

**IN THE HIGH COURT OF JUSTICE  
FAMILY DIVISION**

**CASE NUMBER FD17P00358**

**IN THE MATTER OF THE INHERENT JURISDICTION OF THE HIGH COURT  
AND IN THE MATTER OF CHARLES GARD (DOB 04/08/2016)  
BETWEEN**

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

**APPLICANT**

**AND**

**(1) CONSTANCE YATES  
(2) CHRISTOPHER GARD  
(3) CHARLIE GARD  
(BY HIS GUARDIAN)**

**RESPONDENTS**

**POSITION STATEMENT  
ON BEHALF OF THE PARENTS  
HEARING 24 & 25 JULY 2017**

1. This case is listed for the parents' application for the reconsideration of the Order made on 11 April 2017 based on the three points set out in the earlier position statement:

- (i) New evidence;
- (ii) New appreciation of existing evidence in the light of new evidence; and
- (iii) New legal and factual submissions based on that evidence.

2. In addition to the letter dated 6 July 2017 signed by the 7 international researchers, the Court has heard/read by way of evidence:

- (i) The discussion between experts on 4 July 2017;
- (ii) Witness statements from:
  - (1) Professor B, and
  - (2) Dr M;

- (iii) The written answers to questions put to Professor Hirano;
  - (iv) Oral evidence from Professor Hirano on 13 July 2017;
  - (v) Letters from Neurology Consultants of X P.C and Letter from X Children's Hospital (MD, Chief of the Division of Epilepsy and Clinical Neurophysiology at the X Children's Hospital) in relation to Charlie's MRIs / EEGs confirming there to be no evidence before the Court of irreversible structural brain damage as at April 2017.
- 3. Based on the information provided to them by GOSH, Professor Hirano and Dr M and others explained their proposed treatment for Charlie.
- 4. In summary, the new evidence offered prospects of:
  - (i) Muscle recovery;
  - (ii) Reduced use of artificial ventilation;
  - (iii) NBT crossing the Brain Blood Barrier;
  - (iv) A small but significant chance of ameliorating Charlie's brain function.
- 5. The new evidence included information based on research and the evaluation of research. Professor Hirano expressed chances and did so on a conservative basis.

6. Last Sunday Charlie underwent an EEG and brain MRI. Following careful consideration of the raw data the parents' team of independent international experts (including Professor Hirano who can properly be regarded as one of the world leaders in mitochondrial depletion diseases) remained willing to offer and/or endorse NBT treatment for Charlie.
7. Professor Hirano, Professor B and Dr M – who are busy and world-renowned experts in mitochondrial diseases – took time out of their diaries to travel to London to examine Charlie on Monday 17 July 2017 and to meet with the treating team at Great Ormond Street on the following day.
8. At that MDT meeting on Tuesday 18 July 2017, both Professor Hirano and Professor B (having considered Charlie's head MRI and EEG of the previous week) remained of the view that it was in Charlie's best interests for him to be provided with NBT. They remained willing to treat Charlie with NBT at their respective hospitals.
9. That remained the case when the parties were at Court on Friday 21 July 2017 dealing with final directions for the case.
10. Professor B would have returned to this country on Monday 24 July 2017 to give evidence had this case continued and Professor Hirano made himself available to give further evidence if necessary. Arrangements were also being made for Dr M to give evidence.
11. There were additionally proposals (for the directions hearing on Friday) to limit the case only to the simple issues:
  - (i) Is there any new evidence about the chance of NBT providing Charlie with more brain function than he has now?
  - (ii) If there is, is NBT in Charlie's best interests?

12. The body MRI was carried on Thursday 20 July 2017 at the request of Professor Hirano. Professor Hirano and Professor B considered that analysis of the muscle was important, or even determinative as to whether they would be willing to offer the therapy.
  13. It was the international team not GOSH who had considered that further testing was required:
    - (i) No head MRI had been carried out since January 2017.
    - (ii) No whole-body scan (whether ultrasound or MRI) had ever been carried out on Charlie or proposed by GOSH.
- Neither had been considered necessary by GOSH for the management of Charlie's condition.
14. Following receipt. these latest body MRI images were relayed to the parents' independent panel of international experts. They were reviewed by Professor Hirano and his professional colleagues after the hearing. Similarly, and independently, Professor B in Rome carried an examination of the scans together with his team.
  15. The parents, having considered and discussed the raw data and reports of Charlie's body MRI with Professor Hirano, Professor B and their legal team, are naturally extremely distressed by the results.
  16. Unfortunately, although treatment with NBT was first proposed by the parents in November 2016 and apparently considered by GOSH in January 2017 he has not received this treatment<sup>1</sup> the course of his mitochondrial disease is such that he has suffered extensive muscle atrophy throughout his body.

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<sup>1</sup> An innocuous powder proposed to be put in Charlie's milk who's only known side effect is diarrhoea.

17. Sadly (unlike the condition of Charlie's brain as at April 2017) this damage is irreversible even with NBT.
18. The conclusion reached was that the chances of improvement of muscle function which the treatment had promised (had NBT been provided to Charlie earlier as sought by the parents) cannot now be delivered because there is insufficient muscle tissue for the treatment to now be effective. For Charlie, it is now too late.
19. Having given the case the most anxious consideration with their expert clinicians, the parents recognise that due to the delay in providing Charlie with the nucleoside treatment his muscle condition has deteriorated and the proposed NBT no longer offers a chance of a meaningful recovery to Charlie. It is now no longer in Charlie's best interests to pursue this course of treatment due to his severe muscle atrophy.
20. The parents' legal position and decision that Charlie should receive NBT has always been based on the available evidence of the efficacy of NBT and that it was in his best interests to receive treatment.
21. The issues between the parties as set out in their schedule of evidence filed on behalf of the parents for the hearing on 13 July 2017 include: -
  - (i) That there would be almost 100% chance of NBT crossing the BBB.
  - (ii) That TK2 mouse models provide an analogous scientific rationale for efficacy of NBT in RRM2B patients.
  - (iii) Charlie's January 2017 MRI and EEG showed no evidence of 'irreversible structural brain damage' a position supported by 2 independent expert reports (the authors not being associated to any of the signatories of the letter dated 6 July 2017) and the

raw EEG and MRI data (not disclosed by GOSH before the trial in April) as examined and confirmed by Professor Hirano and Professor B.

(iv) Charlie's neurological condition now is in fact still considerably better (showing there to be no brain death) than the witness evidence presented to this Court by GOSH in April 2017.

22. The application and the proper interests of justice would have required investigation and scrutiny of these matters by this Court.

23. However sadly following the body MRI the parents' worst fears have now been confirmed by their team of international experts that it is now too late to treat Charlie.

24. Given that it is no longer in Charlie's best interests to receive NBT the parents withdraw their Application dated 10 July 2017.

25. During the course of the weekend a communication was made to the Court and to the legal representatives confirming the parents' position.

26. Having made this most painful of decisions that any parents could ever be expected to make they invited the Court not to make any public pronouncement at this point and to confirm that there should be no disclosure of this decision and no publicity of this decision prior to formal announcement in Court.

27. Understandably the parents wish to spend the maximum amount of time they have left with Charlie from now on.

28. The parents have accepted GOSH's invitation for mediation and this has taken place instead of the Court hearing on Monday morning in an effort to resolve the consequential steps that must now be taken in light of the parents'

decision.

29. Any parent would have wished to fight as strongly as Connie and Chris have fought to protect Charlie's best interests and in particular his right to receive appropriate medical treatment, few of us would have had the courage and determination to do so:-

- (i) The parents have always fought for a chance for Charlie to have an improved quality of life, to smile again, learn to walk, talk and live out his life sharing the enjoyment of his family life.
- (ii) Charlie's parents have fought to preserve Charlie's life as long as they have because they were convinced on the basis of the scientific evidence of their international and world-renowned experts in mitochondrial disease that it was in his best interests to do so.
- (iii) They believe that they ought to have been entrusted with the decision (as supported by scientific rationale and their international and world-renowned experts in mitochondrial disease) as to what was in their own child's best interests and fought this in the Courts as long as they were permitted to do so. They believe that they like any parents / patients ought to be able to choose between proposed courses of treatment offered by different reputable clinicians, more so when one avenue leads to certain death.
- (iv) Having lost that legal battle they wished to ensure that there was no realistic chance of being able to give Charlie a meaningful life and agreed for further EEG and MRIs to be undertaken.
- (v) Up to time the body MRI scans were received last Friday they had been advised of new compelling evidence that subject to

one further medical ultrasound scan there was a meaningful prospect (estimated by Professor Hirano of between 10-56%) of giving Charlie that chance of muscle recovery.

(vi) However, once it was established that there was no medical prospect of being able to give Charlie that chance, they accepted legal advice that they had no option but to withdraw their defence to the claim brought by GOSH that it should be permitted to withdraw treatment with the necessary consequence of terminating Charlie's life.

(vii) At no stage did they believe that their continued efforts to protect Charlie's life would cause him pain. Before the Supreme Court GOSH accepted that they did not know one way or the other whether Charlie experienced pain. As acknowledged by the parents' international experts Charlie show tachycardia responses to induced pain evidencing that as like most of us he is not in a continuous state of pain but rather responds to stimulation of pain.

30. The parents recognise the fact that Charlie's case has generated huge controversy. Now that this position has been reached, it is unproductive to continue protests which can only have an adverse effect on the treatment of other patients at GOSH. Charlie's parents have always condemned threats aggression or violence towards those involved in this case and continue to do so.

31. Accordingly, it is regrettable and indeed worthy of a Greek Tragedy that, when on the verge of being able to satisfy this Court (by new evidence and/or a new appreciation of existing evidence) that treatment was in Charlie's best interests, the parents must, consistent with the proper exercise of their parental rights to protect their son's best interests, withdraw their Application.

32. Charlie has waited patiently and peacefully for his right to receive treatment to be realised. Sadly, due to the considerable delay in the commencement of treatment that right and the window of opportunity has been lost for Charlie.
33. However, the parents reiterate their intention to establish a Charlie Gard Foundation with the donations received. Accordingly it is now that his voice will go on to be heard as his legacy seeks to support other young children and families faced with similar circumstances.
34. Charlie's mother would like to say a few final words in Court and invites the Court's permission to do so.

**GRANT ARMSTRONG  
GERARD ROTHSCHILD**

**24 July 2017**