

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE HIGH COURT OF JUSTICE (FAMILY DIVISION)
The Hon Mr Justice Francis
FD17POO103

IN THE MATTER OF CHARLES GARD (DOB 4/8/16)

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 23 May 2017

Before :

LORD JUSTICE McFARLANE
LADY JUSTICE KING
and
LORD JUSTICE SALES

Between :

(1) CONSTANCE YATES
(2) CHRISTOPHER GARD

Appellant

- and -

(1) GREAT ORMOND STREET HOSPITAL
FOR CHILDREN NHS FOUNDATION TRUST

- and -

(2) CHARLES GARD (A CHILD, BY HIS GUARDIAN)

Respondent

(Transcript of the WordWave International Limited
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Official Shorthand Writers to the Court)

Mr Richard Gordon QC, Mr Gerard Rothschild and Mr Grant Armstrong (instructed by
Harris Da Silva Solicitors) for the **Appellant**
Ms Katie Gollop QC and Ms Susanna Rickard (instructed by **Legal Department GOSH**
NHS Trust) for the **First Respondent**
Ms Victoria Butler-Cole and Mr Benjamin Tankel (instructed by **CAFCASS Legal**) for the
Second Respondent

Judgment As Approved by the Court

Lord Justice McFarlane :

1. The focus of the court's attention in this appeal is upon a nine-month old boy, Charles Gard, who suffers from the effects of an extremely rare and grossly debilitating genetic mutation. Charlie (as he is known to all) has already suffered significant irreversible brain damage. Save for the first two months of his life, he has been unable to breathe unaided. Medical staff who care for him in an intensive care unit have, for a number of months, been unable to detect Charlie responding to any stimulus; Charlie's parents, however, believe that he does demonstrate some reactions. Charlie's circumstances are such that, unless an alternative treatment can stall or alter the course of his decline, his current life expectancy is measured in months.

2. Charlie has the benefit of having two most loving parents who are united in their desire to do all that they can to preserve the life of their cherished child, alter the course of the devastating condition from which he suffers, and, if possible, regain for him something of the life that they, in common with all loving parents, had hoped for their offspring. To this end, as a result of their diligent researches, the parents have identified a resource through which, they believe, it may be possible for Charlie to receive treatment which, whilst not curing his condition, might slow or even halt its destructive progress.

3. The doctors who are treating Charlie, who had themselves contemplated the same alternative treatment when he was first in their care in the autumn of 2016, have, following a significant decline in the level of his brain functioning in January 2017 firmly concluded that there is, effectively, no chance of

Charlie now benefiting from its effects. The parents do not agree with the advice that Charlie's treating clinicians have given.

4. In the light of the dispute as to Charlie's future treatment the NHS Foundation Trust for Great Ormond Street Hospital for Children, where Charlie has been an in-patient since October 2016, issued an application in the Family Division of the High Court on 24 February 2017 seeking a declaration that it was lawful and in Charlie's best interests for artificial ventilation to be withdrawn and for his treating clinicians to provide only palliative care for him. They also sought a declaration that it was lawful and in the child's best interests "not to undergo nucleoside therapy" (being the alternative therapy favoured by the parents).
5. Mr Justice Francis heard the hospital's application over the course of three days before giving judgment on 11 April 2017. Despite the strong feelings of sympathy and respect that run like a seam throughout the judge's judgment, his sad but clear conclusion was that it would not be in Charlie's best interests to undergo nucleoside treatment and that, given the parlous nature of his present existence and the bleak prognosis for his imminent demise, the hospital's application to remove him from the ventilator should be granted in consequence of the judge's conclusion that "the only course now in Charlie's best interests is to let him slip away peacefully and not put him through more pain and suffering."
6. The judge's decision is reflected in the court's Order of 11 April in which declarations were made in the following terms:

“(1) Charles, by reason of his minority, lacks capacity to make decisions regarding his medical treatments;

(2) It is not in Charles' best interests for artificial ventilation to continue to be provided to him and it is therefore lawful and in his best interests for it to be withdrawn;

(3) It is lawful and in Charles' best interests for his treating clinicians to provide him with palliative care only;

(4) It is lawful and in Charles' best interests not to undergo nucleoside therapy.

Provided always that the measures and treatments adopted are the most compatible with maintaining Charles' dignity."

7. By a Notice of Appeal dated 2 May 2017 Charlie's parents seek permission to appeal against the declarations made by the judge and seek to reverse the judge's determination and achieve positive declarations that they are entitled to arrange for Charlie to be transferred to a clinic at which he can be provided with nucleoside treatment. By agreement, the hospital has maintained Charlie's current treatment regime pending a full hearing to consider the parents' applications for permission to appeal and, if permission is granted, the appeal itself. That hearing took place before this court on 22 May.

The background in more detail

8. Charlie's genetic condition seemingly had little effect on him during pregnancy. He was born at full term and at a healthy weight on 4 August 2016. Thereafter, however, the condition, which I will explain in more detail in due course, slowly began to have a noticeable effect on his weight, his muscle condition and his overall presentation. By early October the concerned parents sought medical advice and by 11 October Charlie had become lethargic and his breathing had become shallow so that he was admitted to Great Ormond Street Hospital ("the hospital") on that date. Since then Charlie has remained at the hospital on the intensive care unit, breathing solely in response to a

mechanical ventilator. Since his admission to hospital, Charlie's parents, who have been accommodated in family accommodation close to the site, have operated a rota so as to maximise the number of hours during which he has at least one parent with him.

9. Francis J, who had observed the parents throughout the hearing and heard them give their oral evidence said this about them (para 47):

“Charlie's parents have clearly dedicated their lives to him from the moment that he was born. The bond of love that exists between parents and a newborn baby is one of the strongest bonds known to humankind. No one could have done more to support Charlie than these parents have since the day that he was born and I have already paid tribute to them for their love and care and for the dignified way in which they dealt with these proceedings, which I described in court earlier this week as what must be like a “living hell” for them.”

10. Although my exposure to Charlie's parents has been significantly less than that of Francis J, I would expressly endorse those comments. Throughout the appeal hearing they sat immediately in front of the hospital's leading counsel and will have heard a description of their child from her with which they profoundly disagree. At all times, however, they maintained their composure, focus and dignity to a degree which commands the greatest of respect. They have gone from the happy moments and weeks following the successful birth of an apparently healthy baby, through his initial deterioration and then on, at all times at his side, into the unreal but life-sustaining world of a paediatric ITU within a large hospital complex and then, now, into the equally unreal worlds of the law courts and the media. This is all a far cry from the life that they will have hoped and expected to be living as a small family watching their young son, Charlie, grow up in an ordinary way.

11. The medical condition that has led to Charlie’s present condition is rare in the general population, it is very rare in children, and it is extremely rare for it to impact on a baby. Francis J gave the following helpful description (paras 52, 53 an 54):

“52. Charlie suffers from a rare inherited mitochondrial disease called infantile onset encephalomyopathic mitochondrial DNA depletion syndrome, referred to generally as “MDDS”. The disease is caused by biallelic mutations – that is two mutations, one inherited from each parent – in a gene called RRM2B. This gene is needed for replication and maintenance of the mitochondrial DNA and repair of the nuclear DNA. The effect of the RRM2B mutations is that Charlie has severe depletion of the amount of mitochondrial DNA in his tissues.

53. Professor A described these mitochondria as the power stations in virtually every human cell. They create energy from fuel (i.e. food) and oxygen. Professor A described that this energy is needed to fuel every biochemical reaction that occurs in the human body and that the consequences of depletion of mitochondrial DNA is that mitochondrial energy is impaired, which leads to dysfunction of several organ systems. In Charlie’s case, his brain, muscle and ability to breathe are all severely affected. In addition, he has congenital deafness and a severe epilepsy disorder. His heart, liver and kidneys are also affected but not severely.

54. Consequently, Charlie has severe progressive muscle weakness and cannot move his arms or legs or breathe unaided. He used to be able to do these things, which indicates that his condition has progressed since his birth last August.”

12. Further detail is given in Francis J’s judgment (which is publicly available at Neutral Citation [2017] EWHC 972 (Fam)). No issue within the appeal turns upon the underlying detail of his medical condition, and it is not therefore necessary for me to offer more detail here.
13. The alternative treatment for which the parents earnestly argue is called “nucleoside therapy”. In very simple terms, nucleoside therapy involves introducing an alternative source of energy that can be used by the cells in a

patient's body to replace the lack of energy resulting from MDDS. The energy is provided within a chemical compound which is simply added to the patient's food. MDDS, which can affect all human cells, has a particular impact both upon the muscles and upon the brain. There is some limited evidence of nucleoside therapy achieving a positive outcome for patients with a different genetic mutation, known as TK2, where the MDDS primarily affects the muscles, rather than the brain. There has, hitherto, been no attempt to administer nucleoside therapy either to laboratory animals or to a human being with RRM2B deficiency. Despite there being some evidence that the muscles of patients with TK2 mutation have benefited from nucleoside therapy, it does not follow that the energy-giving supplement would have a similar effect upon cells in the brain as, in order to be effective, the compound would have to cross what is known as the 'blood/brain barrier'. As there has been no experimentation even on animals with RRM2B, it is simply not known whether the nucleoside therapy would or would not penetrate and be effective within the brain.

14. Through their researches, the parents have identified Dr I, who is Professor of Neurology at a mainstream Medical Centre in the USA, who is willing to facilitate and oversee the provision of nucleoside therapy for Charlie. Whilst Charlie's parents accept that his present quality of life is one that is not worth sustaining, and one for which they would not continue to fight, they want Charlie to have the chance to benefit from the nucleoside therapy that Dr I is prepared to give him. As a result of the generosity of the public, to whom an appeal was made, the parents have sufficient funds to pay for Charlie to go to the USA for treatment. It is accepted that, dependent though he is upon

mechanical ventilation, it would be possible to transport him under medical supervision across the Atlantic for that purpose, and, again, the funds are available for that to happen.

15. The issue before the judge was, therefore, stark. All, including the parents, agreed that if Charlie were to remain at the hospital under the present treatment regime, the benefits to him being kept alive for the remaining few months of his life were outweighed by the detriments and that the hospital should be permitted to withdraw treatment and, in the judge's words, let him slip away peacefully, receiving only palliative care. Save for Dr I, to whose evidence I will turn in due course, the body of experienced medical opinion available to the judge, which included assessments from two separate external sources of expertise, was unanimous to the effect that the prospect of nucleoside treatment having any benefit was effectively zero and would be futile. Against that evidence, the parents maintained the hope that Charlie might benefit from nucleoside treatment and that the process of moving him to America and administering the treatment would cause him little or no harm. In those circumstances, they assert that the decision that they have made, as Charlie's parents, in favour of nucleoside treatment in the USA should not be overridden by the opinion of the treating hospital or the court.

The hearing before the judge

16. Francis J heard evidence on behalf of the hospital from Professor A, a consultant in paediatric metabolic medicine, and Dr B, a consultant paediatric intensivist, who is therefore responsible for the unit that currently provides

Charlie's care. In addition, the judge received a substantial number of second opinions from leading authorities, in particular the following:-

Dr C, consultant in paediatric intensive care at St Mary's Hospital, London

Dr D, consultant respiratory paediatrician at Southampton Hospital

Dr E, consultant and senior lecturer in paediatric neurology at the Newcastle-Upon-Tyne NHS Foundation Trust (described by the judge as a world expert in rare mitochondrial disorders)

Dr F, consultant paediatric neurologist at St Mary's Hospital, London.

The parents each gave oral evidence and the judge also had evidence from a sister and a staff nurse working on the neo-natal intensive care unit at the hospital.

17. On the question of Charlie's diagnosis and prognosis the experts, sadly, spoke with one voice. He suffers from MDDS which has progressively developed into the current parlous state, with multiple dysfunction of his key bodily systems, in particular those involving the brain, muscles, respiratory and renal systems. EEG testing of his brain function is indicative of severe epileptic encephalopathy with frequent sub-clinical seizure activity. Charlie's muscle condition and/or neurological condition are so poor that the only way to tell that he is having or has had an epileptic seizure is to monitor brain activity; the fact that he is experiencing a fit is not reflected by any movement of his

muscles. Dr E advised the judge that MDDS of the type associated with the RRM2B gene mutation indicates a dire prognosis of relentless progressive neuro-degeneration. Professor A and others advised that a degree of irreversible brain damage had already taken place and that seizures in mitochondrial disease (which have been detected since December 2016) are a sign that death is, at most, six to nine months away.

18. In the light of that unanimously bleak opinion the parents, reinforced, no doubt by their own daily observation of their baby's condition, both (as the judge noted at paragraph 61) "believe and have said that his present life is not worth sustaining unless treatment is available".
19. It follows that the sole issue in the hearing before the judge turned upon the evaluation of the viability of the only alternative treatment option, namely, nucleoside therapy.

Nucleoside therapy: the evidence

20. Between paragraphs 70 and 106 the judge described the detailed evidence that he had received on the all important topic of nucleoside therapy. In the light of the judge's careful account, which is publicly available and against which there is no challenge, it is neither necessary nor useful for me to offer a further summary here. From the judge's account, however, the following elements appear to be of particular significance:

- a) On 30 December 2016 Dr I accepted that there was no direct evidence that the treatment might help and, in particular, whether the nucleoside therapy would cross the blood/brain

barrier, there was, however, in his view, a theoretical scientific basis for saying that it could;

- b) At that stage Dr I advised that an MRI scan of Charlie's brain was required in order to establish a base line, as severe brain involvement was a contra-indication to the therapy being trialled upon him;
- c) Following an MRI scan in January 2017, which appeared to show no structural damage, the hospital was itself considering referring Charlie for nucleoside treatment;
- d) Between 9 or 10 January and 27 January Charlie experienced intermittent episodes of seizure activity with the likely consequence that he had reached the stage of severe epileptic encephalopathy;
- e) At a meeting on 13 January Charlie's treating clinicians informed his parents that as a result of this further decline in Charlie's condition, all of the treating clinicians now agreed that nucleoside treatment would be futile and would only prolong Charlie's suffering. The judge found that this was "a most significant meeting".

21. Francis J heard oral evidence from Professor A and Dr B, who, in their respective roles, are jointly in charge of the teams providing Charlie's care. It is, therefore, important to set out the core aspects of the judge's summary of their evidence (paras 87, 88, 89 and 90):

“87. It is important that I record what Dr. B said in court this week in relation to the issue of nucleoside treatment. He indicated that Charlie is not responsive to his direct surroundings in any purposeful way. He confirmed what had already been said by Professor A, namely that Charlie had deteriorated a great deal. He said that Charlie’s brain is now so damaged that there is no movement. He said that there is no evidence of a sleep/wake cycle, which, he said, is a really strong indicator of how bad Charlie’s brain function has become. He said that Charlie had had a brain deterioration with seizures and poor movement. He said that on Charlie’s brainwave tracing you can see seizure activity, but that now his muscles are so weak there is just an electrical signal present.

88. He said that there were no further treatments available to Charlie which could improve him from his current situation and that this was the opinion of the entire team - including those from whom a second opinion had been obtained -with the view of the entire team that Charlie is deteriorating, that he cannot get better, that he cannot understand anything or develop, that there is no prospect of this and that he should be allowed to slip away peacefully and with dignity.

89. Professor A was also cross examined about the prospect of successful nucleoside treatment. She pointed out, as I have already recorded in this judgment, that this treatment has never been tried on humans or even on animals, not even mice which have this condition, namely RRM2B. She pointed out that there is no evidence in humans that the drugs could cross the blood/brain barrier. She also pointed out that the evidence being used by Dr. I was in relation to patients with TK2 not RRM2B.

90. Crucially, she said that, even if there was an ability to cross the blood/brain barrier, it is not possible to reverse the process for neurones already lost. She said that seizures in mitochondrial disease are a sign that death is, at most, six to nine months away. She said that she and Dr. I did not really differ on the science and both agree that, very sadly, it is extremely unlikely to help Charlie. She said that, in her view, there was a cultural difference in philosophy between treatment in the United States and in the United Kingdom. She said that she tried to have the child at the centre of her actions and thoughts whereas in the United States, provided there is funding, they will try anything.”

22. In addition to the medical expertise to which I have referred thus far, it is right to record that the parents had permission to instruct their own expert, Dr L, a consultant paediatric neurologist at Southampton General Hospital. Dr L's conclusions were effectively in identical terms to the other expert contributions, leading the judge to conclude (paragraph 93):

“Accordingly, the entire highly experienced UK team, all those who provided second opinions and the consultant instructed by the parents in these proceedings share a common view that further treatment would be futile. For the avoidance of any doubt, the word “futile” in this context means pointless or of no effective benefit.”

23. Francis J then turned to consider the evidence given by Dr I as the only expert in the case who was suggesting that there was any potential benefit in nucleoside therapy. Dr I's evidence was given on the basis of the collective experience across the world in administering nucleoside therapy to some 17 or 18 TK2 deficient patients, a good proportion of whom had demonstrated a positive response. Dr I, was, however, clear that there was no evidence that nucleoside treatment had been administered either to an RRM2B animal model or an RRM2B patient. Dr I could not therefore predict the outcome, although he relied upon scientific rationale that the treatment could potentially ameliorate RRM2B deficiency.

24. Dr I gave evidence over a telephone link from the USA on the first day of the hearing before Francis J. He confirmed that he had, that day, seen the most recent EEG for Charlie. The judge records his observation as follows:

“Seeing the documents this morning has been very helpful. I can understand the opinion that he is so severely affected by encephalopathy that any attempt at therapy would be futile. I agree that it is very unlikely that he will improve with that therapy. It is unlikely.”

The judge records that Dr I had confirmed that he had never treated anyone who had encephalopathy and he was, therefore, unable to indicate whether a patient with encephalopathy would respond. He accepted that his opinion was based purely on theory, with no clinical evidence to support it. Insofar as Charlie has already sustained damage to his brain, Dr I accepted that the nucleoside therapy could have no effect on that damage. Francis J then records the following at paragraph 104:

“Crucially, Dr I said that, having seen the 30 March EEG, the damage to Charlie’s brain was more severe than he had thought. He said that he thought Charlie was in the terminal stage of his illness. He said that he thought that the treatment, if administered, was unlikely to be of any benefit to Charlie’s brain. He described the probability as low, but not zero. He agreed that there could be “no reversal of the structure of Charlie’s brain.”

And (at paragraph 105) he said:

“the chances of meaningful brain recovery would be small, which he agreed, he could not distinguish from vanishingly small. He said that he thought that there was only a small chance of meaningful brain function. He said that he was in uncharted territory, especially as we do not know how much structural damage there has been. He conceded that to a large extent, if not altogether, the damage was irreversible.”

25. Francis J’s finding at the conclusion of Dr I’s evidence (paragraph 106) is as follows:-

“The long and the short of Dr I’s evidence is that there is no scientific evidence of any prospect of any improvement in a human with RRM2B strain of MDDS. While there were some reasons to be hopeful that it might make a modest difference in life expectancy, it almost certainly could not undo structural brain damage.”

26. Pausing there, those passages from Dr I’s evidence were plainly regarded by the judge as being crucial. They represent the parents’ case at its highest, yet the only doctor who would contemplate administering nucleoside therapy to

Charlie only considered the prospects of benefit to be unlikely or low, albeit not zero, with a small or vanishingly small chance of meaningful brain recovery.

27. At the beginning of the appeal hearing the court was shown a letter dated 22nd May 2017 from Dr I in which, after a brief summary of his involvement to date, he repeats the offer of therapy in the USA and concludes as follows:

‘I expect that the therapy will be beneficial. In the best-case scenario, Charlie’s condition would stabilize, improve partially or continue to improve with long-term therapy as we have seen in patients with TK2. Ideally, the treatment will ameliorate the seizures and allow more normal brain functions. It is clear that without treatment, Charlie’s disease will progress and will ultimately be fatal.’

28. Mr Gordon asked the court to treat this letter as ‘fresh evidence’. As this is a case involving a child which is of the utmost importance and sensitivity we read the letter and have taken note of its contents. It is, however, plain that the letter does not purport to contain anything new material in terms of research or other data that was not before the judge. Insofar as the letter sets out Dr I’s opinion in terms which may be different from those that he used when giving evidence to the court, this more recent re-statement could not provide a basis for undermining the sophisticated process of evaluation that has already taken place by means of expert report, minuted experts’ discussion and, most importantly, examination and cross-examination before the court. To be fair, other than simply producing the letter, Mr Gordon did not refer to it again or use it as a basis to submit that the judge’s findings as to Dr I’s position should be now be re-visited or set aside.

The position of the parents before the judge

29. Francis J plainly had a great deal of respect for the position of the parents, both because they were Charlie's parents and because they clearly know Charlie "immeasurably better than anybody else does, professional or otherwise" as a result of the very many hours that they have spent in their child's company since he was born.
30. The judge noted a number of important points from the parents' evidence. Firstly, that the parents do not accept that Charlie's condition is as bad as that reported by the medical witnesses. They gave examples of occasions when they consider that Charlie has reacted to their presence or some other stimulus. The core of the parents' case was that they were vying for the chance to give Charlie the treatment that they think he needs so that he could possibly improve. They simply wanted what was best for their son, who "deserves his chance" to undergo nucleoside therapy which they truly believed would work. They are therefore fighting for him because he deserves the chance that may be provided by this treatment.

Pain

31. In the context of the parents' submissions in this appeal regarding "significant harm", to which I will turn and, in any event, it is important to record the judge's summary of the evidence regarding pain in full (paras 113, 114 and 115):

"Pain

113. No one can be certain whether or not Charlie feels pain. Certainly, the view of his parents is that he is reactive to things

that he does not like such as a heel prick or having his nose suctioned. Professor A's view was that it is possible that Charlie can feel pain, but it is not demonstrated. Certainly, as he is undergoing procedures that would cause pain to other people, he might feel pain. She said that he has a sore area on his neck where he has tape on his face. He undergoes suctioning and other invasive treatments. She also expressed her opinion that if Charlie cannot express feelings of pain then this would be an indication of the apparent severity of the damage to his brain.

114. When cross examined by Ms Butler-Cole for Charlie's Guardian, Professor A said that Charlie is likely to have the conscious experience of pain. Professor A expressed the important need to weigh up the potential benefit of the smallest of chances (her view being that there were no chances) against the continued pain of intensive care, ventilator support and so forth. She said that it was her view and the view of other members of the team that Charlie is suffering and that that outweighs the tiny theoretical chance there may be of effective treatment. She said that she did not regard his pain of being of a low level of suffering, but something more significant.

115. Regarding the burdens of treatment itself which has only been tried on those TK2 patients who have received nucleoside therapy, the only side effect known has been diarrhoea which Dr. I said could be controlled by an alteration of the administered dose. Obviously, that would be regarded as an acceptable side effect."

The judge's decision

32. At an early stage of his judgment, Francis J had reminded himself of the legal context within which these anxious, potentially life-terminating, decisions fall to be determined. Although Mr Richard Gordon QC, for the appellant parents, argues that this case should have been determined on a wholly different legal basis, no criticism is made regarding the judge's self-direction as a correct description of the requirements of the law in an ordinary "best interests" case . Against the background of a strong, albeit rebuttable, presumption in favour of a course of action which will prolong life, the judge must decide upon the

course which is in the “best interests” of the child, that term being given a wide meaning so as to encompass medical, emotional and all other welfare issues.

33. In forming his conclusion the judge took account of the considered view of the child’s guardian appointed to represent the child in these proceedings, which was that it was not in Charlie’s best interest to travel to America to receive nucleoside therapy, which was purely an experimental process with no real prospect of improving the child’s condition or quality of life.
34. Having considered the entirety of the evidence with respect to the proposed therapy the judge concluded with this all important finding, at paragraph 119: “the prospect of the nucleoside treatment having any benefit is as close to zero as makes no difference. In other words, as I have already said, it is futile.”
35. The judge then drew his conclusions together in the following terms at paragraphs 126 to 129:-

“126. Very sadly in Charlie’s case there is a consensus across the board, including from his parents, that Charlie’s current quality of life is not one that should be sustained without hope of improvement. I completely accept Ms Roper’s submission that the starting point in any consideration of whether it is in the child’s best interests to withdraw life sustaining treatment is the strong presumption of the sanctity of life. There is a consensus from all of the consultants and doctors who have examined Charlie that nucleoside treatment is futile.

127. Dr I who has not had the opportunity of examining Charlie, and who operates in what has been referred to as a slightly different culture in the United States where anything would be tried, offers the tiniest chance of some remotely possible improvement based on a treatment which has been administered to patients with a different condition. I repeat that nucleoside therapy has not even been tried on a mouse model with RRM2B. As Dr I candidly said,

“It is very difficult for me never having seen him being across the Atlantic and seeing bits of information. I appreciate how unwell he is. His EEG is very severe. I think he is in the terminal stage of his illness. I can appreciate your position. I would just like to offer what we can. It is unlikely to work, but the alternative is that he will pass away.”

128. As the Judge whose sad duty it is to have make this decision, I know that this is the darkest day for Charlie’s parents who have done everything that they possibly can for him and my heart goes out to them as I know does the heart of every person who has listened to this tragic case during the course of the past week or so. I can only hope that in time they will come to accept that the only course now in Charlie’s best interests is to let him slip away peacefully and not put him through more pain and suffering.

129. Having regard to the authorities to which I have been referred and which I have considered carefully, it is clear to me that the question that I have to ask is whether it would be in Charlie’s best interest to have the nucleoside treatment. Having concluded that it would not be in his best interests, it must follow that it is lawful and in Charlie’s best interests for artificial ventilation to be withdrawn and for his treating clinicians to provide him with palliative care only.”

Permission to appeal

36. The parents’ application for permission to appeal to this court is presented by an entirely new legal team, who played no part in the proceedings before Francis J. Five potential grounds of appeal are relied upon. Grounds 1 and 2, which go to the jurisdiction of the court and the different approach which, it is argued, should be taken, as a matter of law, to cases where a choice falls to be made between two viable treatment options. Ground 3, which is in more conventional terms, asserts that the judge fell into error in conducting the ordinary “best interests” evaluation. Ground 4 claims that no, or insufficient, regard was had to the relevant rights of Charlie and the parents under Articles 2, 5 and 8 of the European Convention on Human Rights, and the Fifth

Ground asserts that the parents and their legal team were placed at an unfair procedural disadvantage as a result of the late disclosure of documents.

37. Having heard Mr Gordon and the other parties make submissions at length relating to Grounds 1 and 2, I consider that the matters encompassed in those two grounds are of sufficient substance to justify granting permission to appeal. Insofar as the human rights' arguments made within Ground 4 supplement Grounds 1 and 2, I would also grant permission to appeal in relation to Ground 4 on that limited basis.
38. Conversely, I do not consider that the arguments encompassed within Grounds 3 and 5 establish any reasonable prospect of success on appeal and, if My Lady and My Lord agree, I would refuse permission to appeal with respect to those two grounds for the following reasons which can be shortly stated.
39. Ground 3, which asserts errors in the judge's assessment of Charlie's best interests, is sub-divided into seven sub-paragraphs.
40. It is logical to take sub-paragraphs (iv) and (v) first in that they assert, firstly, that the judge failed properly to analyse the neurological evidence and, secondly, that he incorrectly characterised nucleoside therapy as "futile".
41. The proposed appeal relating to the analysis of the neurological evidence relies upon an alleged confusion within the judgment arising from the judge's use of the word "structural" before the words "brain damage" at a number of points. It is said not to be clear how the judge came to conclude that Charlie had "structural" brain damage when, at paragraph 79 he stated that an MRI scan "appeared to show no structural damage".

42. As the judgment makes plain, the MRI scan referred to in paragraph 79, was performed in early January. That did not show any “structural damage”. That finding, did not, however, conflict with the clear evidence of the UK experts, with which Dr I agreed on this point (see paragraph 98), that as a result of his condition, and more particularly the pattern of regular seizures, Charlie had sustained a loss of neurones (Professor A, paragraph 90) after the EEG had been taken and that his brain was “now so damaged that there is no movement” (Dr B, paragraph 87). The evidence led Dr I to say in his evidence to the judge “I can understand the opinion that he is so severely affected by encephalopathy that any attempt at therapy would be futile. I agree that it is very unlikely that he will improve with that therapy.”
43. The addition of the word “structural” in front of the term “brain damage” may, in the circumstances of this case, not have added anything to the overall unanimous opinion of the medical experts, that irrespective of whether particular damage to the structure of the brain could be identified, it was clear that Charlie had sustained significant damage to individual neurones in his brain and that such damage was irreversible.
44. In relation to the judge’s use of the word “futile” it is argued that there is a distinction between the medical definition of futility and the concept of futility in law, as emphasised by the Supreme Court in *Aintree University Hospitals NHS Foundation Trust v James* [2014] AC 591. Medicine looks for “a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering”, whereas, for the law, this sets the goal too high in cases where treatment “may bring some benefit to the patient even

though it has no effect on the underlying disease or disability” (Baroness Hale at paragraph 43). In the present case, tragically, this is a difference without a distinction in the light of the judge’s finding that the potential benefit of nucleoside therapy would be “zero”. It would therefore be, as the judge held at paragraph 90, “pointless and of no effective benefit”.

45. The arguments raised with respect to the judge’s findings as to the condition of Charlie’s brain and the futility of nucleoside treatment do not establish any reasonable prospect of overturning the judge’s conclusions on this all important aspect of the case.
46. The evaluation of the remaining grounds of appeal must therefore be undertaken on the basis of the judge’s findings in relation to Charlie’s neurological condition and the lack of any identifiable benefit for him arising from nucleoside treatment.
47. Turning back now to the first three sub paragraphs of Ground 3, which relate to process and the attribution of weight, it is said, firstly, that the judge failed to draw up a balance sheet or otherwise properly to identify and weigh all the relevant benefits and burdens of the two options. Secondly, that he failed to give proper consideration or weight to the presumption of the sanctity of life, and, thirdly, that he gave undue weight to the possibility of pain and suffering.
48. In my view, with respect, these three sub-paragraphs misunderstand the judge’s judgment. Tragically, on the evidence before the judge, and on the basis of his findings, this was not a “balance sheet” case. Unless Charlie was to go to America for nucleoside therapy, all of the evidence, including the opinion of the parents, led to the sad conclusion that it would be in his best

interests now to withdraw treatment as there was no benefit for him in continuing to maintain his current level of existence for the remaining few months of his life. In terms of any balance sheet, therefore, absent the prospect of any benefit from nucleoside treatment, to which I will turn in a moment, there was, awfully, nothing to be put on the other side of the balance in favour of preserving life other than the presumption in favour of doing so itself.

49. Turning to nucleoside treatment, the judge's finding in that regard, having heard and evaluated all of the evidence, including that of Dr I taken at its highest, was that the treatment was "futile" and that the prospect of the treatment having any benefit for Charlie was "as close to zero as makes no difference". That finding by the judge is plainly of the utmost importance. It is not challenged on appeal. In terms of any "balance sheet", despite the earnest and loving hopes of Charlie's parents, the judge's finding means that no positive benefit is to be attributed to nucleoside therapy. To postpone the withdrawal of treatment, which is otherwise accepted to be the better course for this young child, to go to America to receive treatment which has "zero" prospect of improving his condition, would only prolong his existence in a manner which all, most sadly, agree can no longer be justified as being in his best interests.
50. In the circumstances of this case, therefore, sub-paragraphs (i)-(iii) of Ground 3 are, in my view, unarguable.
51. In the light of the judge's findings as to the lack of any benefit to be gained from nucleoside therapy, sub-paragraph (vi) of Ground 3 asserting that the

judge failed to resolve uncertainty as to the overall benefit of that therapy must fall away.

52. Finally, under Ground 3, sub-paragraph (vii) asserts that the judge wrongly took into account a perceived difference in medical culture between the UK and the USA. For the reasons that I have given, it is plain that the judge's determination was not based upon any question of cultural difference, but upon the core evidence as to the ability of this young baby, in his current condition, to achieve any benefit from this untried and untested form of treatment.
53. Ground 5, which relates to the alleged unfairness of the process, was not given any prominence by Mr Gordon in his oral presentation of the appellants' case. Cases of this nature require prompt hearing and determination by the courts. Inevitably, the hospital will have a wealth of documentary material about the young patient which falls to be disclosed to the parents and their representatives. It is clear that a process of disclosure took place, albeit that some material did not arrive until either shortly before the hearing started or, in some cases once it was under way. The process inevitably places a substantial professional burden upon the parents and their legal team. In this case, however, and despite the passage of some 5 or 6 weeks since the High Court hearing, we have not been taken to any document or other material which, with hindsight, can now be seen to have a significance which was not understood at the hearing. Neither is it said that the necessarily short preparation time prevented the parents from putting to the witnesses or raising with the judge some important new point. Thus, regrettable and burdensome

though the late delivery of a substantial body of material may have been, there are, in my view, no grounds for holding that that factor led to an adverse impact on the overall fairness of the proceedings before the judge.

The parents' new legal argument: "significant harm" and jurisdiction

54. Mr Gordon and the parents' new legal team, who in common with their predecessors commendably act pro bono in this case, have developed a legal argument that is not only new to these proceedings, in the sense that it was not run before the judge, it is indeed, a wholly new point of law (save insofar as it can be based upon the earlier High Court decision of *Re King* [2014] EWHC 2964 (Fam)). It is therefore helpful to set out the relevant part of Grounds 1 and 2 in full:

"1. The judge erred in making an order that prevented Charlie from receiving medical treatment by expert physicians in a reputable hospital overseas in circumstances where there was no risk of that treatment causing significant harm to Charlie.

Per *Re King*, the court may not interfere with a decision by parents in the exercise of their parental rights and responsibilities with regard to their child's medical treatment, save where there is a risk the parents' proposed course of action may cause significant harm. *Re King* is good law. It is consistent with prior authorities and correct as a matter of principle. It was cited in argument but not addressed at all in the judgment."

...

2. The judge had no jurisdiction to grant an order on the application of one clinical team preventing a second clinical team from carrying out a treatment that the latter had offered in the reasonable exercise of its professional judgment ... The declaration made by the judge has *de facto* injunctive effect in that it prevents Charlie's parents from removing from GOSH to undergo treatment in the USA.

The judge would have had no power to grant such an injunction, had one been sought. It is no part of GOSH's

statutory function to prevent other clinical teams from carrying out reasonable treatments. GOSH has nevertheless obtained an order with substantially the same effect”.

55. I have set both grounds out at this stage so that the extent of the appeal on these two separate legal points can be understood. I now propose to take each in turn.

Ground 1: “Significant Harm”

56. By the time he came to present oral argument on behalf of the appellants Mr Gordon had developed his submissions beyond those that had been trailed in the skeleton argument to the extent that he now submits that there are two distinct categories of case relating to the medical treatment of children, which he has, for working purposes, simply named “Category 1” and “Category 2”.
57. The cases that fall into “Category 1” include all of the previously decided and reported medical treatment cases, save and except for that of *Re King*. The legal test to be applied to such cases is the conventional, and now well settled, “best interests” test adopted by Francis J in the present case.
58. Mr Gordon submits that in a “Category 1” case the parents who oppose the course of treatment for which the treating clinicians apply, do not have a viable alternative therapeutic option to put before the court. The distinction that would lead a case to be allocated to “Category 2” is that a viable alternative treatment option is put forward by the parents and the court is, therefore, required to choose between the two. In these “Category 2” cases Mr Gordon submits that the law affords both priority and protection to the privileged position of a parent giving or withholding consent to medical treatment for their child so that the parents preferred treatment option should

only be overridden if it is established that the pursuit of that option is likely to cause the child to suffer “significant harm”.

59. The attribution of categories to this range of cases in the manner that I have described arises entirely from the work of Mr Gordon and the appellants’ legal team in this case. The distinction that they seek to draw between the two categories turns upon whether or not parents who object to the course of treatment recommended by the child’s treating clinicians are putting forward their own alternative viable therapeutic option. Mr Gordon accepts that, at present, “Category 1” is populated with every single one of the reported cases dealing with disputes concerning the medical treatment of children, save for *Re King*, which is the only reported case currently in “Category 2”. If this appeal is successful, Charlie’s case will join *Re King* in Category 2 because it, too, submits Mr Gordon, involves parents who are putting forward a viable alternative treatment option.
60. Mr Gordon accepts that the law regarding “best interests” decisions, as it has been developed over the years and is now understood to be settled, applies in full to “Category 1” cases. In relation to “Category 2” cases he submits that the structure of the legal decision making process must necessarily be different in order to afford priority and protection to the autonomy of parents who must have the ability to choose for themselves as between two viable treatment options, unless pursuing their choice would be likely to cause “significant harm” to their child.
61. The reference to a test based on “significant harm” arises from the judgment of Baker J in *Re King*, which was a case involving a choice between two types

of radiotherapy treatment for a five year old boy who suffered from a serious form of brain tumour. The case achieved widespread publicity when the parents, who disagreed with the treating hospital's plan for conventional radiotherapy, removed their child from the ward and took him to Spain. Following extensive media and police activity, the parents were arrested in Spain and the family was, eventually, brought back to England. It then fell to Baker J to preside over the best interests proceedings established to determine whether the boy would receive conventional radiotherapy or, as the parents firmly preferred, a new type of specifically targeted radiotherapy known as 'Proton' therapy.

62. Once the family had been found, and the high level of tension involved in the flight and ensuing hue and cry had died down, the treating hospital indicated its agreement to the parents seeking Proton therapy for their child in Prague as they wished, provided sufficient funding was in place. By the time the case came on for final hearing before Baker J therefore, there was no dispute between the parties as to the child's treatment plan. But, as the child remained a ward of court, it fell to the judge, in exercising the parental responsibility that attaches to the court in wardship, to give his approval to the plan. As the reported judgment of Baker J demonstrates, the court order permitting the parents to take their child abroad for treatment had been made some few days earlier and the child was already on route to Prague. The judge's judgment is largely taken up with a detailed factual account of the family's flight, the subsequent developments and the various legal processes that had been involved. It does not appear that the matter had been contested in any manner before the court, or, importantly, that there had been any matters of law

concerning medical treatment for the judge to determine prior to making his decision. It was, therefore, in that context that Baker J offered the following summary of the legal principles to be applied to the decision of whether or not to approve the proposed treatment plan (paras 28-34):

“28. The legal principles to be applied can be summarised as follows.

29. First, and most important, Ashya’s welfare is my paramount consideration.

30. Secondly, I have regard to Ashya’s human rights under the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950. In particular, I bear in mind his right to life under Art 2 and his right to respect for a private and family life under Art 8.

31. Thirdly, it is a fundamental principle of family law in this jurisdiction that responsibility for making decisions about a child rest with his parents. In most cases, the parents are the best people to make decisions about a child and the State – whether it be the court, or any other public authority – has no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give.

32. When Mr and Mrs King took Ashya from hospital on 28 August, the medical staff were, understandably, very concerned that the boy would suffer significant harm by being removed from the specialist care they were providing. When the local authority was informed about what had happened, and that it was believed that the parents had left the country, the social workers understandably concluded that there were reasonable grounds for believing that Ashya was at risk of suffering significant harm by being driven across Europe without medical assistance at a time when he urgently required post-operative therapy. I therefore conclude that the local authority acted entirely correctly in applying to the High Court, and further that His Honour Judge Sir Gavyn Arthur was right, on the evidence before him, to make Ashya a ward of court. My comments are confined to the matters within the family jurisdiction. I make no comment as to whether or not it was appropriate to seek a European arrest warrant. I merely observe that one consequence of this course was that Ashya was separated from his parents and left alone for several days in the Spanish hospital. As I observed at the hearing on 2 September, whatever the rights and wrongs of his parents’ actions, it was not in Ashya’s best interests to be separated from them in such circumstances.

33. The steps taken by the local authority and His Honour Judge Sir Gavyn Arthur on 29 August were entirely justified on the evidence then available. As at that date, there were reasonable grounds for believing that Ashya was at risk of suffering significant harm. A week later, the picture had changed and the court was faced with a completely different decision. The parents had put forward a treatment plan that was coherent and reasonable, and made arrangements for funding and transport. The local authority and Cafcass on behalf of Ashya, did not oppose the plan. The Hospital Trust, whilst not being in a position either to recommend or provide the treatment proposed by the parents, did not oppose the plan in principle, although they invited the court to adjourn making a final decision until receiving express confirmation from the oncology unit in Prague, which was to provide treatment alongside the Proton Therapy Centre, that Ashya would be accepted for treatment.

34. Having considered the evidence, I concluded that there was no reason to stand in the way of the parents' proposal. In some cases, this court is faced with a dispute between medical authorities and parents who are insisting on a wholly unreasonable course of treatment, or withholding consent to an essential therapy for their child – for example, a blood transfusion. This is manifestly not such a case. The course of treatment proposed by Mr and Mrs King is entirely reasonable. Ashya has a serious medical condition. Any parents in the position of Mr and Mrs King would do whatever they could to explore all options. Some parents would follow the advice of the local doctors to use conventional radiotherapy, others would prefer the relatively untested option of proton therapy (assuming the funds can be made available to meet the cost of transport and treatment) in the hope that the toxic effects of radiation will be reduced. Both courses are reasonable and it is the parents who bear the heavy responsibility of making the decision. It is no business of this court, or any other public authority, to interfere with their decision. Although I understood the Trust's anxiety that at the time of the hearing the oncology unit in Prague had not expressly accepted Ashya as a patient, I concluded that I could rely on the observations made by the Proton therapy Centre in the passage quoted above, that they did not anticipate any disagreement. Accordingly, I gave permission for Ashya to be taken by his parents to Prague. In the event, the oncology unit at the Motol hospital gave its consent this morning, and Ashya duly flew to Prague earlier today."

63. Mr Gordon submits that *Re King* now clarifies how, in a case such as the present where a choice is to be made between two viable treating options, the analytical exercise must be approached by the courts. The parents' decision must be respected insofar as it does not present a risk of significant harm to

the child. Within that exclusive zone, it is for the parents, in the exercise of their parental rights and duties, to decide what course of treatment is in the child's best interests.

64. The phrase "significant harm" is the key element within the "threshold criteria" in the Children Act 1989 s.31. As a matter of statutory jurisdiction a court may only make a public law order placing a child in the care of or under the supervision of, a local authority, if, prior to determining what, if any, order is best for the child, the court is satisfied that the child concerned is suffering or is likely to suffer significant harm, and that the harm, or likelihood of harm, is attributable to parental care or the child being beyond parental control.
65. Mr Gordon submits that the legal test for medical treatment described by Baker J in *Re King* is entirely consistent with the statutory scheme for care orders established by CA 1989 s.31. In doing so he makes reference to the well known dicta of Hedley J in *Re L (Care:Threshold Criteria)* [2007] 1 FLR 2050 to the effect that children are best brought up by their natural families and that the law and society must therefore accept and tolerate very diverse standards of parenting, with the State, only exceptionally, intervening with compulsive powers when a court is satisfied that the "significant harm" criteria in CA 1989 s.31 are satisfied.
66. Mr Gordon submits that a similar rationale underpins the application of the "significant harm" criteria in the context of medical treatment decisions concerning a child's upbringing which must primarily fall within the authority of the parents. The ability of the State to intervene to prevent a parent pursuing a positive treatment plan should, therefore, be limited, in like manner to any

other interference with parental authority, by the imposition of a threshold requirement based upon “significant harm”.

67. Insofar as the respondents to this appeal seek to rely on authority to submit that all treatment issues are to be determined upon ordinary “best interests” principles, without any additional filter or threshold based on “significant harm”, Mr Gordon argues that such submissions are misplaced, being founded, as they are, entirely upon cases which fall within Category 1, which, therefore, on his case, have no application where a “Category 2” choice falls to be made between two viable treatment options.
68. Mr Gordon seeks to gain some support for his argument from a recent decision by MacDonald J in *Barnett London Borough Council v AL* [2017] EWHC 125 (Fam), where the issue was whether or not a 7-month old child who was the subject of an interim care order in favour of a local authority should be given two particular vaccinations to which his mother objected. Rather than simply relying upon the parental responsibility afforded to them under the interim care order, the local authority applied to the court for a declaration that it was in the child’s best interests to receive the recommended vaccinations. Although the judge’s determination was undertaken on a straightforward “best interests” basis, Mr Gordon points to paragraph 33 of the judgment where MacDonald J said this:

“In the circumstances, as in *In re A (Welfare of Children: Immunisation)* and whilst the C2 application made by the local authority on 21 October 2016 is for an order in existing Children Act proceedings, the application the local authority pursues before this court must in fact be an application for relief under the inherent jurisdiction of the High Court. The local authority requires leave to make such an application,

which application for leave is to be considered against the criteria set out in section 100(4) of the Children Act 1989. Being satisfied that the relief sought by the local authority does not contravene section 100(2) of the Children Act 1989 and that the criteria for granting leave to the local authority to make an application under the inherent jurisdiction set out in section 100(4) of the Act are met, I granted permission for the local authority to make an application for relief under the inherent jurisdiction of the High Court.”

The significance that the appellant seeks to draw from that passage arises from the judge’s reference to the criteria for granting leave to the local authority to make an application which is set out in CA 1989, s.100(4) which states:

“s.100(4) The court may only grant leave if it is satisfied that –

(a) ...

(b) there is reasonable cause to believe that if the court’s inherent jurisdiction is not exercised with respect to the child he is likely to suffer significant harm.”

69. Mr Gordon also refers to a decision of this court in *Re C (Children) (Child in Care: Choice of forename)* [2016] EWCA Civ 374; [2017] Fam 137 which concerned a local authority application seeking to restrain a mother from naming her twin children “Cyanide” and “Preacher”. In the course of her judgment, My Lady, King LJ, giving a judgment with which the other two members of the court agreed, was required to consider whether or not the jurisdictional threshold imposed upon a local authority seeking to access the court’s inherent jurisdiction, as set out in CA 1989, s.100(4) had been satisfied. At paragraph 102 with respect to the child who might be named “Cyanide”, King LJ concluded that a reasonable belief that the child was likely to suffer significant harm was established. At paragraph 115 King LJ, having observed that the name “Preacher” might not in itself have led the court to conclude that there was a likelihood of significant harm, nevertheless

held that the welfare of that child should also be considered by the court within the inherent jurisdiction as to make a distinction between these two twins on the important issue of naming would be incompatible with their welfare.

70. Turning to the judgment in this case, Mr Gordon submits that the judge fell into error in that he treated this as a Category 1 case and therefore applied the well-established best interests test applicable to such cases. Although the suggested existence of “Category 1” and “Category 2” cases has only very recently been developed by counsel for the purposes of this appeal, Mr Gordon points to the fact that *Re King* was cited before the judge, but not referred to in the judgment. The question of harm is, it is said, only dealt with by the judge in a cursory and inconsistent manner. At paragraph 113, under the heading ‘Pain’, Francis J noted that “no-one can be certain whether or not Charlie feels pain”. The judge, however, does go on at paragraph 114 (set out at para 31 above), to record that the view of Professor A and the team was that Charlie was suffering and that the level of suffering was something that was more significant than low level pain.
71. Earlier in her evidence, Professor A had, however, accepted that although it was possible that Charlie could feel pain, that had not been clinically demonstrated. Mr Gordon submits that the judge failed to state any clear conclusion on the issue of pain, save that, in the closing words of paragraph 128, referring to the best interests decision, the judge said “and not put him through more pain and suffering”.

72. The appellants' case with respect to there being a threshold based on "significant harm" in this case is roundly refuted before this court by the hospital and by Charlie's guardian. Ms Gollop QC, for the hospital, submitted that the fact that there was an offer of treatment in the USA could not alter the approach to be taken in law that had been established by the highest level of authority over the past two or more decades. In addition to that primary submission, she pointed to the potential, were the law to develop in the manner submitted by the appellants, that many more cases would come to court, with parents seeking to avoid submitting to the inherent jurisdiction by relying upon the suggestion of some alternative form of therapy.
73. Ms Gollop places particular reliance upon a passage in the judgment of Lord Donaldson MR in *Re J (a minor) (wardship: medical treatment)* [1991] Fam 33 at page 41, as follows:

"The doctors owe the child a duty to care for it in accordance with good medical practice recognised as appropriate by a competent body of professional opinion: see *Bolam v. Friern Hospital Management Committee* [1957] 1 W.L.R. 582. This duty is, however, subject to the qualification that, if time permits, they must obtain the consent of the parents before undertaking serious invasive treatment.

The parents owe the child a duty to give or to withhold consent in the best interests of the child and without regard to their own interests.

The court when exercising the *parens patriae* jurisdiction takes over the rights and duties of the parents, although this is not to say that the parents will be excluded from the decision-making process. Nevertheless in the end the responsibility for the decision whether to give or to withhold consent is that of the court alone.

It follows from this that a child who is a ward of court should be treated medically in exactly the same way as one who is not, the only difference being that the doctors will be looking to the court rather than to the parents for any necessary consents.

No one can dictate the treatment to be given to the child - neither court, parents nor doctors. There are checks and balances. The doctors can recommend treatment A in preference to treatment B. They can also refuse to adopt treatment C on the grounds that it is medically contra-indicated or for some other reason is a treatment which they could not conscientiously administer. The court or parents for their part can refuse to consent to treatment A or B or both, but cannot insist upon treatment C. The inevitable and desirable result is that choice of treatment is in some measure a joint decision of the doctors and the court or parents.”

74. Based upon Lord Donaldson’s judgment in *Re J*, it plainly contemplates a choice between a number of treatment options with, in the event of a dispute, it being the responsibility of the court to determine the issue, without reference to any additional requirement related to “significant harm”. “Best interests” is the established yardstick which applies to all cases and there is no justification for this court now to endorse the creation of a sub-set of cases based upon establishing significant harm.
75. Ms Gollop described the suggestion that this case did not engage with issues of “significant harm” as extraordinary. By way of example, she referred to the recent decision of this court in *Re A (HR)* [2016] EWCA Civ 759, in which the court endorsed reference to guidance issued by the President of the Royal College of Paediatrics & Child Health entitled ‘Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: A Framework for Practice’. The guidance describes cases where life is limited in quality in the following terms:

“When life is limited in quality

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatments itself. These comprise:

A: Burdens of treatment where the treatments themselves produce significant pain and suffering so as to outweigh any potential actual benefits;

B: Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life.

C: Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life."

Ms Gollop points to the apparent attribution of equal weight as between the three sub-categories, (a), (b) and (c) so that, although (c) does not include reference to pain, suffering or distress, the very condition of it being difficult or impossible to derive benefit from continued life justifies consideration alongside those cases where "significant harm" might be established solely by reference to evidence of the experience of pain. Ms Gollop submits that for Mr Gordon's threshold to be applied, all cases in group C would be excluded in a manner which is wholly contrary to the approach hitherto taken by medical practitioners and by the court.

76. Returning to *Re A*, Ms Gollop points to a passage in the first instance judgment of Parker J, which engages with item C in the Royal College guidance:

"Even if I am wrong in that assessment [that the child experiences pain and suffering], and even if his life were completely pain free, I would come to the conclusion that there is no measurable benefit to him to continue in his present condition and it is simply inhumane to permit it to continue."

That approach, albeit *obiter*, was plainly endorsed, submits Ms Gollop by the Court of Appeal, of which both My Lady, King LJ and I, were members.

77. Ms Gollop submits that *Re King* is an unusual case in that all of the issues had been agreed and there was no requirement upon the judge to give a reasoned judgment. It is not apparent from the judgment that there had been legal argument or that the judge understood or intended to be establishing any statement of the law which differed from the well-known or previously decided authorities from the higher appellate courts.
78. In her response to the appeal, Ms Butler-Cole submitted that in every case where there is a dispute it follows that the parents are putting forward an alternative view to that of the clinicians, whether or not they are able to identify a particular form of alternative treatment and a practitioner willing to deliver it.
79. Ms Butler-Cole submitted that it is not unusual for lawyers acting on behalf of parents to seek to establish bespoke sub-categories, to which a different test might apply. A prime example, upon which she relied, is to be found in the summary of the submissions of James Munby QC and Peter Jackson (as they both then were) for the Official Solicitor in *Re J* (1991) Fam 33 at pages 35 and 36, where counsel can be seen to be identifying a sub-group of cases and suggesting, as an alternative, only withholding lifesaving treatment where the continuation of life is going to be “intolerable” for the child and “bound to be full of pain and suffering”. That approach was roundly rejected, submits Ms Butler-Cole by Lord Donaldson at page 56, as follows:

“This brings me face to face with the problem of formulating the crucial equation. In truth it cannot be done with mathematical or any precision. There is without doubt a very strong presumption in favour of a course of action which will prolong life, but even excepting the “cabbage” case, to which

special considerations may well apply, it is not rebuttable. As this court recognised in *Re B* [1988] AC 199, account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment itself. In *Re B* was probably not a borderline case and I do not think that we are bound to, or should, treat Templeman LJ's use of the words "demonstrably so awful" or Dunn LJ's use of the word "intolerable" as providing a quasi-statutory yardstick."

80. Under the accepted approach to best interests cases the weight to be attached to the views of a child's parents may vary and, where there is real scope for debate as between two treatment options, the views of the parents may well be very important.

81. Returning to the question of the appropriate yardstick, Ms Butler-Cole focused on the well-known passage in the judgment of Waite LJ in *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242 at page 253:

"What is the court to do in such a situation? It is not an occasion – even in an age pre-occupied with "rights" – to talk of the rights of the child or the rights of a parent or the rights of the court. The cases cited by Butler-Sloss J are uncompromising in their assertion that the sole yardstick must be the need to give effect to the demands of paramountcy of the welfare of the child."

82. In reply, Mr Gordon submitted that the newly-formulated categories correctly reflect the underlying law. By imposing the withdrawal of life-sustaining treatment upon the child of parents who hold a legitimate contrary view favouring alternative viable treatment involves intervention by the State on the family's right to private and family life on a massive scale. He submitted that ECHR Art 8 is at the core of this case and that, absent a finding that the course of action preferred by the parents would be likely to cause their child

“significant harm”, it was neither necessary nor proportionate for the State to override the parents’ legitimate choice of treatment.

Ground 2: “No jurisdiction”

83. I now turn to the appellants’ second ground of appeal.
84. On the question of jurisdiction, Mr Gordon submits that it is necessary to divide the hospital’s application to the court into two parts. Insofar as the application seeks a declaration as to the lawfulness or otherwise, of the hospital’s own plan to withdraw treatment, provide only palliative care, and decline, itself, to institute nucleoside therapy, Mr Gordon accepts that the application is unremarkable in legal terms and is simply a manifestation of the current law on “best interests” and good practice. On the other side of the divide, however, Mr Gordon submits that the hospital’s application actively to prevent any other person from arranging and delivering nucleoside therapy was an application that was outside the hospital’s powers as a public authority and/or outwith the court’s jurisdiction in the absence of proof of “significant harm”.
85. Mr Gordon submits that by the time the case came to court there was no question of the hospital providing nucleoside therapy itself and the consequence, indeed the avowed purpose of the hospital seeking declarations with respect to nucleoside therapy, was solely to prevent the parents from seeking such therapy themselves. On the appellants’ case, the English hospital can have no legitimate interest in seeking to prevent the American team from carrying out the therapy. Reference is made to the judgment of Hedley J in *Portsmouth NHS Trust v W* [2005] EWHC 2293 (Fam) (paragraph 36):

“Where a clinician concludes that a requested treatment is inimical to the interests of the patient, and ... his professional conscience, intuition or hunch, confirms that view ... he may refuse to act and cannot be compelled to do so, though he should not prevent another from so acting, should that clinician feel able so to do.”

86. Reference is also made to the case of *Broadmoor Special Hospital Authority v Robinson* [1999] QB 775, particularly at paragraph 30 (Lord Woolfe MR) paragraph 38 (Morritt LJ), and paragraphs 54-55 (Waller LJ). Although the underlying facts in the *Broadmoor* case are significantly different to those in the present proceedings, as is the underlying jurisdiction of the court, Mr Gordon submits that that case is authority for establishing that a public body may only take action within the compass of its own statutory power.
87. The appellants’ argument moves on to submit that the declaration as to nucleoside treatment made by the judge is effectively in the form of an injunction, the aim of which is to impose the clinical view of the hospital upon the parents, backed up with the force of law. As a point of principle, submit the appellants, the hospital had no legal standing to interfere with decisions taken by the parents in the exercise of their parental responsibility, and the court, correspondingly, had no jurisdiction to uphold and support the hospital’s position in that regard. There have been no other application before the court (in particular, no application made on behalf of the child himself), the court lacked jurisdiction to make any declaration as to nucleoside therapy, other than to hold that it was lawful, in the circumstances, for the hospital, itself, to refuse to provide that treatment.
88. In response to the second ground of appeal, Ms Gollop submits that, the issue as to nucleoside treatment having arisen between the hospital and the parents,

the hospital were entitled to raise it for determination within their overall application. She argues that the characterisation afforded to the hospital's application by Mr Gordon, to the effect that the hospital was seeking to impose its view on the parents, is wholly insupportable. In common with health bodies who bring these anxious cases to court when the need arises, their role was simply to raise the matter properly and fairly within court proceedings and for a judge to determine the issue. The decision maker is, therefore, the judge and not the treating clinical team. If the judge concludes that it is necessary, as being in the best interests of the child, to place an embargo upon a particular form of treatment, whether undertaken in the hospital or elsewhere, then it is his role and duty to do so. If, as may sometimes be necessary, it is necessary to support such a declaration with an injunction, then, again, this is a matter for the judge and not the hospital to determine.

Discussion

89. To evaluate the validity of Mr Gordon's primary submission that there is a distinct category of cases to which a significant harm threshold applies it is necessary to go back to basic principles. I have already quoted the relevant extract from the *Aintree* decision, and from the decision of *Re J* relating to yardsticks.
90. Two or three further references are now required. The first comes from the case of *Re Z (Identification: Restrictions of publication)* [1997] Fam 1, at page 32). In his judgment, the then Master of the Rolls, Sir Thomas Bingham said this:

"I understood the mother's counsel to advance two reasons why discretion could only be properly exercised to the effect contended for. The first was that the court should never override the decision of a devoted and reasonable parent, such as this mother was found to be. I would from my part accept without reservation that the decision of a devoted and responsible parent should be treated with respect. It should certainly not be disregarded or lightly set aside. But the role of the court is to exercise an independent and objective judgment. If that judgment is in accord with that of the devoted and responsible parent, well and good. If it is not, then it is the duty of the court, after giving due weight to the view of the devoted and responsible parent, to give effect to its own judgment. That is what it is there for. Its judgment may of course be wrong. So may that of the parent. But once the jurisdiction of the court is invoked its clear duty is to reach and express the best judgment it can."

91. The second additional authority is *Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242. I refer firstly to the judgment of Lady Justice Butler-Sloss, at page 250 in these terms:

"From the decisions to which I have referred which bind this court, it is clear that when an application under the inherent jurisdiction is made to the court, the welfare of the child is the paramount consideration. The consent or refusal of consent of the parents is an important consideration to weigh in the balancing exercise to be carried out by the judge. In that context, the extent to which the court will have regard to the view of the parent will depend upon the court's assessment of that view. But as Sir Thomas Bingham MR said in *Re Z*, the court decides and in so doing may overrule the decision of a reasonable parent.

Applying those principles to the present case, the first argument of [counsel] that the court should not interfere with the reasonable decision of a parent is not one we are able to entertain even if we wish to do so. His suggestion that the decision of this mother came within that band of reasonable decisions within which a court would not interfere would import into this jurisdiction the test applied in adoption to the refusal of a parent to consent to adoption. It is wholly inapposite to the welfare test and is incompatible with the decision in *Re Z*."

92. Secondly that of Lord Justice Waite, firstly at page 253, to which I have already made reference, and then at 254:

"In this instance, however, in agreement with Lady Justice Butler-Sloss, I consider that the judge was betrayed into an error of law by his concern with the need to form a judgment about the reasonableness of the mother's approach. An appraisal of parental reasonableness may be appropriate in other areas of family law (adoption, for example, where it is enjoined by statute), but when it comes to an assessment of the demands of the child patient's welfare, the starting point - and the finishing point too - must always be the judge's own independent assessment on the balance of advantage or disadvantage of the particular medical step under consideration. In striking that balance, the judge will of course take into account as a relevant, often highly-relevant factor, the attitude taken by a natural parent, and that may require examination of his or her motives. But the results of such an inquiry, must never be allowed to prove determinative. It is a mistake to view the issue as one in which the clinical advice of doctors is placed in one scale and the reasonableness of the parent in the other."

and then further down that page:

"All these cases depend on their own facts and render generalisations - tempting though they may be to the legal or social analyst - wholly out of place. It can only be said safely that there is the scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare, widely accepted by the generality of mankind; and at the other end lie highly problematic cases where there is genuine scope for a difference of view between parent and judge. In both situations, it is the duty of the judge to allow the court's own opinion to prevail in the perceived paramount interests of the child concerned, but in cases of the latter end of the scale, there must be a likelihood (though never of course a certainty) that the weight of the scope of general debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis, the best interests of every child, include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature."

93. In terms of principle and the approach of the court, I also have in mind the more recent iteration of the Royal College's Guidelines, to which I have made reference, and indeed, this court's decision in the case of *Re A*, where King LJ set out a statement of the law with which I both fully agreed and agree.

94. Those statements of principle seem to me entirely clear. They more than amply encompass the case where a parent may be objecting to a proposed course of treatment on the basis that they have a preferred alternative course of treatment. Even if such a case may fall at the more favourable end of the spectrum described by Lord Justice Waite, the court does not evaluate the reasonableness of the parents' case, or, as these authorities indicate, introduce any other factor or filter, before it embarks upon deciding what is in the best interests of the child.
95. When thoughtful, caring, and responsible parents are putting forward a viable option for the care of their child, the court will look keenly at that option, in the same way that a court in family proceedings, when it gets to the welfare stage of any case, looks at the realistic options that are before it. The court evaluates the nitty-gritty detail of each option from the child's perspective. It does not prefer any particular option simply because it is put forward by a parent or by a local authority. The judge decides what is in the best interests of the child by looking at the case entirely through eyes focused on the child's welfare and focused upon the merits and drawbacks of the particular options that are being presented to the court.
96. If one option is favoured by a parent, that may give it weight, or as Lord Justice Waite put it, incline the court to be "influenced by a reflection that in the last analysis, the best interests of every child, include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature". Notwithstanding that that is the case, in the end it is the judge who has to choose the best course

for a child. Where, as in the case of *Re King* before Mr Justice Baker, there really was nothing to choose as between the benefits and detriments of the two forms of radiotherapy, the court readily stood back and allowed the parents to make their choice.

97. Where, however, as in this case, the judge has made clear findings that going to America for treatment would be futile, would have no benefit and would simply prolong the awful existence that he found was the current state of young Charlie's life, he was fully entitled, on the basis of those findings to conclude as he did. The consequence of that conclusion is that the proposal for nucleoside therapy was not a viable option before the court.
98. It is not therefore necessary to look for further examples beyond the clear and authoritative statements of the law to which I have referred. Indeed, save for the case of *Re King*, Mr Gordon does not suggest that further investigation would produce any other authority which would contradict the law as it is as described in these and so many other cases.
99. Turning to the decision of *Re King* itself, I agree with the observations made about that case by Ms Gollop. The circumstances which led Baker J to give a judgment seem largely to have been driven by the previous media attention and, rightly, a perceived need for the court to draw matters together with a clear, authoritative and detailed account of what had taken place. The primary focus of the narrative part of the judgment which occupies well over two thirds of the total, primarily focuses on the actions of the state, in the guise of the local authority, and the court in seeking to track down, arrest and then

detain the parents. The medical issue had been resolved and it played no part in the judge's determination.

100. I have already quoted from the key paragraph in Baker J's judgment upon which Mr Gordon relies, which is paragraph 31. The statement in paragraph 31 relating to significant harm must, in my view, to be interpreted within its own context and that context is provided by the two subsequent paragraphs, 32 and 33, which relate entirely to the legitimacy of the actions of the local authority, and I stress the words "local authority", and the court in seeking and making orders to track down and apprehend the parents.
101. Insofar as the actions of a local authority are concerned, Mr Justice Baker was entirely correct to refer to "significant harm" given the statutory power preventing any local authority in intervening in the ordinary care of a child given to him or her by a parent, unless the threshold criteria in Children Act 1989, s 31 (or s 100) are met.
102. There is no indication in the context within which this part of the judgment appears, or in the actual words in paragraph 31, that Baker J was at that stage referring to medical treatment. In paragraph 34, however, he was referring to medical treatment, but he did so by reference to the wholly unusual course of events. There is no indication in that part of his judgment that he held that a threshold of significant harm applied to the decision as to the choice of treatment.
103. On the basis that all parties were satisfied that the course of treatment proposed by the parents was reasonable, there was no ground for the court to

interfere with the decision, and that led the judge to say as he did, that it was indeed, "no business" of the court to do so.

104. My primary conclusion, therefore, on looking at *Re King*, is that Mr Justice Baker's words provide no basis for saying that he was holding that any test based on significant harm is to be applied to cases relating to the medical treatment of children. Even if I am wrong in holding as I do, and Mr Justice Baker was purporting to set out such a test, a one sentence statement in the course of a short judicial endorsement of a consent order where no point of law had been an issue, no authority had been cited, and where the judge makes no attempt to justify such a radical development of, or departure from, previous, long-established authority, provides the very weakest of bases for Mr Gordon's weighty submissions.

105. If, contrary to my primary reading, Mr Justice Baker did intend to state, where a parent puts forward a viable option for treatment, that the High Court only has jurisdiction to interfere with a parent's choice of that medical treatment if the child is likely to suffer significant harm as a result, then, in my view, such a statement has no foundation as a matter of law, is contrary to established authority and is therefore plainly in error.

106. Moving on in the Appellants' argument to the reference made to the *Barnett* case and the case of change of forename case of *Re C*, reference to those authorities was, in my view, misplaced. The focus of each of those two cases was upon the requirement in CA 1989, s 100(4) for a local authority to obtain leave to make an application under the inherent jurisdiction. It is correct that, before granting leave, the court is required to have reasonable cause to believe

that the child is likely to suffer significant harm if the inherent jurisdiction is not invoked, but the application of the provision is expressly limited to local authorities.

107. A primary purpose of the Children Act 1989 was to delineate, limit and provide structure for the roles respectively of local authorities and the courts. Prior to the Children Act coming into force, local authorities had regularly resorted to the inherent jurisdiction of the High Court in order to achieve some form of control over the lives of individual children and their families. A clear purpose of the 1989 Act was to close down or at least limit that avenue and to channel all such cases through the statutory scheme embodied in Section 31 of the Act, which requires the state in the guise of a local authority to satisfy the court that the significant harm threshold criteria are established before the court can consider going on to make orders to give the local authority power to control the life of an individual child in a family.

108. That is the purpose of Section 100(4). It has no wider application. Certainly, Mr Gordon does not argue that the words of Section 100(4) directly apply to medical treatment cases. It follows that the oblique references in the *Barnet* case and in *Re C* to the need establish belief in a likelihood of significant harm before a local authority may bring an application under the inherent jurisdiction, are to be construed within the narrow structure of s 100(4), which applies only to local authorities. The statutory provision is no more than an express exception to the general position of unrestricted access to the inherent jurisdiction by parties (whether they be public bodies or lay). The reference to

it in these two cases does not have any wider application in respect to applications that are not made by a local authority.

109. There is, in contrast to the regime applicable to local authorities, no statutory requirement for a hospital to go through the Section 100 hoop. In any event to suggest that this is so, if parents happen to have identified a potential alternative form of treatment, but not otherwise, identifies a process which would be haphazard and otherwise fraught with difficulty.
110. It is also argued that where there is a viable, alternative treatment available, then, absent the court being satisfied that the carrying out of the treatment would cause the child significant harm, the parents' view must prevail, even if their proposed course of treatment is not in the child's best interests. That must be the submission that is made to the court in this case given the judge's finding. The judge has held that to travel to America is not in Charlie's best interests, yet it is submitted that the parents' views to the contrary must prevail in the absence of significant harm.
111. It is neither necessary nor appropriate, in my view, to import such a test or to create a new category of case. There is no justification for it in any previously decided authority, even, as I have explained, *Re King*.
112. It goes without saying that in many cases, all other things being equal, the views of the parents will be respected and are likely to be determinative. Very many cases involving children with these tragic conditions never come to court because a way forward is agreed as a result of mutual respect between the family members and the hospital, but it is well recognised that parents in the appalling position that these and other parents can find themselves may

lose their objectivity and be willing to "try anything", even if, when viewed objectively, their preferred option is not in a child's best interests. As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view.

113. On the facts of this case in my view, Mr Gordon's submission, unfortunately for the parents, does not even begin to have traction. The submission is based upon there being a viable alternative form of treatment available. I have already stressed the importance of the judge's findings as to the utility of the treatment proposed in America. He formed a very pessimistic view of it and rated it as "futile" with the prospects of success effectively being "zero". Those findings, in my view, completely undermine, on a factual basis, the submission which Mr Gordon has most skilfully and carefully developed. There is no viable, alternative treatment for poor Charlie. That is the incontrovertible consequence of the judge's findings. There being no viable, alternative treatment, the question of whether, as a matter of law, there is a group of cases to be labelled 'Category 2', simply and most sadly does not arise for Charlie.

114. Finally, in this regard, it is plain that the judge was not invited to consider the law in the way that it is now put before this court, let alone to consider the existence of 'Category 2' cases with the need to establish a threshold for significant harm. I have made extensive reference to the evidence as recorded by the judge regarding Charlie's current state. It is clear, in my view, that if

the judge had been invited to form a conclusion on whether Charlie was or was not suffering significant harm currently, that finding would have been made. At paragraph 49 the judge records the evidence of the doctors, the medical staff who have knowledge of the current state of Charlie's life in the hospital and each of the other experts as follows:

'In some parts of the media this has been referred to as "pioneering treatment". In fact, this type of treatment has not even reached the experimental stage on mice let alone been tried on humans with this particular strain of MDDS. It is the view of all those who have treated and been consulted in relation to Charlie in this country and also in Barcelona that such treatment would be futile, by which I mean would be of no effect *but may well cause pain, suffering and distress to Charlie*. This is the principal issue with which I have to grapple in this case.' [emphasis added]

It must follow from that unanimous professional and expert evidence, that to move Charlie to America and expose him to treatment over there would be likely to expose him to continued pain, suffering and distress.

115. The administration of nucleoside therapy, which involves no more than the introduction of some powder into the nutritional feed to Charlie's body and may, at most, trigger some adverse bowel reaction, may be relatively benign and may not itself cause significant harm. The prospect of significant harm arises, however, in the context of such treatment from the judge's finding that it would be of no benefit for Charlie and that he would need to continue with the regime of life-sustaining treatment, which the judge concluded was not otherwise in his best interests, so that the nucleoside therapy could be administered.

116. Turning to ground 2, I can deal with matters more shortly. Much of Mr Gordon's submission on this point, on my understanding, assumes that ground 1 is successful. In any event, so far as the argument is made that Great Ormond Street Hospital was acting outside their legal powers in bringing this application, it is to be recalled that the issue as to alternative therapy was one raised by the parents and not by the hospital. The hospital brought the application before the court on conventional terms seeking a declaration about their treatment plan for withdrawal of life support and provision limited to palliative care with no requirement on their part to consider nucleoside therapy. The wider issue of nucleoside therapy was raised by the parents because, as the proceedings progressed, the information about Dr I became more clearly defined, and, by the time of the hearing, he was plainly before the court offering to treat the child. A choice therefore had to be made by the judge, rather than the hospital, following a full assessment of Charlie's best interests.

117. It therefore fell to the judge to decide the issue, rather than it being a matter of Great Ormond Street Hospital having forced its opinion on the parents and thereafter having sought the sanction of the court. The judge decided the issue on the ordinary, best interests' basis, made an order declaring the result of that determination was that nucleoside treatment was not in Charlie's best interests. If necessary, and one hopes it that the situation will not arise, such an order would be backed up by an injunction in due course; but, if so, it would be an injunction made by the court. In short terms, I accept the submissions made by Ms Gollop in this regard.

118. It is incorrect to cast this process insofar as it relates to prohibiting nucleoside therapy as being driven by the hospital. The order results from a 100 per cent, child focused, court-led evaluation where the one issue was whether or not the therapy was in the child's best interests. The fact that as part of that evaluation the court's evidential focus was largely on the merits of nucleoside therapy, notwithstanding the very clear views of the hospital and the limited benefit Dr I himself was able to identify, demonstrates that the judge regarded the views of Charlie's parents as an important part of the process upon which he was engaged. It follows that I do not consider that ground 2 has established any basis for overturning the judge's decision, or more particularly the orders that he has made. It follows that I therefore conclude that the appeals on grounds 1 and 2, supported as they are by the Human Rights arguments that have been made under Ground 4, must be dismissed.

119. For the parents, this is a devastating outcome. They have gone more than the extra mile in trying to hold on to the hope that they have for their child. The system requires any dispute to be determined by a judge. The judge did not agree with them. He, after giving what is clearly the most anxious consideration to the issues, determined that there really was only one course for young Charlie, and that was for his life to be brought to a close as a result of the orders that the court made. I can see no reason for disagreeing with that outcome or for holding that any of the grounds we have considered cause the judge's order to be set aside. I would therefore dismiss the appeal with the result, if My Lady, My Lord agree, that the judge's orders remain as they are, in full.

LADY JUSTICE KING:

120. I agree. I would only add that I would wish to join My Lord, Lord Justice McFarlane, in his expression of admiration, respect and sympathy to the parents for the way in which they have endured, with devotion and stoicism, the distress, fear and uncertainty of the last months since Charlie was admitted to hospital.. I am conscious too that, as a consequence of our decision today, they must now call upon their remaining resources, both individually and together as a couple, to face the dark days that lie ahead.
121. Charlie and his parents have had the benefit of being treated at not only the centre of excellence that is Great Ormond Street Children's Hospital, but of his having been under the care of a world-leading expert on mitochondrial disorders. I would wish to acknowledge the skill and care given to Charlie by the doctors and nurses at Great Ormond Street. The fact that, for wholly understandable reasons, the parents have been unable to accept the view of the hospital that Charlie should now receive only palliative care, should not be interpreted as undermining any recognition of the dedication of the medical team who wish only to act in Charlie's interests and who will now continue to look after him with the same care and compassion for the rest of his life..
122. Lord Justice Sales, having had the advantage of (Inaudible) Lord Justice McFarlane's judgment, has asked me to indicate on his behalf that he too agrees that this appeal should be dismissed.

