

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 24 JULY 2017**

1. The hearts of all at GOSH go out to Connie Yates and Chris Gard. Over the weekend, they communicated their desire to spend all the time they can with Charlie whilst working with the hospital to formulate the best possible plan for his end of life care. The agony, desolation and bravery of their decision command GOSH's utmost respect and humble all who work there. Whilst GOSH has striven to work with them throughout, Charlie's needs have taken priority. It is greatly hoped that in the days ahead, it will be possible to extend to his parents the same quality of care with which Charlie has been provided and to concentrate on the family as a whole.

2. Charlie's parents have fought long and hard for what they have been led to believe was a treatment that would give him a chance to be the Charlie he was before the effects of his illness became evident. Since nucleoside treatment ("NBT") is not invasive when added to food and there is no evidence that it has caused significant damage to the TK2 deficient patients to whom it has been administered, they have, rightly and urgently, sought to know: *Why not give Charlie that chance? What does he have to lose?* They feel now, and perhaps will feel for some long time to come, that if only GOSH had treated Charlie months ago, they would have been spared the impossible decision they make now.
3. These deeply affecting questions deserve answers. From the moment of his diagnosis at GOSH, Charlie's prognosis was known to be bleak. The early infantile onset of his extraordinarily rare disease, his generalised myopathy and the respiratory failure which left him dependent on a ventilator, were all factors indicating that his life's span was likely to be very limited indeed. Despite the sombre prognosis, GOSH's mitochondrial expert contacted counterparts across the world, including Professor Hirano, to explore the possibility of experimental treatment, NBT.
4. No animal or human with Charlie's condition, RRM2B deficiency ("RRM2B"), has been treated with NBT and therefore an application to the Rapid Response Clinical Ethics Committee was prepared in January. NBT was and is a possible treatment for GOSH patients suffering with TK2 deficiency ("TK2"), a similar genetic disorder, but there is a crucial difference between the two conditions. TK2 affects muscle (and is treated with 2 compounds) whereas RRM2B affects muscle, other organs and brain (and would be treated with 4 compounds – see GOSH's Position Statement of 13 July, paragraph 18).
5. Charlie started having seizures before Christmas, those being a recognised complication of infantile onset RRM2B. Shortly before the planned ethics committee application, he suffered increased seizure frequency and likely severe epileptic encephalopathy. The entire treating team (acknowledged by the mitochondrial centres in New York and Rome to be their equal) formed the view that Charlie had suffered irreversible neurological damage and that as a result, any chance that NBT might have

had of benefitting Charlie had departed. That sad conclusion led to the best interests application made in February and decided by the High Court on 11 April 2017.

6. Charlie's parents believe that his brain was not damaged, that it was normal on MRI scan in January and that treatment could have been effective at that time during the months that followed. There remains no agreement on these issues. GOSH treats patients and not scans. All aspects of the clinical picture and all of Charlie's observations indicated that his brain was irreversibly damaged and that NBT was futile. Those were the Judge's findings in April, upheld on appeal in May and on further appeal in June. As the weeks have passed, the unstoppable effects of Charlie's aggressive, progressive, depletive disorder have become plainer to see.
7. At the first hearing in Charlie's case in March, GOSH's position was that every day that passed was a day that was not in his best interests. That remains its view of his welfare. Even now, Charlie shows physical responses to stressors that some of those treating him interpret as pain and when two international experts assessed him last week, they believed that they elicited a pain response. In GOSH's view there has been no real change in Charlie's responsiveness since January. Its fear that his continued existence has been painful to him has been compounded by the Judge's finding, in April, that since his brain became affected by RRM2B, Charlie's has been an existence devoid of all benefit and pleasure. If Charlie has had a relationship with the world around him since his best interests were determined, it has been one of suffering.
8. Throughout, his parents' hopes have been sustained by advice received from overseas. Mitochondrial disorders comprise a specialised and small international field. The experts in that field meet, collaborate and exchange ideas on a very regular basis and it is that valued collaboration that allows progress to be made and patients to be provided with the best possible care. Professor Hirano ("the Professor"), whose laboratory research has an international reputation, is very well known to the experts at GOSH and he communicated with them about NBT treatment for Charlie at the very end of December. In January, GOSH invited the Professor to come and see Charlie. That invitation remained open at all times but was not taken up until 18 July after being extended, once again, this time by the Court.

9. In the months between January and July, the Professor provided written and oral evidence for the best interests hearing in April and, after the Court decided that NBT was not in Charlie's best interests, he went on to provide further written evidence for the Court of Appeal and the Supreme Court. Most recently, on 6 July, he co-signed the letter indicating that he had new information that changed the picture for Charlie, that brought this case back before the High Court.

10. When the hospital was informed that the Professor had new laboratory findings causing him to believe NBT would be more beneficial to Charlie than he had previously opined, GOSH's hope for Charlie and his parents was that that optimism would be confirmed. It was, therefore, with increasing surprise and disappointment that the hospital listened to the Professor's fresh evidence to the Court. On 13 July he stated that not only had he not visited the hospital to examine Charlie but in addition, he had not read Charlie's contemporaneous medical records or viewed Charlie's brain imaging or read all of the second opinions about Charlie's condition (obtained from experts all of whom had taken the opportunity to examine him and consider his records) or even read the Judge's decision made on 11 April. Further, GOSH was concerned to hear the Professor state, for the first time, whilst in the witness box, that he retains a financial interest in some of the NBT compounds he proposed prescribing for Charlie. Devastatingly, the information obtained since 13 July gives no cause for optimism. Rather, it confirms that whilst NBT may well assist others in the future, it cannot and could not have assisted Charlie.

11. In the months ahead, all at GOSH will be giving careful thought to what they can learn from this bruising court case that might enrich the care it provides to its most vulnerable patients and families. It is hoped that those who, like the Professor, have provided the opinions that have so sustained Charlie's parents, their hopes and thus this protracted litigation with its many consequences, will also find much upon which to reflect.

12. GOSH is a tertiary referral centre and a centre of research excellence. It celebrates and enthuses about gene therapy and experimental treatment of all types. But it also believes in its patients as people. The hospital strives to work with children and parents to strike a balance of treatment benefits and burdens that combines evidence and compassion. Where that balance falls ethically in favour of pioneering treatment, GOSH shares each

family's excitement at the journey that follows. GOSH believes that novel therapies are best provided in the context of formal clinical trials. The hospital does not treat its most vulnerable children simply because it can and on no account does it treat them purely because novel treatment furthers GOSH's research.

13. For its part, GOSH rededicates itself to working with each child and each child's family to discern, as best as the art of medicine and the most modern advances in science allow, the treatment options most consistent with the best interests of each. That is the hospital's duty of care and each child, whether treated at GOSH or elsewhere, deserves no less.

14. The Judge has said that were his view heeded, mediation would be compulsory. Those words will not be forgotten by GOSH and more will be done in that regard. If and when mediation is not wholly successful, it is right that the Court and not any doctor, team or organisation determines a child's best interests. The Court's difficult task in this case would have been close to impossible were it not for the able and tireless pro bono assistance provided to Charlie's parents by two teams of solicitors and barristers. GOSH wishes to thank them all. GOSH also wishes to thank Mr. Justice Francis for his decision making and for hearing and guiding the parties with such sensitivity and wisdom.

15. All of GOSH's thoughts go with Charlie and his mother and father - the hospital wishes each of them peace in their hearts at the end of this day and each day to come.

KATIE GOLLOP QC

24 July 2017

Serjeants' Inn Chambers