden. "What we knew about trisomy 18 then was that it was incompatible with life," Ms Roper said. "We were hoping that it would be Down's syndrome instead."

Yet the more academic papers the couple read, the more they became convinced that it would be worth trying to resuscitate their baby. Faced with resistance from their doctors, Mr Gomez and Ms Roper asked for second opinions from two other hospitals and won the support of their local MP, the Labour backbencher Chuka Umunna, before taking their case to an ethics committee.

They won the argument and Rumer was born on September 24 last year. She needed support with her breathing but was discharged in early November. However, she suffered further breathing problems and died from a viral infection on New Year's Day.

Ms Roper said that the couple had encountered discrimination and a reluctance to save their daughter's life at almost every stage. "I've worked in the NHS for years, and it was like having your eyes opened," she said. "They genuinely believe that it is in the best interests of a child with trisomy 18 not to treat it."

She believes that this attitude is changing in light of more research. The couple will talk about their experience at the European Neonatal Ethics Conference in Oxford next month.