

CHARLIE'S LAW WILL GIVE HOPE TO PARENTS DESPERATE TO SAVE THEIR CHILD

A year after the death of Charlie Gard, medical opinion is swinging behind the campaign to enhance families' rights, finds *Katherine Forster*

When Charlie Gard died in July last year, seven days short of his first birthday, it seemed as though the whole world knew about his case. Donald Trump had weighed in; so had the Pope. Armies of doctors and lawyers debated, while parents with healthy children counted their blessings. Yet at the centre of the whirlwind was an ordinary mum, dad and baby.

Charlie had spent 9½ months at Great Ormond Street Hospital in London diagnosed with mitochondrial DNA depletion syndrome. The hospital said there was no cure and no hope. But his parents, Connie Yates and Chris Gard, wanted him to have pioneering treatment. They raised £1.35m and found hospitals abroad willing to treat him.

Great Ormond Street said no and a prolonged court

battle ensued, which the parents ultimately lost.

The money raised for Charlie's treatment is now being used for research into treatments for mitochondrial disease. His parents are campaigning for a "Charlie's law" to ensure that the families of seriously ill children (or those who cannot speak for themselves) will be properly supported and protracted legal battles avoided. Parents could win the right to choose to move their children to reputable alternative hospitals.

Last week an amendment by Lord Mackay of Clashfern

to the Mental Capacity Bill began its progress through the Lords. This could pave the way for further amendments that would extend the scope of the legislation towards a Charlie's law.

"It was hell what we went through. It's hell having a sick child and it was hell being dragged through the courts to fight for his life," Connie, 32, tells me in a cafe in Holborn, central London.

Her long blonde hair is held in a clip and she is tiny. "When me and Chris are together, people 100% recognise us," she admits.

"No one is ever horrible to

us in person but we get a lot of abuse online."

Connie, previously a carer for young adults with learning disabilities, keeps her emotions in check as we talk: "I have to try to be numb about it... but if I talk about the day he died, I cry."

The couple are driven by a determination that no one else should suffer the fate they endured. "I feel like I can't rest until things change," Connie says.

Charlie's law has support across the medical and political spectrum, including many who had sided with Great Ormond Street at the



Chris Gard and Connie Yates with son Charlie

time, such as the neonatologist and ethicist Professor Dominic Wilkinson.

Cases can be kept out of the courts, the couple maintain, by better access to mediation and clinical ethics

committees. They had requested mediation but it did not happen. An ethics committee was scheduled but then cancelled. Legal aid should be available if necessary, they believe. "We felt like we didn't have a voice throughout the whole thing. We didn't stand a chance from the start," Connie says.

"We will live with the 'what ifs' for ever."

The proposed alternative treatment was an oral compound that would have been added to his milk. Its worst side-effect would apparently have been diarrhoea. "I loved my son so

much and I wouldn't have wanted him to suffer. He didn't have the best quality of life, but he was stable, he wasn't in pain and we weren't fighting to keep him like that: we just wanted to give him a chance to get better," Connie says.

"You take your child into hospital and you leave your parental rights at the door – you are not the decision maker any more."

Had he lived, Charlie would now be two. Milestones such as Christmas or his birthday are most difficult for Connie: "There's always someone missing."