



F5 Care Decisions in Desperate Cases in Infancy: *Parens Patriae* or Birth Parents' Responsibility — Lessons From the Case of Charlie Gard

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The goal of this presentation is to highlight the differing approaches taken in common law jurisdictions where there are differences of opinions between parents and health care professionals as to the care that should be provided to a desperately ill infant.

This presentation will impact the forensic science community by analyzing how care decisions can best be made when there are significant differences between medical professionals and the natural parents as to the appropriate care that should be given to a desperately ill child.

Charlie Gard was born on August 4, 2016. Initially, he developed normally, but his parents took him to their family physician in early October after he failed to gain weight. He was referred to Great Ormond Street Hospital (GOSH), a tertiary pediatrics referral center. Respiratory failure developed and he required ventilatory support. By the end of October, a clinical diagnosis of Mitochondrial DNA Depletion Syndrome (MDDS) was made. This was confirmed as the RRM2B variant. Functional RRM2B is required for the synthesis of mitochondrial DNA. Non-functional RRM2B results in depletion of mitochondria in body tissues, including brain and muscle. The outcome of the disease is early death from respiratory failure.

GOSH consulted, nationally and internationally, on options for Charlie, including possible Nucleoside Bypass Therapy (NBT). His condition deteriorated; he began having fits and became unresponsive. By February 2017, the GOSH staff decided that there were no useful treatment options left and that it was in his best interest that active treatment ceased and palliative care be instituted. His parents did not agree, believing that Charlie was not non-responsive and adhered to the view that NBT might have something to offer him. A Crowd Funding appeal for his treatment in the United States raised £1.3 million (US\$1.6 million). The GOSH staff felt this would be futile and, if Charlie had any pain perception left, it would be distressing for him.

His parents and GOSH could not agree on Charlie's best interest. Thus, GOSH asked the High Court to exercise its residual *parens patriae* function and decide what was best for Charlie. His parents were represented by counsel *pro bono*. Charlie was represented by counsel appointed by the Children and Family Court Advisory and Support Service (CAFCASS), an independent body that represents children in legal proceedings relating to their welfare.

The Judge, dealt with the question that United States commentators raised as to what business it was of the court's rather than the parents, said, "The duty with which I am now charged is to decide, according to well laid down legal principles, what is in Charlie's best interests. Some people may ask why the court has any function in this process, why can the parents not just make the decision for themselves? The answer is that, although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child's best interests. The Great Ormond Street Hospital has made an application and it is my duty to rule on it, given that the parents and the hospital cannot agree on the best way forward."

The Judge adjourned the hearing in February to allow the parents to obtain additional evidence. This included evidence from a United States expert agreeing that as encephalopathy had developed, treatment with nucleosides was very unlikely to lead to improvement. He also said that if Charlie was in the United States, he would nonetheless treat him at the parents' request.

The Court ordered that Charlie should receive palliative care only and not receive nucleoside therapy. The family appealed, first to the Court of Appeal, which held against them, then to the United Kingdom Supreme Court, which affirmed the judgment, and finally to the European Court of Human Rights, which, in effect, declined to take jurisdiction. Subsequently, GOSH received opinions from experts in the United States and Italy suggesting that NBT might be beneficial to Charlie.

The Judge held another hearing, ordering that there should be a meeting of experts following examination of Charlie and his imaging and laboratory findings. It was then agreed in Court that NBT would not now be beneficial to Charlie. On July 24, the Court ordered that he should be taken to a hospice for palliative care with a timetable allowing time for his parents to agree with GOSH on how it should be accomplished. No agreement was reached. Charlie was taken to the hospice on July 28 and died shortly thereafter.

Nowhere in this sad saga has there been mention of "Death Panels," euthanasia, or Charlie being a prisoner of the State or the NHS. There are two main lessons: (1) as every law student knows, always read the full judgment, not just the headlines, before commenting; and, (2) when dealing with a child's welfare, formal mediation is desirable before initiating litigation.

Parental Responsibility, *Parens Patriae*, Care Withdrawal