Neutral Citation Number: [2017] EWHC 972 (Fam)

Case No. FD17P00103

IN THE HIGH COURT OF JUSTICE

FAMILY DIVISION

Royal Courts of Justice

Date: Tuesday, 11th April 2017

Before:

MR. JUSTICE FRANCIS

(In Public)

- -

BETWEEN:

GREAT ORMOND STREET HOSPITAL Applicant

- and -

(1) CONSTANCE YATES
(2) CHRIS GARD
(3) CHARLES GARD
(A Child, By his Guardian Ad Litem)

Respondents

- -

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MS. D. POWELL QC (of Counsel) appeared on behalf of the Applicant.

MS. S. ROPER (of Counsel) appeared on behalf of the Respondents.

MS. V. BUTLER-COLE (of Counsel) appeared on behalf of the Guardian.

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JUDGMENT (as approved by the Judge)

MR. JUSTICE FRANCIS:

DECISION AND SUMMARY REASONS

1 I start by just reminding everybody that this case is subject to agreed reporting restriction orders that have been made in order to protect the anonymity of the medical team and those that have given second opinions, both here and abroad. In the event of any doubt as to the nature and scope of those reporting restrictions, please obtain a copy of the orders made from any of the lawyers involved in the case.

2 I extend my thanks to the members of the press who have attended this hearing for their understanding of the sensitive issues that arise in this case and the need to protect the confidentiality of the medical staff involved, both here and abroad. It has been agreed also, and I so ordered, that the identity of Charlie's Guardian should remain confidential.

3 Following discussions with counsel acting for Charlie's parents, it has been agreed that I shall give my decision with brief reasons now and then adjourn for a short time before I give my full judgment. This note, which I am going to read now and then which I am going to distribute, is intended to be a summary of the decision; but any reporting of the case should be based on my full judgment shortly to be delivered in open court, subject to those reporting restrictions.

4 This, as we all know, is the final hearing of an application by the Great Ormond Street Hospital for Children NHS Foundation Trust, pursuant to the inherent jurisdiction of the court, in relation to Charles Gard (known to all as "Charlie") who was born on 4th August 2016 and who is therefore just over eight months old.

5 By their application dated 24th February 2017, the applicants ask the court to make the following orders:

(1) That Charlie, by reason of his minority, lacks capacity to make decisions regarding his medical treatment;
(2) that it is lawful, and in Charlie's best interests, for artificial ventilation to be withdrawn;
(3) that it is lawful, and in Charlie's best interests, for his treating clinicians to provide him with palliative care only; and
(4) that it is lawful, and in Charlie's best interests, not to undergo nucleoside therapy provided always that the measures and treatments adopted are the most compatible with maintaining Charlie's dignity.

6 Plainly, by reason of his age, it is not in issue that Charlie lacks capacity to make decisions regarding his medical treatment. Charlie has been represented throughout this hearing by his Guardian and by very experienced counsel.

7 The parents have been represented by experienced and dedicated solicitors and counsel who have acted pro bono and I wish publicly to pay tribute to them for their excellent assistance to the court and, I am sure, to their clients.

8 Great Ormond Street Hospital has been represented throughout by very experienced leading counsel.

9 Charlie's parents, Constance Yates (known as "Connie") and Chris Gard, oppose the orders that are sought by the applicants.

10 The matter came before the court on 3rd March this year when I adjourned the proceedings so that Connie and Chris could file their evidence, and in particular obtain evidence from the USA, as to the treatment that might possibly be available for Charlie. When Chris started his evidence, he described himself as Charlie's proud father. I am in no doubt at all that he and Connie are Charlie's proud parents.

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

12 The relevant legal principles which guide the exercise of my discretion are well settled. It is important that I stress that I am not applying a subjective test. I am not saying what I would do in a given situation, but I am applying the law.

13 In *Wyatt v. Portsmouth NHS Trust*, the Court of Appeal set out what is referred to as the "intellectual milestones" for Judges making a decision of the kind which faces me today. The Court of Appeal said as follows:

> "In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed

> point of view of the child. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. The term ‘best interests’ encompasses medical, emotional, and all other welfare issues.”

14 Charlie’s parents have sadly, but bravely, acknowledged and accepted that the quality of life that Charlie has at present is not worth sustaining. He can only breathe through a ventilator and, although they believe that he has a sleep/wake cycle and can recognise them and react to them when they are close, they realise that he cannot go on as he is, lying in bed, unable to move, fed through a tube, breathing through a machine. In my full judgment, I shall set out the full details of his medical condition.

15 All of Charlie’s treating doctors at Great Ormond Street Hospital are agreed that Charlie has reached the stage where artificial ventilation should be withdrawn, that he should be given palliative care only and that he should be allowed to die peacefully and with dignity. Charlie has been served by the most experienced and sophisticated team that our excellent hospitals can offer. His case has also been considered by an expert team in Barcelona, which has reached the same conclusion. Charlie’s condition is exceptionally rare and I am confident that I have had reports from around the world from those who know it as well as anyone can.

16 It seemed at the outset of this hearing that there might have been a lone voice in the USA that was offering what had been described in some reports as “pioneering treatment”. Understandably, Charlie’s parents have grasped that possibility. They have done all that they could possibly have done. They have very publicly raised funds. What parents would not do the same? But I have to say, having heard the evidence, that this case has never been about affordability, but about whether there is anything to be done for Charlie.

17 At one stage, Great Ormond Street Hospital got as far as deciding to apply for ethical permission to attempt nucleoside therapy here - a treatment that has never been used on patients with this form of MDDS - but, by the time that decision had been made, Charlie’s condition had greatly worsened and the view of all here was that his epileptic encephalopathy was such that his brain damage was severe and irreversible that treatment was potentially painful but incapable of achieving anything positive for him.

18 I was aware that I was to hear evidence from the doctor[1] in the USA who was, reportedly, offering what had been referred to as “pioneering treatment”. Before he gave evidence, I encouraged the treating consultant at Great Ormond

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[1] Referred to below as Dr. I, Professor of Neurology at a Medical Centre in the USA.

Street Hospital to speak with him which he was able and willing to do. I am truly grateful to these experts for the time that they have given to this case. The outcome of that discussion is illuminating. The doctor in the USA said as follows:

> "Seeing the documents this morning has been very helpful. I can understand the opinions 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."

19 However, the US doctor made it clear that, were Charlie in the United States, he would treat him if the parents so desired and could pay for it. As I have already said, funding in this case is not an issue. The US doctor also confirmed during this telephone conversation that he had never treated with nucleoside therapy anyone who had encephalopathy. Therefore, he was unable to indicate from any scientific basis whether a patient with encephalopathy would respond positively.

20 Charlie suffers from the RRM2B mutation of MDDS. No one in the world has ever treated this form of MDDS with nucleoside therapy, although patients with a different strain, TK2, have received nucleoside therapy with some recorded benefit. In mouse models, the benefit to TK2 patients was put at about 4% of life expectancy. There is no evidence that nucleoside therapy can cross the blood/brain barrier which it must do to treat RRM2B, although the US doctor expressed the hope that it might cross that barrier.

21 There is unanimity among the experts from whom I have heard that nucleoside therapy cannot reverse structural brain damage. I dare say that medical science may benefit objectively from the experiment, but experimentation cannot be in Charlie's best interests unless there is a prospect of benefit for him.

22 The Great Ormond Street Team believe that Charlie can probably experience pain, but is unable to react to it in a meaningful way. Their evidence was that being ventilated, being suctioned, living as Charlie does, are all capable of causing pain. Transporting Charlie to the USA would be problematic, but possible. Subjecting him to nucleoside therapy is unknown territory - it has never even been tested on mouse models - but it may, or may not, subject the patient to pain, possibly even to mutations. But if Charlie's damaged brain function cannot be improved, as all seem to agree, then how can he be any better off than he is now, which is in a condition that his parents believe should not be sustained?

23 It is with the heaviest of hearts but with complete conviction for Charlie's best interests that I find that it is in Charlie's best interests that I accede to these

applications and rule that Great Ormond Street Hospital may lawfully withdraw all treatment, save for palliative care, to permit Charlie to die with dignity.

24 I want to thank the team of experts and carers at Great Ormond Street and others who cannot be named for the extraordinary care that they have provided to this family. Most importantly of all, I want to thank Charlie's parents for their brave and dignified campaign on his behalf; but more than anything to pay tribute to their absolute dedication to their wonderful boy from the day that he was born.

(Short Adjournment)

FULL JUDGMENT

25 This is the full judgment following the short reasons given half an hour or so ago.

Introduction

26 This is the final hearing of an application made by the Great Ormond Street Hospital for Children NHS Foundation Trust, pursuant to the inherent jurisdiction of the High Court, in relation to Charles Gard (known to all as "Charlie") who was born on 4th August 2016 and who is therefore just over eight months old.

27 By their application dated 24th February 2017, the applicants ask the court to make the following orders:

(1) That Charlie, by reason of his minority, lacks capacity to make decisions regarding his medical treatment;
(2) that it is lawful, and in Charlie's best interests, for artificial ventilation to be withdrawn;
(3) that it is lawful, and in Charlie's best interests, for his treating clinicians to provide him with palliative care only; and
(4) that it is lawful, and in Charlie's best interests, not to undergo nucleoside therapy provided always that the measures and treatments adopted are the most compatible with maintaining Charlie's dignity.

28 I have already indicated that I have acceded to the applications made by the hospital.

29 Plainly, by reason of his age, it is not in issue that Charlie lacks capacity to make decisions regarding his medical treatment. However, Charlie's parents,

Constance Yates and Chris Gard, oppose the other orders that are sought by the applicants. In this judgment, I shall refer to Charlie's parents, respectively, as "the mother" and "the father".

The proceedings

30 The matter originally came before the court on 3rd March this year when I adjourned the applications and listed them for final hearing on 3rd April 2017.

31 On 3rd March, I also made an order joining Charlie as a party to the proceedings and a Guardian was appointed from the CAFCASS High Court Team, pursuant to rules 16.2 and 16.4 of the Family Procedure Rules 2010. I also gave directions for the disclosure of evidence and the filing of statements.

I also made an order on that date that the applicants should generally furnish such treatment and nursing care as may be appropriate to ensure that Charlie suffers the least distress and retains the greatest dignity consistent, insofar as possible, with maintaining life until the final hearing.

32 By agreement, the court also made a declaration on that date that Charlie lacks capacity to make medical treatment decisions relating to any need he may have for treatment.

33 On 28th March, I gave permission to the mother and the father to obtain independent expert evidence from a Consultant Paediatric Neurologist as to Charlie's clinical condition. The report was due to be filed no later than 31st March, but, in the event, was produced on the second day of this hearing (5th April). In the light of the serious issues raised in this case, I was plainly not going to allow any point to be taken about the late submission of the report.

34 Since the case was originally listed, the nature and the scope of the issues have grown and in the event the hearing took place on 3rd, 5th and 7th April with me giving judgment today on 11th April.

The Law

35 I think it is helpful if, at the outset of this judgment, I set out what the nature and scope of my responsibilities are by reference to the applicable legal principles.

36 As I have said, by reason of his age and his condition, Charlie lacks capacity to consent to or refuse medical treatment. Some people might ask why the court becomes involved at all, why should the parents not be the ones to decide? A child's parents having parental responsibility have the power to give consent

for their child to undergo treatment, but overriding control is vested in the court exercising its independent and objective judgment in the child's best interests. This principle has been enunciated in many cases over the years, including by Ward LJ in *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR at p.480.

37 The relevant legal principles which guide the exercise of jurisdiction by the Court of Protection are well settled. It is important that I stress that I am not applying a subjective test. I am not saying what I would do in a given situation; I am applying the law.

38 In *Wyatt v. Portsmouth NHS Trust* [2000] 1 FLR 554, the Court of Appeal set out what it referred to as the "intellectual milestones" for a Judge making a decision of the kind with which I am faced today. They said as follows:

> "In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. The term 'best interests' encompasses medical, emotional, and all other welfare issues. The court must conduct a balancing exercise in which all the relevant factors are weighed and a helpful way of undertaking this exercise is to draw up a balance sheet."

39 The nature of these milestones was elaborated upon by Holman J in *An NHS Trust v. MB (A Child represented by CAFCASS as Guardian ad Litem)* [2006] 2 FLR 319. He said as follows:

"(i) As a dispute has arisen between the treating doctors and the parents, and one, and now both, parties have asked the court to make a decision, it is the role and duty of the court to do so and to exercise its own independent and objective judgment.
(ii) The right and power of the court to do so only arises because the patient, in this case because he is a child, lacks the capacity to make a decision for himself.
(iii) I am not deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.
(iv) The matter must be decided by the application of an objective approach or test.

(v) That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.

(vi) It is impossible to weigh such considerations mathematically, but the court must do the best it can to balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies.

(vii) Considerable weight (Lord Donaldson of Lymington MR referred to 'a very strong presumption') must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive; and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.

(viii) These considerations remain well expressed in the words as relatively long ago now as 1991 of Lord Donaldson of Lymington in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33 at page 46 where he said:

> 'There is without doubt a very strong presumption in favour of a course of action which will prolong life, but … it is not irrebuttable … 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… We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life …. Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.'

(ix) All these cases are very fact specific, i.e. they depend entirely on the facts of the individual case.

(x) The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very

> understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

In considering this judgment, I have had in mind all of those milestones so well elaborated by Holman J in the *MB* case.

40 I must also have regard, and I do so, to the Supreme Court judgment in *Aintree University Hospital NHS Foundation Trust v. James* [2013] UKSC 67 and in particular to the following passages:

> [19] any treatment which the doctors do decide to give must be lawful. As Lord Browne-Wilkinson put it in *Airedale NHS Trust v Bland* [1993] AC 789, which concerned the withdrawal of artificial hydration and nutrition from a man in a persistent vegetative state, '. . . the correct answer to the present case depends upon the extent of the right to continue lawfully to invade the bodily integrity of Anthony Bland without his consent. If, in the circumstances, they have no right to continue artificial feeding, they cannot be in breach of any duty by ceasing to provide such feeding'. Generally, it is the patient's consent which makes invasive medical treatment lawful."
>
> [21] "The fundamental question is whether it is lawful to give the treatment not whether it is lawful to withhold it. In *Bland* Lord Goff, with whose judgment Lord Keith and Lord Lowry expressly agreed, pointed out that the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of treatment."

41 The Supreme Court continued:

> "[22] Hence the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it.

> [39] …in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.”

42 I have also had regard to the many other cases that are in the bundle of authorities before me, but it seems to me that the cases to which I have just referred very clearly set out the guiding principles which I must have full regard to when considering Charlie’s position.

43 Having set out the legal principles which govern the decisions of the court in these difficult cases, I now turn to set out the relevant background and facts material to this case.

Relevant background

44 Charlie was born at full term and at a healthy weight on 4th August 2016. His parents report that, after the first few weeks, they noticed that he was less able to lift his head and support himself than other babies of a similar age. They visited their GP and, by 2nd October, it was reported that Charlie was not gaining any weight, despite being breastfed every two to three hours. An MRI scan was performed, an ECG carried out and an nasogastric tube was inserted giving Charlie a high calorie formula which increased his weight.

45 By 11th October, Charlie had become lethargic and his breathing became shallow. He was transferred to the Great Ormond Street Hospital for Children on 11th October and has remained there ever since.

46 Charlie’s parents have stayed with him throughout the time that he has been at the hospital and they have been provided with family accommodation close to the site, so that they can be with him as much as possible. The father would usually arrive on the ward at about 9.30am and stay until at least midnight. The mother would usually arrive on the ward at about 11.30am and stay until three or four o’clock in the morning. The mother said in court that she had spent some 3,200 hours with Charlie since he was born.

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.

48 Charlie’s parents accept that his present quality of life is one that is not worth sustaining. As his mother bravely put it, “We would not fight for the quality of life he has now”. However, as I shall set out in more detail later in this judgment, they wish to take him to the United States for nucleoside therapy treatment.

49 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.

The Medical Evidence presented by Great Ormond Street Hospital

50 I remind everybody that none of the treating doctors or relevant medical personnel are to be named in any reporting of this case and, in due course, a transcript of this judgment will be obtained and anonymised.

51 The principal witness on behalf of Great Ormond Street Hospital was Professor A. In her report, as amplified by her oral evidence, she set out the details of Charlie’s condition.

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.

55 Professor A is one of the leading experts in the world with a special interest in mitochondrial diseases. She has written approaching 140 scientific articles and book chapters about mitochondrial disease and, yet, even with twenty-five years' experience and an internationally recognised expertise, she told the court that she has only been involved with six paediatric cases including Charlie and only three of these had infantile onset. Tragically, Charlie has infantile onset RRM2B deficiency which is the most severe form.

56 Professor A first because aware of Charlie's case on Tuesday, 25th October 2016. Although mitochondrial disease was already strongly suspected, investigations were carried out including blood and urine tests, a series of genetic investigations and muscle biopsy. The amount of mitochondrial DNA was determined in the muscle biopsy and reveals that Charlie had just 6% of the levels found in age matched, healthy, controlled subjects. Professor A's clear opinion is that this level will have progressively reduced since then. The definition of MDDS is having less than 35% of controlled levels indicating that 6% is very low and this enabled Professor A and her team to diagnose Charlie as having MDDS.

57 In mid-November 2016, Charlie had a genetic test known as Rapid Genome Sequencing. This was carried out as part of a research project and is not generally available on the NHS, but it shows the biallelic RRM2B mutations and these were subsequently confirmed by the NHS molecular genetics laboratory at the Oxford University Hospital NHS Foundation Trust. Accordingly, there is no doubt about Charlie's diagnosis.

58 The court has also been assisted by the written and oral evidence of Dr. B, who is employed as a Consultant Paediatric Intensivist on the Paediatric and Neonatal Intensive Care Unit at Great Ormond Street Hospital. He has been in his post since February 2004. He described Charlie's severe symptoms as follows:

- Progressive respiratory failure
  Charlie has been ventilator dependent since presentation at the Great Ormond Street Hospital and this has progressed so severely that he now has no spontaneous respiratory effect. In other words, he is kept alive by the ventilator.

- Hypotonia/Myopathy
  Charlie has progressive weakness of his muscles including his breathing muscles leading to his progressive respiratory failure. He can no longer move his arms or legs and he is not consistently able to open his eyes enough to be able to see. Indeed, this leads to the difficulty that his brain is failing to learn to see. He cannot react in terms of reaching for fingers or other objects. He cannot grasp them.

- Brain Activity
  Dr. B confirmed that, whilst Charlie is not brain dead, he is persistently encephalopathic. In other words, there are no usual signs of normal brain activities such as responsiveness, interaction or crying. Dr. B confirmed that this is supported by repeated electrical tests in the form of EEGs.

- Bilateral profound sensorineural hearing loss
  Charlie is deaf as part of this underlying condition.

- Persistently elevated lactate
  This is, I was told, the characteristic feature of mitochondrial disease. It was indeed the strongest pointer to this diagnosis in Charlie when he first came to Great Ormond Street. Charlie suffers also from acute mitochondrial crises.

59 Dr. B explained in his oral evidence that, even before Charlie began to suffer from seizures on 15th December 2016, the clinical consensus was that his quality of life was so poor that he should not be subject to long term ventilation, resulting in the advice of the Ethics Committee in November 2016 not to offer Charlie a tracheostomy. Dr. B said that, since that time, Charlie has suffered significant deterioration in brain function evidenced by the development of persistent seizures.

60 A large number of second opinions from world leading authorities have been obtained. Dr. C, Consultant in Paediatric Intensive Care at St. Mary's Hospital, concluded that Charlie suffers from a severe and progressive myopathy due to a genetic disorder with mitochondrial DNA. He continued that, "sadly, Charlie's life is therefore limited both in quality and quantity and

there is no reasonable prospect for recovery" and, in his view, the severity of his condition is such that it could be argued that Charlie would derive no benefit from continued life. His view is that it would be reasonable and in accordance with current Royal College of Paediatrics and Child Health guidance to withdraw life sustaining treatment.

61 As I have already noted, Charlie's parents both believe and have said that his present life is not worth sustaining unless treatment is available.

62 Dr. D, Consultant Respiratory Paediatrician at Southampton Hospital, has provided an opinion on the benefits or otherwise of inserting a tracheostomy. She agreed with the opinion of the team at Great Ormond Street Hospital that this would not be in Charlie's best interests given his current clinical state. She also stated that placing a tracheostomy would be contradictory to the previously agreed medical and ethical recommendation.

63 The court has also been provided with a letter from Dr. E, Consultant and Senior Lecturer in Paediatric Neurology at the Newcastle Upon Tyne NHS Foundation Trust. Dr. E specialises in rare mitochondrial disorders and is regarded as a world expert in the subject. He referred, in particular, to the fact that Charlie has developed an epileptic encephalopathy, which has been detailed on several EEGs, some of which have been prolonged recordings capturing a wealth of neurophysiological data on Charlie whilst awake and asleep as well as during seizures. Dr. E said this:

> "Indeed, the most recent EEG performed on 10th January 2017 was very similar to that recorded in December 2016 and which was indicative of a severe epileptic encephalopathy with frequent sub-clinical seizure activity. Subsequent to Charlie's initial cranial MRI scan performed on 7th October 2016, he has had two further scans on 19th October and 6th January 2017. The most recent of these does not show any major pathology, but does reveal some subtle increased signal in the subcortical white matter of the occipital lobes. This would be a typical finding in patients with mitochondrial DNA depletion syndrome."

64 Dr. E reviewed Charlie on 20th January this year. He noted that at the time of his examination the only spontaneous movements were some perioral mouthing. He said that some of these seemed to be in response to nailbed pressure or supraorbital pressure, but some of them seemed to occur spontaneously. He reported that Charlie had no anti-gravity movement in his limbs and that there was no spontaneous movement of his fingers, hands, toes or feet. Furthermore, there was no spontaneous eye opening. He reported the pupils were equal and briskly reacted to light.

65 Dr. E confirmed the clear diagnosis that has already been made that Charlie suffers from a severe form of MDDS due to heterozygous mutations in the RRM2B gene. He said that this condition is associated with a dire prognosis of relentless progressive neurodegeneration. He confirmed that the most recent cranial MRI indicates some degree of increased signal in occipital white matter. He concluded that Charlie is in a parlous state; that he has multi-system involvement with brain, muscle and renal dysfunction. He said that Charlie's brain and muscle involvement is profound and that he has a severe epileptic encephalopathy.

66 I have also had the benefit of a report in the form of a letter from Dr. F, Consultant Paediatric Neurologist at St. Mary's Hospital. She concluded that Charlie's diagnosis is unfortunately that of a progressive and life limiting condition. The involvement of multiple systems in combination with clinical findings and being ventilator dependent, she concluded, are all poor prognostic signs.

67 I have had the benefit of a witness statement of Ms G, who is a sister on the Neonatal Intensive Care Unit at Great Ormond Street Hospital. I have taken into account everything that she says.

68 I heard oral evidence from Ms H, who is employed as a staff nurse working exclusively in the Neonatal Intensive Care Unit at Great Ormond Street Hospital. She described how, since December 2016, she has spent over two hundred hours in Charlie's bed space often with his parents present. She said that she had not seen evidence of Charlie responding to his parents. She had not seen him grasp his mother's fingers nor had she seen him touch or grasp her fingers. She said that it was impossible to tell if Charlie is awake or asleep. She said that it is impossible to know whether Charlie suffers pain, pleasure or comfort.

69 Ms. H gave a detailed diary of her shifts caring for Charlie, all of which I have read and taken into account but do not repeat in detail for the purposes of this judgment. She said that comparing her first shift to the most recent shift looking after Charlie, the only real change from a nursing point of view has been that he now needs four different types of seizure medication. She said that, even though Charlie has been putting on weight, he has not been clinically improving at all.

Nucleoside Therapy

70 The parents in this case have done what any parent would do for their child. They have searched far and wide for the possibility of a cure or, if a cure is not

available, treatment that would prolong life or even slightly improve the condition.

71 In the course of her researches, the mother came across reference to nucleoside treatment which it is agreed has been used on patients with a different and less severe mitochondrial condition known as TK2 mutation. This primarily causes myopathy, but does not affect the brain in the majority of cases. There is some evidence that patients with TK2 mutation have benefited from nucleoside therapy.

72 In late December 2016, a fellow parent with whom the mother had been in contact had discussed the nucleoside therapy which his child was receiving and emailed a Dr. I, Professor of Neurology at a Medical Center in the USA, suggesting that the nucleoside therapy regime might also help patients with RRM2B deficiency.

73 It is accepted amongst all of the medics from whom I have heard and whose papers I have read that in order to assist with the latter, that is RRM2B, the drugs would have to cross what is known as the blood/brain barrier allowing the medication to work on cells in the brain in the same way as in the rest of the body.

74 Understandably, having heard about this possibility, the mother wanted to follow it up. The day after he received the email, Dr. I confirmed that nucleoside therapy had not been used on either mice or humans with RRM2B mutation; but said that, hypothetically, the administration of three of the possible four phosphates might be beneficial. Dr. I acknowledged that he was giving this advice on the basis of scant data, but considered that the treatment might be reasonable in view of Charlie's dire condition.

75 Accordingly, Charlie's information was conveyed to Dr. I electronically and the same day, 30th December 2016, Dr. I and Professor A spoke. This was an unofficial conversation and there is no record of it, but Professor A indicated that Dr. I agreed during this conversation that the therapy was unlikely to help Charlie's severe neurological disease.

76 In any event, Professor A emailed Dr. I with four essential questions and I now turn to set out those questions and the answers that were given.

- Question 1: "What is the evidence that this treatment might help?"

  Dr. I's response: "There is no direct evidence, but there is a theoretical scientific basis for saying it could."

- Question 2: “Could the drugs cause toxicity?”

  Dr. I’s response: “The only toxicity seen is dose related diarrhoea”.

- Question 3: “As the drugs do not cross the blood/brain barrier, is there any possibility of efficacy in a child with an epileptic encephalopathy?”

  Dr. I’s response: “This had been previously suggested in published research, but there is theoretical and anecdotal evidence that the drugs could in fact cross this barrier and, therefore, have effect on the brain. In particular, TK2 patients who have been treated have not developed seizures or encephalopathy’s as had those who were not treated.”

- Question 4: “If we were to embark on a clinical trial, how long would you suggest and what outcome measures?”

  Dr. I’s response: “A three month trial should be sufficient and a range of outcome measures suggested.”

There is a note there which says “It is worth noting that Dr I suggested a range of non-invasive measures preferable to more invasive ones, such as a further MRI brain scan”.

77 A telephone conference was arranged between Professor A, Dr. B, Dr. J, Consultant Metabolic Paediatrician, and Dr I. In an email shortly after that discussion, Dr. I confirmed that there was a “theoretical possibility” of the nucleoside treatment being of some benefit to Charlie. However, he made it clear that a baseline MRI was necessary as severe brain involvement was a contraindication to the therapy being trialled.

78 The parents have been supplied with literally thousands of pages of notes that relate to Charlie’s case. Reference has been made to a limited number of these notes and I have re-read them before giving this judgment.

79 Following the aforementioned telephone conference with Dr. I, a further MRI was performed and appeared to show no structural damage. Indeed, a note on 9th January 2017 stated that Charlie will go in the next weeks for nucleoside treatment. Professor A drafted an application to the Ethics Committee so that this could be considered in England and there was a provisional placing on the list for a tracheostomy to be performed on Charlie on 16th January 2017.

80 Whatever the reasons for it, there appears to have been some level of misunderstanding or disagreement between the parents and the hospital.

Professor A told me, and I completely accept as correct, that funding was never an issue and that if the view had been taken that nucleoside therapy would be of benefit to Charlie then it would have gone ahead. This is contrary to the view that may be formed by others in the context of the parents' passionate and successful appeal to members of the public to provide funding for treatment in America.

81 I should say that the issue of funding has not formed any significant part of this hearing, although I understand from press reports that the funding target of £1.2million has been met or possibly exceeded. It is imperative that I make clear that this case is not about money and, if anyone were to suggest that Charlie would have nucleoside treatment but for the cost, they would be completely wrong.

82 It is apparent that Charlie experienced a further episode of seizure activity, which started on around 9th or 10th January and continued intermittently until 27th January. Accordingly, the Ethics Committee meeting which had been planned for 13th January was postponed because of increased seizure frequency and likely severe epileptic encephalopathy.

83 On 13th January, Charlie's consultant neurologist, Dr K, and his ICU Consultant had a meeting with Charlie's parents. Dr. K informed the parents that Charlie was suffering severe epileptic encephalopathy and that all teams agreed that the treatment of nucleoside would be futile and would only prolong Charlie's suffering. This was, I find, a most significant meeting.

84 There is an unfortunate email from Dr. B to Dr. E which included the words "parents are spanner in the works. Recent deterioration with worsening seizures means trial is not in his best interests". I can understand how distressing it must have been for the parents to read this email when they were later shown the hospital records. However, in my judgment, it is important to view this comment in its proper context. The context was private notes passing between two eminent consultants about what was in Charlie's best interests.

85 I heard lengthy evidence from Dr. B, who was cross examined in some detail and with great care and expertise by Ms. Roper on behalf of the parents. It is absolutely clear to me, and I so find, that Dr. B had Charlie's best interests at heart, both when he was giving his evidence and also when he wrote that email to Dr. E, however much he may now wish that he had phrased it differently.

86 Of course, had he known that the email would have been read by the parents, he would have worded it differently. But the clear meaning which he intended to convey, and in my judgment properly intended to convey, was that it was no longer in Charlie's best interests to be subjected to nucleoside therapy; but that

the difficulty with this decision lay in the fact that Charlie's parents were still pursuing this path. In my judgment, Dr. B showed through his evidence that he is a dedicated Consultant Paediatric Intensivist operating with immense skill and compassion at the very highest level of medicine in this country and I reject any criticism that may have been made of him during these proceedings.

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.

91 As I have already indicated, I gave the parents permission to instruct their own expert. Accordingly, the parents instructed Dr. L, Consultant Paediatric

Neurologist at Southampton General Hospital. I have the benefit of his reported dated 4th April. Dr. L concluded his report by saying that

> "The nature of Charlie's condition means that he is likely to continue to deteriorate, that he is likely to remain immobile, that he will exhibit severe cognitive impairment, that he will remain dependent on ventilatory support to maintain respiration, will continue to need to be tube fed and that he will always be dependent on mechanical ventilation to maintain life."

92 In almost every material respect, Dr. L's conclusions coincided with the reports to which I have already referred in this judgment. Tragically for these loving parents, their own instructed expert was able to offer nothing at all to support their case.

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.

<u>Dr. I</u>

94 Against all of the above tragic background, I come next to analyse the evidence of Dr. I who is the only expert in this case who has been suggesting that there is any potential benefit in nucleoside therapy. Although Dr. I has not seen Charlie, he has, as I have indicated above, had full access to his medical records.

95 In his letter dated 23rd March 2017, Dr. I referred to the fact that treatment of the TK2 mutant mice with nucleoside therapy had improved the mice. He referred to the fact that his international collaborators in Spain, Italy, Central South America and he had treated seventeen TK2 deficiency patients with nucleoside therapy. He pointed out that these collaborators had 22.9 years of cumulative experience with this therapy and that he had personally initiated therapy for patients.

96 He said that all eighteen patients are alive and continuing therapy. In 13 out of 14 of them, body mass index increased. One patient was able to walk at baseline and, after four years, became able to walk 320 metres. It is, however, crucial in this context to understand that, in his letter, Dr. I was talking about patients with TK2 and not RRM2B. In respect of the latter, he said this:

> “Given the lack of data on this treatment in an animal model or RRM2B patients, I cannot predict the outcome, although there is scientific rationale that the treatment could potentially ameliorate RRM2B deficiency.”

He said that the treatments cross biological barriers including the blood/brain barrier.

97 Dr. I kindly made himself available to give evidence by telephone and, indeed, cancelled a significant lecture that he was due to give in order to assist this court and I am grateful to him.

98 On the first day of this hearing I suggested that Professor A and Dr. I spoke, if possible, by telephone to see whether they could reach any form of consensus or at least narrow any issues between them. I have the notes of that telephone conversation. The conversation started by Dr. I being asked whether he had seen the most recent EEG for Charlie. Dr. I confirmed that he had received the results that very morning. He said the following:

> “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.”

99 However, he made it clear that, were Charlie in the US, he would treat him, although he would defer to “ICU people” (as he called them) to make the decision. He was asked this question:

> “You understand that the nucleoside part was a secondary part and that the main reason for the application to the court is that we believe he is suffering and has no hope of improving. So we have primarily applied for active ventilator support/proactive ventilator support to be withdrawn.”

To this Dr. I replied:

> "Perhaps, if I were there, I would support it. Not seeing the child, not seeing progression, it's difficult for me to make an assessment."

100 Dr. I also confirmed during this telephone conversation that he had never treated anyone who had encephalopathy. Therefore, he was unable to indicate whether a patient with encephalopathy would respond.

101 In giving evidence to the court by telephone, Dr. I said that in the RRM2B mutation the nuclear DNA is affected, but the effect of the nucleoside therapy means that the job is done in a different way. He said that he is not certain that it is effective with RRM2B, but it should be in theory. He confirmed that it was purely theoretical and that there was no clinical evidence to support the theory. He also volunteered that TK2 does not generally affect the brain. He said that there was no direct evidence that nucleoside therapy has had any beneficial effect on the brain of TK2 patients, although he thought that there is a high chance of some penetration to the brain but he could not say whether it would be sufficient. He admitted that nucleoside therapy could not affect structural damage to the brain. He also said that the drug was more likely to cross the brain barrier in a newborn baby than a baby over eight months old, such as Charlie.

102 In relation to the experiments on TK2 mice, he said that there is evidence of an increased lifespan from between 13 and 36 days against a normal mouse lifespan of two years. In other words, he said this was a little over 4% of normal lifespan.

103 Dr. I said that he had treated four patients directly and that he had been indirectly involved with fourteen others. He said that there were no published case studies, although he did have a manuscript. Of the four that had been treated, none were infants the time when the therapy started. Of the other fourteen, he believed that one or two were infants. None of the fourteen had encephalopathy or seizures and fewer than 10% of them had brain involvement, so he agreed that it was not in any way a reliable statistic.

104 Crucially, Dr. I said that, having seen the 30th March EEG, the damage to Charlie's brain was more severe than he had thought. He said that he thought that 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.

105 Dr. I was asked by Ms. Powell on behalf of the Great Ormond Street Hospital what level of functioning could reasonably be expected. He said that the main functioning would be improvement of weakness and that some patients had improved their upper strength and four of eight patients had been able to reduce their time on ventilators, but he agreed that the effect on brain function would be less or minimal or non-existent. He said that 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 unchartered 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.

106 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 to life expectancy, it almost certainly could not undo structural brain damage.

The Position of the Parents

107 There is no doubt, of course, that the parents know Charlie immeasurably better than anybody else does, professional or otherwise. The mother calculated that she had spent some 3,200 hours in his company since he was born and I dare say that the father has spent, more or less, the same number of hours in Charlie's company and I have already set out above the dedicated hours that the mother and father have spent with their son of whom they are rightly so proud.

108 The parents do not accept that Charlie is as bad as reported by the medics in this case. The father was the first of the parents to give oral evidence and he did so with immense bravery and dignity. The father explained that, if Charlie is looking at him, if he put a toy in front of his face, Charlie tries to open his eyes more and hold his hands and will know who they are.

109 The father was adamant that Charlie could sense when he and/or the mother were with him. He said that if, for example, Charlie needs a suction of his nasal drain, his heart rate would go up. He said that there were things that he did not like, for example, having a suction or a heal prick. He said that, although Charlie was unable to cough, he had a way of moving his tongue about which was similar to coughing.

110 He and Charlie's mother were vying for the chance, he said, to give Charlie the treatment that he needs so that he could possibly improve. He said that if there was no chance of it working then he would not be insisting on it. He said:

> "We aren't fighting because we cannot bear to lose him. He's my boy. It's what's best for him. His doctors have let him seize for seven or eight hours without medication. I would do anything for him. He deserves his chance. We would not fight for the quality of life he has now. We firmly believe that he was sent to us as we are the only ones who look after him. We truly believe that these medicines will work. After three months we would want to see improvement and, if there wasn't, we would let go. This is not the life we want for Charlie. A chance to keep fighting, he deserves that chance. We are doing this for him."

111 The mother, in essence, confirmed the evidence that the father had already given. She said that she thinks that Charlie responds to her, that he can feel pleasure, that he enjoys tickles. She was able to report that he does not like his feet being tickled because he opened his eyes when she does it. He prefers a stroke to the head. She, too, said that she would like to give Charlie a chance to improve by having the nucleoside treatment. She said that she would not be here now if she knew that it would go nowhere. She knows that it is a treatment and not a cure.

112 Crucially, she said that she did not think that Charlie's brain function is as bad as everyone else is saying. She denied that Charlie did not have a sleep/wake cycle. She said that she knows full well when he is awake and when he is asleep. She said that he was on a sedative when the EEG recording was last done. She said that when he sleeps, his pulse is low and (as she put it) "he chills".

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 views 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 Position of Charlie through his Guardian

116 As I have set out above, Charlie has been joined as a party and represented by his Guardian. I am very grateful to Charlie's Guardian for the way that he has presented his evidence both in writing and through his counsel, Ms. Butler-Cole.

117 On behalf of the Guardian, Ms. Butler-Cole's closing submissions begin as follows:

> "The Guardian has listened closely to the oral evidence during the hearing this week and has concluded that it is not in Charlie's best interests to travel to America to receive nucleoside therapy. This is not pioneering or lifesaving treatment, but a purely experimental process with no real prospect of improving Charlie's condition or quality of life.
>
> The Guardian has further concluded that it is not in Charlie's best interests to continue life sustaining medical treatment. A conclusion which it is understood Charlie's parents are likely to accept if there is not to be any attempt at providing nucleoside therapy."

118 The Guardian reminded me, when I asked about the extent to which Charlie's brain damage could be improved, that Dr. I had said "I think to a large extent it is irreversible, but I cannot say it is completely irreversible". The Guardian also reminds me that there is no direct evidence to suggest that nucleoside therapy has a positive effect in cases of RRM2B mutation. Nucleoside therapy has never been used on any patient with that mutation nor, as I have said, even tested on an animal model.

119 This evidence prompted me to ask the question as to whether it would be worth giving it a try on the basis that, without experimentation, medicine cannot advance. The answer to this is now very clear in my mind. 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.

120 As the Guardian put it, even if the treatment was to enter Charlie's brain and have a therapeutic effect, the highest point of the evidence (Dr. I) was that if Charlie's seizures were controlled he would presumably be able to interact with others, to smile, to look at objects and to use his hands to grab objects. This evidence was not, as the Guardian put it, obviously consistent with the view expressed a little later in Dr. I's evidence that he thought that Charlie's brain damage was to a large extent irreversible, nor to Dr. I's acceptance of the fact that Charlie was not responsive prior to developing seizures and that that was suggestive of underlying irreversible brain damage.

121 Against that, there is the serious prospect - in Professor A's view a likelihood - that Charlie does feel pain, even though he may be unable to express his reaction to pain. The Guardian's view is that it cannot be in Charlie's best interests to subject to him to experimentation and the pain that this will cause in circumstances where there is no prospect of benefit. But, moreover, it is clear to me that the legal test which I have to apply is what is in Charlie's best interests not what is in the best interests of medical experimentation.

122 The Guardian submitted that, although Charlie's parents were understandably confident that Charlie does display purposeful movements and behaviour, medical evidence is to be preferred. Crucially, however, Charlie's parents accept that his current quality of life is not good and that they would not seek that it should be sustained without hope of improvement.

My Decision

123 I have already indicated my decision that I intend to grant the applications which have been brought by Great Ormond Street Hospital.

124 Ms. Roper on behalf of the parents submitted to me that the case law does not contain any analogous examples of cases where life sustaining treatment has been withdrawn, even from a profoundly disabled child with a desperately poor quality of life, where there is an available treatment which has the potential materially to improve that quality of life. In my judgment, it is putting it far too high to say that there is an available treatment with potential materially to improve Charlie's quality of life.

125 Ms. Roper also referred me to the judgment of Dame Elizabeth Butler-Sloss in the case of *Simms* [2002] EWHC 2734. At para.61, Dame Elizabeth Butler-Sloss said this:

> "I am satisfied from all the evidence that both JS and JA have a life that is worth preserving and that any treatment that might be beneficial would be of value to them. It has to be recognised that the treatment proposed for these two patients would not lead to recovery. Nonetheless, on the totality of the medical evidence I find that that there are possible benefits both to JS and JA from this pioneering treatment. The chance of improvement is slight but not non-existent."

Later, in the same paragraph, the Judge noted that:

> "There is undoubtedly evidence that there is some value to their lives."

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 to 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 interests 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.

130 I end with this procedural note: I have already expressed the opinion that I believe that it would, in all cases like this, be helpful for there to be some form of Issues Resolution Hearing or other form of mediation where the parties can have confidential conversations to see what common ground can be reached between them. I believe that that type of hearing, be it Judge led or some other form of private mediation, would have led to a greater understanding between the parents and the clinical team in this case. I am not saying that it would necessarily have led to a resolution, but I think in many such cases it would and I would like to think that in future cases like this such attempts can be made.