

FAMILY DIVISION

IN THE MATTER OF THE INHERENT JURISDICTION OF THE HIGH COURT

AND IN THE MATTER OF CHARLES GARD (DOB 04/08/2016)

B E T W E E N:

**GREAT ORMOND STREET HOSPITAL FOR CHILDREN
NHS FOUNDATION TRUST**

Applicant

and

CONSTANCE YATES (1)

CHRIS GARD (2)

**CHARLES GARD (3)
(a Child by his Guardian)**

Respondents

**GOSH'S POSITION STATEMENT
HEARING ON 13 JULY 2017**

1. Charlie is a beautiful, tiny baby afflicted by one of the cruellest of diseases. His depletive genetic disorder leaves him with no muscle function at all now and deprived of his senses, unable to breath and, so far as can be discerned after many months of encephalopathy, without any awareness. At the moment, he is on a low dose of oral morphine. Before that was started quite recently, all of those caring for him at GOSH hoped very much that Charlie did not experience pain. They did so in the knowledge

that if he did not, it was because he had no experience at all because he was beyond experience.

2. In one respect, Charlie is immensely fortunate and that is in having parents of great fortitude and devotion. All at GOSH wish to pay tribute to their dedication to their only child and their tireless pursuit of a cure for him. The hospital feels certain that they have done all that they have for Charlie out of love and because they could not have done anything less even if they had wanted to.
3. Great Ormond Street is a children's hospital. It looks after some of the sickest children in the world and seeks to improve the quality of life of each. Many of the patients seen make enormous strides and for some there is a cure. But for some, there is a cloud without a silver lining. As an institution and as individuals, GOSH and its staff strive to forge relationships of trust and understanding with all families the better to support its child patients in difficult times.
4. It is only very rarely that there develops between GOSH and a child's parents a dispute which requires judicial resolution and to the hospital's immense regret, that has happened in Charlie's case. All at the hospital have given anxious thought as to why Charlie's situation, which though desperate is not, sadly, exceptional has developed in such a contentious way.
5. Looking back over the months since the end of March, the hospital perceives that there has been one important agreement and two important disagreements. Those caring for Charlie and his parents have agreed about Charlie's current lack of quality of life. When he gave evidence to the High Court in April Mr. Gard said this: *"He's not got a quality of life. I'm not going to stand here and say he's fine. He's not got a quality of life but that's not what we're fighting for. We're fighting for a chance to give him the treatment that he needs to possibly improve."*
6. As to the disagreements, one is a difference of opinion about the risks, benefits and ethics of providing four compound nucleoside treatment for Charlie after a time when his brain had become profoundly affected by his genetic disease. The other has been a more fundamental and unbridgeable divide of principle.

7. Charlie's parents fundamentally believe that they alone have the right to decide what treatment Charlie has and does not have. They do not believe that Great Ormond Street should have had the right to apply to the Court for an independent, objective decision to be made. They do not believe that there is any role for a Judge or a court. They believe that only they can and should speak for Charlie and they have said many times that they feel they have been stripped of their rights as parents.
8. GOSH holds and is bound by different principles. A world where only parents speak and decide for children and where children have no separate identity or rights and no court to hear and protect them is far from the world in which GOSH treats its child patients.
9. Throughout this court process, Charlie has been represented by his Cafcass Guardian who has visited him in hospital, spoken to Charlie's parents, nurses and doctors and written reports that ensure that as much as is possible for a desperately unwell baby, Charlie's own viewpoint is articulated and given weight. When asked what happens to the role of the Guardian if their belief that only they have the right to decide on Charlie's treatment is correct, Charlie's parents answer that he does not need a Guardian because they will speak for him.
10. GOSH believes in its core that every patient is his or her own, unique and special person and that it owes a duty of care to each. The hospital's mission statement is "The child first and always" and the hospital does not treat any child differently or as less of an individual because of the severity of illness or disability or because of infancy. If anything, special care is given to discover and work out with parents what is best for very vulnerable patients who cannot speak for themselves.
11. This is not just Great Ormond Street's core belief, it is its duty. The GMC's Guidance "*0-18 years: guidance for all doctors*" emphasises two matters in particular. The first is treating children as individuals and acting in the child's best interests. The second is, if it is necessary to do so, putting the child first. Paragraph 4 of the Guidance says: "*When treating children and young people, doctors must also consider parents and others close to them but their patient must be the doctor's first concern.*"

12. The decisions of the High Court, the Court of Appeal and the Supreme Court have all reaffirmed the fact that for the hospital and those who work there, Charlie's welfare is paramount. And importantly, GOSH notes this part of the Supreme Court's decision made on 8 June 2017:

“Finally, the European Court of Human Rights has firmly stated that in any judicial decision where the rights under Article 8 of the parents and the child are at stake, the child's rights must be the paramount consideration. If there is any conflict between them the child's interests must prevail.”

13. At the heart of Charlie's parlous and terrible condition is the question, how can it be in his best interests for his life-sustaining treatment to be withdrawn? Charlie has been treated on GOSH's neonatal intensive care unit for many months now and very sadly, the question that arises for him arises for other patients and families at the hospital too. GOSH has treated over a thousand patients with mitochondrial disease and offers pioneering treatment, including nucleoside treatment, where appropriate. Despite all the advances in medical science made by GOSH and the other hospitals around the world, there remain some conditions that we cannot cure and we cannot ameliorate.

14. It has been and remains the unanimous view of all of those caring for Charlie at Great Ormond Street that withdrawal of ventilation and palliative care are all that the hospital can offer him consistent with his welfare. That is because in the view of his treating team and all those from whom GOSH obtained second opinions, he has no quality of life and no real prospect of any quality of life.

15. The team did not come to that view alone. Where there are very difficult and serious decisions to be made, the hospital seeks out and welcomes opinions from others. This is a vital part of the duty of care where there may be room for doubt. Before asking the Court to make a decision, GOSH sought independent opinions from three different specialists each of whom came to the ward and assessed Charlie.

16. The individuals cannot be named but reports were obtained from a paediatric neurologist at a London hospital and a report from a paediatric intensive care specialist at a different London hospital. In addition, a second opinion on nucleoside treatment

was obtained from a mitochondrial specialist in the North of England. All three independent opinions confirmed the parlous nature of Charlie's condition and his very poor prognosis. The view of the North of England consultant was that a three month trial of NBT treatment would not be in Charlie's best interest.

17. The Judge was provided with these independent reports. But in addition, Charlie's parents also instructed their own expert. That doctor (who also cannot be named) assessed Charlie in April. He reached the same conclusions about Charlie's condition as the specialists whom GOSH had consulted.
18. At a three day hearing in April, the Court listened to evidence from two of Charlie's treating doctors at GOSH and the nurse who had spent the most time by his bedside. They were able to describe the deterioration they had seen in Charlie since his admission. The Judge also heard from the American professor contacted by Charlie's parents who agreed to treat Charlie with as yet unlicensed drugs under what in America is called the compassionate use exception. (Treatment would be conditional on the Federal Drug Administration authorising first use ever in a human being of 4 NBT compounds. GOSH understands that to date, the professor has not made any such application).
19. The Court made clear findings about the efficacy of treatment. And clear findings about Charlie's grievous condition and his lack of quality of life. The Judge made three best interests declarations about Charlie. These were:
 - 1) That it is not in his best interests for artificial ventilation to continue.
 - 2) That it is in his best interests to be provided with palliative care only.
 - 3) That it is in his best interests not to undergo nucleoside therapy.
20. At the Court of Appeal, Charlie's parents presented new evidence from the American professor offering to treat Charlie. The judges considered it carefully and listened to Charlie's QC who did not seek to argue that the new evidence changed the Judge's findings of fact of his balancing of the evidence. The Supreme Court said that the Judge had applied the correct legal test and the European Court of Human Rights found that Charlie's rights and voice had been properly heard through his Guardian and that the findings of the UK courts were meticulous and could not be challenged.

21. Since Charlie's parents believe that only they have the right to decide what medical treatment is right for Charlie and when he should stop having treatment, it is not surprising that they appealed each decision and tried to change the legal test. Any proper system of justice must have a system of appeal and GOSH supports Charlie's parents' right to challenge the judicial decisions. What has been very difficult, however, is the effect on Charlie of the delay.
22. Charlie cannot make any choices for himself and throughout this time, he has had to endure months on a ventilator which means that air is forced into his lungs because he cannot use his muscles to breathe. He has had no quality of life because of the combined effect of seeing, hearing, moving or responding to any stimulus in any purposeful way. He has grown bigger but growth has not been accompanied by health. The reverse is true and there are signs of deterioration.
23. GOSH is always willing to learn and well understands that genetics is a fast moving area of medicine where breakthroughs are being made all the time. When, in July, Charlie's parents said they had new evidence that would change the Judge's findings as to Charlie's best interests, GOSH did not hesitate to return to Court so that the Judge could evaluate it.
24. GOSH understands that the American professor who wishes to treat Charlie in America will be giving evidence to the Court by video link and looks forward to hearing what he has to say about the beneficial effect of NBT treatment on Charlie's quality of life and awareness. As it has done throughout, GOSH will act in accordance with Charlie's best interests and its duty of care to him. It will continue to provide him with the highest possible quality of care, to respect his dignity and the confidentiality of the details of his condition and treatment and to honour Charlie's rights as his own, unique human being.

KATIE GOLLOP QC
Serjeants' Inn Chambers
13 July 2017