Neutral Citation Number: [2017] EWHC 1909 (Fam)

Case No: FD17P00103

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 24 July 2017

Before :

THE HONOURABLE MR JUSTICE FRANCIS

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Between :

GREAT ORMOND STREET HOSPITAL — **Applicant**

- and -

(1) CONSTANCE YATES
(2) CHRISTOPHER GARD
(3) CHARLIE GARD (by his Guardian) — **Respondents**

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Ms K Gollop QC (instructed by **GOSH Legal Services**) for the **Applicant**
Mr G Armstrong & Mr G Rothschild (instructed by **Harris da Silva Solicitors**) for the **Respondents**
Ms V Butler-Cole (instructed by **CAFCASS**) for the **Guardian**

Hearing dates: 10, 13, 14, 21 & 24 July 2017

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Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MR JUSTICE FRANCIS

Mr Justice Francis:

1. It is impossible for any of us to comprehend or even begin to imagine the agony to which Charlie's parents have been subjected in recent weeks and months as they have had to come to terms with the decision that they have now made. A lot of things have been said, particularly in recent days, by those who know almost nothing about this case but who feel entitled to express opinions. Many opinions have been expressed based on feelings rather than facts. My task today is to deal with the applications that are before me and to make the declarations which are now unopposed. Before I do so I must, again, pay tribute to Chris Gard and Connie Yates for the love and care which they have at all times given to their wonderful boy Charlie. I said in my judgment on 11 April that there are few, if any, stronger bonds known to humankind than the love that a parent has for his or her child; to lose a child, particularly at such a tender age, and in such tragic circumstances, is grief of a magnitude of immense proportions. These parents should know that no parent could have done more for their child. They have, however, now accepted that Charlie's life cannot be improved and that the only remaining course is for him to be given palliative care and to permit him to die with dignity.

2. By application dated 7 July 2017, Great Ormond Street Hospital for children NHS foundation trust ("Gosh") applies for the following:
"the hospital asks the court to affirm the declarations made 11/04/17 if necessary after hearing further evidence. In view of the unique situation that has developed, the hospital also asked the court to make orders in the same terms. The hospital would not normally seek orders and does so for the following reasons among others: in his judgement, Francis J said that it was in Charlie's best interests to be allowed to slip away peacefully. Decisions expressed as orders would better enable hospital to achieve that aim than would further declarations; the declarations have been interpreted by the White House, and thereafter by the parents through their solicitors, as permitting Charlie's transfer to another hospital for NBT treatment. Aside from the fact that the declarations say that treatment is not in Charlie's best interests. The hospital does not understand this line of reasoning but has no expectation that it would be possible to reach agreement about the legal effect of the declarations. Therefore orders are sought to remove any ambiguity; orders are enforceable. Despite all of the hospitals best endeavours, this appears as potentially necessary. Not for the first time the parents through their solicitors raised the prospect of criminal proceedings against the hospital and its staff. The Hospital understands that no court order best interests proceedings can afford it or its staff from prosecution."

3. On 11 April 2017, after a hearing lasting several days which included detailed oral evidence from a number of experts, including an expert independently instructed by Charlie's parents, who agreed with the experts from GOSH, and having of course heard evidence from the parents themselves, I made the following declarations:

    i. Charlie, by reason of his minority, lacks capacity to make decisions regarding his medical treatment;
    ii. it is not in Charlie's best interests for artificial ventilation to continue to be provided to and it is therefore lawful and in his best interests to be withdrawn;

iii. it is lawful and in Charlie's best interests for his treating clinicians to provide him with palliative care only;
iv. It is lawful and in Charlie's best interests not to undergo nucleoside therapy.
Provided always that the measures and treatments adopted of the most compatible with maintaining Charlie's dignity.

4. The parents asked me to give them permission to appeal this decision which I refused. The parents renewed the permission application to the Court of Appeal. The Court of Appeal gave permission to appeal on two new grounds which had not been argued before me, but then dismissed the appeal and refused permission to appeal to the Supreme Court.

5. The parents appealed to the Supreme Court and their application for permission to appeal was dismissed by the Supreme Court on 8th June.

6. The parents then appealed to the European Court of Human Rights on 19 June. The decision of the European Court was handed down on the 28 June 2017. In a comprehensive judgment, the European Court declared the application inadmissible.

7. Accordingly, the decision which I made on 11 April has been considered in detail, and upheld by three levels of appeal court and the parents' appeal remedies have been exhausted. During all the time when the parents were pursuing their various appeals, GOSH agreed to continue to treat Charlie.

8. Within a few days of the decision of the European courts, the parents' solicitors contacted GOSH asserting that there was evidence and that there was a duty to refer the matter back to the court. The new evidence which that letter asserted can be summarised as follows:

a) the Bambino Gesu Children's Hospital, Rome is willing to accept the transfer of Charlie;

b) Dr. Hirano and the associated medical centre in the USA remain willing to accept the transfer of Charlie;

c) on the basis of new laboratory findings, Dr. Hirano considers:

i) the likelihood of a positive effect and benefits to Charlie of the proposed nucleoside therapy to be markedly improved compared to the views expressed in court;

ii) the likelihood that the proposed nucleoside therapy will cross the blood brain barrier to be significantly enhanced.

9. In spite of these assertions, Dr. Hirano had still not seen Charlie.

10. The letter continued to assert that the best interests assessment and declaration have been overtaken by events and were potentially unsafe and that the best interests assessment is now weighted significantly in favour of preserving Charlie's life and providing NBT. Moreover, the case had by this stage escalated to an international

scale and had even involved President Trump, the Vatican and Theresa May. In these circumstances it is right and proper that GOSH have made this application. It is, however, tragic to reflect upon the fact that more than three months have now passed since the declaration that I made in April. During the most recent hearings I have had to balance on one hand the need to deal with this case as expeditiously as possible and on the other hand the need to give proper consideration to a very considerable amount of evidence. I am aware that the legal teams on all sides have worked tirelessly around the clock in their endeavour to assist the court.

11. From the outset of this second hearing, I made it clear that I could only change the decision that I made on 11 April on the basis of compelling new evidence. No one has sought to assert that this approach is incorrect, nor could they, given the detailed judgment that I gave in April, having considered all of the medical evidence, and the review of that judgment by the three layers of appeal to which I have already referred. I also made it clear that I could only consider the case on the basis of evidence and not on the basis of partially informed or ill-informed opinion, however eminent the source of that opinion. I made it clear that I would always listen carefully to any new and material evidence. The world of social media doubtless has very many benefits but one of its pitfalls, I suggest, is that when cases such as this go viral, the watching world feels entitled to express opinions, whether or not they are evidence-based. When I became a judge, I took the same oath that all judges in England and Wales take and I promised to do right to all manner of people after the laws and usages of this Realm. When jurors are sworn in in criminal trials they promise to try the case according to the evidence.

12. I have at all times endeavoured to remain faithful to that oath, to apply the law having heard and considered the evidence. When Dr Hirano was kind enough to give up his time to give evidence by video link to this Court some two weeks ago, I invited him to travel to England to see Charlie and this is an invitation which he was good enough to take up, doubtless at extreme inconvenience to himself and, I daresay, to other patients of his. It seems to me to be a remarkably simple proposition that if a doctor is to give evidence to this court about the prospect of effective treatment in respect of a child whose future is being considered by the court, that Dr should see the patient before the court can sensibly rely upon his evidence. My task has always been to determine what is in Charlie's best interests, not what benefit there could be to scientific research.

13. Other eminent practitioners both from GOSH and from around the world attended a multidisciplinary meeting last week on Monday 17th July. There was a considerable degree of consensus but the view was taken that further scans needed to be carried out to establish whether the position that GOSH has for some time been maintaining is correct. Last week further MRI scans were conducted of Charlie's entire body and it transpired that in some places Charlie now has no muscle at all, and in other places there is significant replacement of muscle by fat.

14. The consequences of the MRI scans were briefly referred to in court last Friday. The parents have had to face the reality, almost impossible to contemplate; that Charlie is beyond any help even from experimental treatment and that it is in his best interests for him to be allowed to die. Given the consensus that now exists between parents, the treating doctors and even Dr Hirano, it is my very sad duty to confirm the

declarations that I made in April this year, and I now formally do so. I do not make a mandatory order.

15. I remind myself, and others listening to this judgment, that the nucleoside therapy for which the parents had been contending has not even been tried on mice with the same strain of mitochondrial disease from which Charlie suffers, let alone humans.

16. There are four matters to which I feel that I need to make reference before we finish. The first is that I wish to thank all of the medical experts from whom I have heard evidence in this case. I know they have made themselves available to the court and to the parents when they were doubtless needed by other patients. Furthermore, I wish to thank all of the men and women at Great Ormond Street Hospital who have worked tirelessly since last October to treat Charlie. Great Ormond Street Hospital has for a very long time been, and continues to be, held in exceptionally high regard around the world for its excellence and expertise in the treatment of sick children. It has sadly come in to the public domain recently that some of the staff at that hospital have been subjected to serious threats and abuse. I made it clear before, and make it clear now, that I am completely satisfied that these fine parents have nothing whatever to do with those threats. Each and every man and woman working at Great Ormond Street Hospital is dedicated to the treatment of sick, very often desperately sick, children. These surgeons, physicians, doctors, nurses, ancillary staff, technicians and all others working there are dedicated to the pursuit of excellence in the treatment of sick children and it is in my judgment a disgrace that they should have been subjected to any form of abuse whatsoever and it is to be condemned.

17. Secondly, I wish to thank all of the lawyers in this case who have assisted the court but, in particular, the team who have worked for the parents because they have done it not for financial reward but have given their services free. It is not for judges to make political points and I do not now seek to do so. However, it does seem to me that when Parliament changed the law in relation to legal aid and significantly restricted the availability of legal aid, yet continued to make legal aid available in care cases where the state is seeking orders against parents, it cannot have intended that parents in the position that these parents have been in should have no access to legal advice or representation. To most like-minded people, a National Health Service trust is as much an arm of the state as is a local authority. I can think of few more profound cases than ones where a trust is applying to the court for a declaration that a life-support machine should be switched off in respect of a child. Mercifully, Mr Gard and Ms Yates have secured the services of highly qualified and experienced legal team whose lawyers have been willing to give their services pro bono. I am aware that there are many parents around the country in similar positions where their cases have been less public and where they have had to struggle to represent themselves. I cannot imagine that anyone ever intended parents to be in this position.

18. Thirdly, I think it my duty to comment briefly on the absurd notion which has appeared in recent days that Charlie has been a prisoner of the National Health Service or that the National Health Service has the power to decide Charlie's fate. This is the antithesis of the truth. In this country children have rights independent of their parents. Almost all of the time parents make decisions about what is in the best interests of their children and so it should be. Just occasionally, however, there will be circumstances such as here where a hospital and parents are unable to decide what

is in the best interests of a child who is a patient at that hospital. It is precisely because the hospital does not have power in respect of that child that this hospital makes an application to the court, to an independent judge, for a determination of what is in that child's best interests. In circumstances where there is a dispute between parents and the hospital, it was essential that Charlie was himself independently represented and a guardian was therefore appointed to represent Charlie so that there was someone who could independently report to the court as to what was in his best interests. Our judges are fiercely independent of the state and make decisions, having heard evidence and having considered the law. Our law in relation to children in circumstances such as this is governed by section 1 of the Children Act 1989 which contains a proposition which I suggest would be hard to criticise. Section 1 provides as follows:
"when a court determines any question with respect to the upbringing of a child the child's welfare shall be the court's paramount consideration".

19. The application which GOSH made in April and which they bring now is guided by that simple proposition. I set that out in April in detail in my judgment it is neither necessary nor appropriate for me to do so again now. However, I do encourage the many commentators who wish to opine on this case to have regard to what I said in that April judgment and to what was said subsequent to it by the Court of Appeal, Supreme Court, and the European Court of Human Rights. My task has been to consider what is in Charlie's best interests and it is that that I have done. The hospital trust correctly applied to the family division of the High Court for the exercise of the High Court's independent judgment.

20. Fourthly, I want to mention, again, the subject of mediation. Almost all family proceedings are now subject to compulsory court led dispute resolution hearings. This applies in disputed money cases, private law children cases and in all cases involving the welfare of children who might be the subject of care proceedings. I recognise, of course, that negotiating issues such as the life or death of a child seems impossible and often will be. However, it is my clear view that mediation should be attempted in all cases such as this one even if all that it does is achieve a greater understanding by the parties of each other's positions. Few users of the court system will be in a greater state of turmoil and grief than parents in the position that these parents have been in and anything which helps them to understand the process and the viewpoint of the other side, even if they profoundly disagree with it, would in my judgment be of benefit and I hope that some lessons can therefore be taken from this tragic case which it has been my duty to oversee.