

IN THE HIGH COURT OF JUSTICE

IN THE MATTER OF THE INHERENT JURISDICTION OF THE HIGH COURT

AND IN THE MATTER OF S.8 CHILDREN ACT 1989

B E T W E E N

GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST

Applicant

-AND-

(1) CONSTANCE YATES
(2) CHRIS GARD
(3) CHARLES GARD
(A CHILD, BY HIS GUARDIAN)

Respondents

POSITION STATEMENT OF THE GUARDIAN

FOR HEARING 24 JULY 2017

1. The Guardian understands that Charlie's parents seek to withdraw their application for a re-hearing, in light of the new evidence obtained in preparation for and as a result of the visit to the UK by Dr Hirano and Dr B. Pursuant to FPR r.29.4, the court's permission is required to withdraw the application.
2. The Guardian approached the evidence in respect of nucleoside therapy with an open mind in March/April 2017 and again in the more recent application by Charlie's parents. In April 2017, the unanimous evidence of the numerous medical experts, including Dr Hirano, was that Charlie had largely irreversible brain damage and that meaningful improvement in his brain function following nucleoside therapy was

highly unlikely. At that time, the Guardian found significant Dr Hirano's comment that if he were in London and was familiar with the progression of Charlie's disease, perhaps he might have supported GOSH's application to withdraw ventilation: *'perhaps if I were there, I would support it. Not seeing the child, not seeing the progression, it is difficult for me to make an assessment.'*

3. The transcript of the joint experts' meeting on 18 July 2017 records that:
 - a. The experts were in agreement that Charlie's brain dysfunction is severe, that his brain function has deteriorated since the start of 2017, and that he has microcephaly, with MRI evidence suggesting that parts of Charlie's brain had suffered atrophy (ie. irreversible loss of neurons).
 - b. Dr Hirano's view was that it was difficult to have an accurate picture of the reversibility of the damage to Charlie's brain, because of his severe muscle weakness, although his view was that Charlie had both brain damage (irreversible) and brain dysfunction (potentially reversible). He said *'I think there's some degree of dysfunction that theoretically could be recovered....there could be some brain function that would allow him perhaps to smile or – I certainly don't expect that he would be normal. That's clear.'* Later, Dr Hirano said *'there's potential to recover some neuronal function from the dysfunction and I cannot tell you how much, and I'd say the probability of success is low.'* Later still, Dr Hirano said *'...the question is, are there neurons that are dysfunctional that could be recovered? I don't know.'*
 - c. Dr Hirano considered that Charlie did respond to pain, though he could not say how severe the discomfort was to Charlie from his day to day experiences such as suctioning. He said *'...there's some justification for some discomfort if we can reasonably expect – maybe reasonably again is a bad word – but there's a small likelihood of clinically meaningful improvement, let's say.'*
 - d. Dr B said that *'we probably will not have a great impact [by giving the treatment]'*. He suggested that at the time he made his offer to provide treatment to Charlie he had not been fully aware of Charlie's condition, saying *'it has been very useful to come here and see it because not all of this was conveyed to us and it's good to just see it ourselves.'*

4. As a result of the discussions at the experts' meeting, further MRI scans of Charlie's body were carried out, to see whether his muscles were largely replaced by fat, meaning that the nucleoside therapy would not have any realistic prospect of improving the muscle weakness. The Guardian has seen the reports of those scans which show that in some places, Charlie has no muscles, and in other parts of his body including his limbs, the fatty replacement of the muscle is very significant.
5. Before this court, the issue has always been whether nucleoside therapy was in Charlie's best interests, not whether it might be of benefit to children with other forms of mitochondrial disease, or whether its provision might be in the best interests of a child at an earlier stage of the illness than Charlie was in April 2017.
6. In light of the further information obtained in recent weeks about Charlie's condition, it was sadly not surprising to the Guardian to learn that Charlie's parents, following discussion with Drs Hirano and B, had come to the conclusion that nucleoside therapy was not in Charlie's best interests. The Guardian recognises how incredibly difficult it must have been for Charlie's parents, who have provided the most devoted and loving care to him since the day he was born, to be confronted with the extent of the deterioration in his condition and to accept that nucleoside therapy could not help.
7. The Guardian hopes that a legacy of these very distressing and emotional proceedings will be recognition that better communication is required at an early stage, not just between doctors and parents, but also between doctors offering novel treatments and those caring for the patient. If novel therapies are to be offered, it appears to the Guardian to be imperative that those offering to provide them are fully aware of the clinical condition and medical history of the particular patient and have had extensive discussion with the treating team, so that offers are made on an informed basis and without setting up false hopes and expectations.

VICTORIA BUTLER-COLE

39 Essex Chambers

24 July 2017