



Neutral Citation Number: [2021] EWHC 2517 (Fam)

Case No: FD21P00625

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

IN THE MATTER OF THE INHERENT JURISDICTION
AND IN THE MATTER OF N (A Child)

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 15/09/2021

Before:

MRS JUSTICE ARBUTHNOT

Between:

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

Applicant

- and -

A

**First
Respondent**

- and -

H

**Second
Respondent**

- and -

N

**Third
Respondent**

(by her Children's Guardian)

Miss Katie Gollop QC (instructed by **Hill Dickinson LLP**) for the **Applicant**
Dr Barbara Green (appearing **pro bono** via **Advocate**) for the **First Respondent**
The Second Respondent appeared in person
Mr Conrad Hallin (instructed by **CAFCASS Legal**) for the **Third Respondent**

Hearing dates: 14th September 2021

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.

.....

MRS JUSTICE ARBUTHNOT

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mrs Justice Arbuthnot:

Application

1. This application for a declaration made by Great Ormond Street Hospital for Children NHS Foundation Trust concerns the most delightful 11 year old girl who is described by the doctor who treats her at Great Ormond Street Hospital (“GOSH”) and all the professionals who have met, her as a smiley, positive, thoughtful and very polite young girl with a zest for life.
2. The Trust (“GOSH”) asks the Court to approve the use of an experimental therapy called CAR T cell therapy to treat this young girl’s leukaemia. The application is opposed by the father but supported by the mother and the Guardian.

Background

3. The young girl I am concerned with is N and she was born in January 2010. She is one of five children of a family with there soon to be a sixth, due today.
4. In March 2016, the family heard the news that any family dreads, that their beloved daughter had acute lymphoblastic leukaemia (“ALL”), N was aged six.
5. From March 2016 to October 2020, she underwent a number of conventional therapies but relapsed. She was resistant to all treatments offered by GOSH. N spent those years in and out of hospital, facing the rigours of the treatments and their grave side effects with courage and fortitude. All of us in this Court have been struck by this bravery which has continued for almost half her life.
6. At the outset of this awful disease, she had a good chance of a cure but by October 2020, that chance had reduced.
7. The pressure of this disease on the family has been intense and mounting as treatment after treatment failed. The extent of the burden on the father is shown by the fact that despairing that his daughter would be cured and losing confidence in conventional medicine, he took her to Egypt to see if he could find a non-conventional cure.
8. In October 2020, without notice to GOSH, when the clinical plan for N was for a bone marrow transplant, the family went to Egypt. There, the father found N various homeopathic or natural remedies, some of them based on a healthy diet. Sadly, they failed. N was not cured.
9. The family came back to London in February 2021. The mother in her evidence explained that on 19th February 2021, the father left the family home.
10. The father in his evidence explained that he still does the school run and is in everyday touch with his children and he has daily conversations with N. From the evidence it was clear that in the early days of N’s treatment, before the family left for Egypt, it was the father who usually came to the clinical appointments with N. In more recent times, since the separation, the mother has not wanted to have meetings with N’s doctors with the father present.

11. In April 2021, N had her third relapse and was treated, but by June 2021, it was clear that the ALL was getting worse and GOSH came to Court to get approval for antibody treatment to be administered to N. The mother supported GOSH's application whilst the father opposed it.
12. The father gave evidence at the June 2021 hearing in front of Hayden J and said he was concerned about the serious side effects of the antibody treatment and wanted a non-specified non-conventional route for N. The Court approved the antibody treatment having heard from N's lead Consultant Paediatric Haematologist.
13. Despite an 80% chance of a cure, N was unlucky and after two attempts at antibody treatment in June and July 2021 and a slight reduction of her ALL, it has gradually increased. She has had recent admissions to hospital for a number of days but is currently an outpatient being regularly seen by GOSH and her local hospital.

Current situation

14. The Consultant Paediatric Haematologist and the experienced Guardian described N as feeling tired, suffering bone pain on standing and getting intermittent headaches. She needs to use a wheelchair for longer distances. She is at risk of infection. The quality of her life is reducing. The Consultant Paediatric Haematologist said N now has 100% leukaemia blasts in her bone marrow. Although N is currently stable her state of health is precarious, to say the least.
15. The mother in her evidence to the Court, painted a vivid picture of N's suffering at home when she said that N would scream in pain for perhaps 20 minutes at a time before the morphine took effect. I can only imagine how harrowing that must be not just for N but also for her mother and any of her siblings who witness this.
16. The current situation is that all the therapies have failed, the conventional ones including the antibody therapy approved by the Court in June 2021 and the homeopathic or natural ones tried in Egypt by the father. The little girl who is a patient at one of the world's best children's hospitals now has only one last chance at life and a slim one at that.
17. Not to dress it up, with 100% leukaemia blasts in her bone marrow, N is likely to die within two to four months, unless an experimental therapy is tried. If she does not take part in the experimental therapy, she could be expected to enter hospital within one to two months to receive morphine via a syringe driver to control pain which the consultant said would be "excruciating" in her bones and head and to control infection.

CAR T cell therapy

18. The new therapy is called CAR T cell therapy. The Consultant Paediatric Haematologist set out in his statement a medical, technical explanation about how it works along with the risks. I hope he will forgive my mistakes if I put his language into simple and I hope plain English.
19. The particular form of CAR T cell therapy which is being suggested for N is allogeneic as opposed to autologous (cells taken from the patient). In allogeneic CAR

T cell therapy, white blood cells are taken from donors who have not had cancer or chemotherapy and are modified to attack the leukaemia. The patient, in this case N, goes through a debulking chemotherapy to reduce her leukaemia to enable her to receive the CAR T cells. Once she receives the cells, the aim is that they reduce the leukaemia further to enable her to receive a bone marrow transplant. The Consultant Paediatric Haematologist described the CAR T cells as a bridge to a bone marrow transplant which N cannot receive in her current state. It is only the bone marrow transplant that will cure N.

20. Clearly all these procedures will take a long period of time and most, if not all of this time, N will spend in hospital. It is difficult to say how long she will be in hospital for but it could be for as long as five months. This is a long time for this little girl who is longing to start secondary school and to do all the things that girls of her age do.
21. Once a child has received the allogeneic CAR T cells, there are a number of risks and possible side effects which could occur. Understandably, the father is particularly concerned about the side effects and in his view the risk of the procedure outweighs the benefits. In view of the father's evidence and Dr Green's submissions on this point, I set out the evidence from the Consultant Paediatric Haematologist's statement in full at [45] page C10 and C11:

“45.1. Cytokine Release syndrome (CRS): CAR T cells can make the cells in the body produce chemicals called “cytokines” and this is expected during the treatment. If cytokines are present in large amounts, these may then cause symptoms such as fever, severe difficulties in breathing and low blood pressure. Sometimes this is called a ‘cytokine storm’. We give the child medicines to help stop them from developing this side effect and they are monitored very closely after the CAR T cells infusion. CRS may be life-threatening, and sometimes we use a medicine called Tocilizumab. In a similar previous study around 1 in 3 patients required intensive care. There is at least a 50% chance that [N] will require to go to PICU for supportive care as a result of the CRS.

45.2. Graft versus Host Disease (GvHD): Even though most CAR T cells have been modified so they can only fight leukaemia cells, some of them could still attack normal cells. When this happens, it causes Graft versus Host Disease (GvHD). Around 1 in 10 patients developed this problem in a similar study. Symptoms of GVHD include skin rashes and gut problems (like being sick and having diarrhoea) and liver disease. Limited GvHD will be managed with topical therapies (steroid or tacrolimus ointment). If GVHD is more serious, it will require systemic steroid use. GVHD is a risk associated with allogeneic, rather than autologous CAR T cells, and therefore it was not something [N] experienced with her previous infusion of autologous CAR T cells (Kymriah).

45.3. Nervous system complications: After CAR T cell infusion, the child may develop symptoms affecting the nervous system. Mild neurological symptoms after similar CAR T therapy were previously seen in around a third of patients, and include sudden changes in behaviour, confusion, speech difficulties or loss of sensation and seizures. These symptoms may occur between 4-15 days post-CAR T infusion and they usually disappear in time but can occur later and may last longer. Supportive care will be given which can include intensive care.

45.4. Tumour Lysis Syndrome (TLS): When leukaemia cells die, they may release chemicals in the blood, including potassium, phosphate and uric acid. Large amounts of these chemicals can cause damage to organs like the kidneys and the heart. This is a known side effect of anti-cancer therapies and we expect to see this in less than 1 in 10 patients that receive CAR T cells. We will monitor [N] closely we will give her prophylactic medicines she needs to limit this risk. Sometimes, patients with high tumour load (high numbers of leukaemia cells) are given extra chemotherapy medicines before CAR T therapy to reduce the numbers of leukaemia cells, and this would be the approach for [N] as explained above (including the debulking chemotherapy).

45.5. Reduced immunity: CAR T cells target all the cells that have a CD19 tag on their surface. This means that they will kill leukaemia B cells, but also the normal B cells that carry the CD19 flag. B cells are responsible for making antibodies that can protect the body against some forms of infections. If there are not enough normal B cells left to produce antibodies, she will be more at risk of getting infections. We will monitor this, and immunoglobulin therapy may be given to prevent infections.

45.6. Risks of developing new cancer related to CAR T cell therapy: The CAR T cells were designed by making changes to genes inside the cells using a disabled virus and CRISPR technology. There is a very low risk that these cells that have been modified could start to divide out of control and grow in a similar way to leukaemia cells. We think that the risk is very small, and this type of side effect has not been reported in any study using engineered T cells, but it has been seen after gene therapy where patients own stem cells were modified and given back.

45.7. Risk of a positive HIV test result: A disabled virus that cannot replicate is used to engineer the CAR T cells. Routine blood tests that are used to detect HIV may pick up cells modified in this way and may give a 'positive' result. This does not mean the child has a HIV infection. We expect the results to become 'negative' again after bone marrow transplant.

Benefits associated with allogeneic CAR T cell therapy

46. If successful, the allogeneic CAR T cells could help fight [N]'s leukaemia and enable her to enter remission. This would mean that she could have a bone marrow transplant.

This is the only realistic chance of a cure for [N], and the only realistic option which may prolong her life. The likelihood of success is around 10-20%.”

22. There are also serious risks and side effects from the debulking chemotherapy which will precede the CAR T therapy and the bone marrow transplant which hopefully will follow the CAR T. The Consultant Paediatric Haematologist explained that the 10% to 20% likelihood of success referred to above was a reference to the overall procedure including the transplant.
23. Dr Green pointed out in her submissions as indeed the father did in his evidence that only two children had gone through the allogeneic CAR T cell therapy and only one of those two had survived. The Consultant Paediatric Haematologist explained that the child who died, died because the leukaemia had returned. The second child was leukaemia free, eight months after the procedure. The Consultant Paediatric Haematologist also said that N had avoided the worse side effects from previous therapies and that might stand her in good stead. He also pointed out that the fact that other treatments had not worked did not mean to say the CAR T cell therapy would not work either.
24. The Consultant Paediatric Haematologist's evidence was compelling, that CAR T cell therapy was N's only chance at life.
25. With any patient, even one as young as N, entering an experimental trial, he had a duty to speak to the patient to explain the risks to her. He had held therefore a meeting with N on 3rd September 2021.
26. At the meeting, N's mother who speaks fairly good English was there along with an interpreter as well as N's deputy keyworker and a senior specialist nurse who was a conduit for information flowing between the family and the hospitals and between GOSH and the local hospital. She helpfully explained her important role to the Court.

27. N's father had not been informed about the meeting and his position was that the conversation with N should never have taken place. I agree that the father should have been informed that the doctor was going to speak with N but I do not accept that N should not have had the procedure explained to her. An added complication for GOSH is that the father and mother have now separated and it was not appropriate to repeat the conversation with N for the benefit of the father. It was upsetting enough for N to have the risks explained to her without them being repeated on a separate occasion.
28. N had been given a patient information leaflet by GOSH the week before the meeting on 3rd September 2021. Designed for 11 to 15 year olds, it explained the experimental CAR T therapy in age appropriate terms. N had not read the leaflet and her mother in evidence explained that N did not like reading and did not want to read it but that the mother had gone through the leaflet with her. The leaflet explained the risks. The mother and N had had more than one conversation about this before the meeting on 3rd September.
29. The mother said she had explained the risks and side effects and the doctor explained them again on 3rd September 2021. Both acted appropriately in my judgment. N knew that her leukaemia had returned and that her options were limited although rightly the doctor never said to her that without treatment she was likely to die within two to four months.
30. In response to the doctor and as noted by the witness deputy keyworker nurse, N said she wanted to go on the study as she wanted to get better. It was clear from the Guardian's evidence after meeting N at home on 10th September 2021, that she wanted to have the normal life of any 11 year old. She said to the Guardian she thought that treatment was a good idea but she was uncertain because she wants to go to her new secondary school and do things like going to the park and not be in hospital for a period of time.
31. N said to the Guardian she was eight out of 10 sure she wanted the treatment. Later in the 45 minute private conversation, she confirmed to the Guardian she was 80% sure and 20% uncertain. I noted that in Dr Green's closing submissions the father said he had spoken to N during the hearing and she said she was "50 50" about the treatment. I suspect her views will depend to some extent on whom she is speaking to. She loves her parents very much and the Guardian said it was clear that N was aware that one parent supported the study whilst the other did not. Entirely appropriately, no one has actually spelt out to N what the alternative to the experimental treatment is.
32. N's case has been considered by the GOSH Multi-Disciplinary Team and by the Paediatric Bioethics Service at a meeting on 25th August 2021. On balance, they supported the use of CAR T cell therapy but were aware that it had a small chance of being successful.
33. On 6th September 2021, a second opinion was obtained from a Consultant Paediatric Haematologist at the Bristol Royal Hospital for Children. He was asked about N's best interests. He said that N's chances were slim but it was not unethical to proceed and not futile for her to pursue the CAR T therapy on offer.

The law

34. The law has been set out in the written submissions I received. I cannot better the analysis of the test this Court must apply than the one set out in Mr Hallin's submissions on the law, which I adopt.
35. The mother is representing herself so I hope that she would consider it helpful for me to set out the principles this Court must apply to the decision about N's treatment (and I take much of this from Mr Hallin's submissions).
36. Consent to medical treatment of a child can be obtained from those with parental responsibility (in this case the mother and the father), the child if he or she is over the age of 16 or is otherwise of sufficient maturity and comprehension to take a decision of the relevant gravity or the Court exercising its inherent or statutory jurisdiction over children.
37. The law allows for the following hierarchy of authority in relation to a refusal of medical treatment: the refusal of the child patient, of whatever age, will not prevail in law against the consent of a person with parental responsibility or the Court. The refusal of a parent will not prevail against the consent of a child of 16 and over, or of a younger child of sufficient maturity and understanding to consent to the treatment in question (Gillick competent). Finally, the refusal of the child (of any age) or of the parents will not prevail against the authority of the Court exercising its statutory or inherent jurisdiction.
38. Gillick competence is not applicable in this case as the parties are agreed that N is not competent in the sense of not merely having an understanding of the nature of the proposed treatment but of having a full understanding of the treatment and also of the consequences of a failure to treat. Although I accept the doctor and N's mother explained the possible side effects of the experimental therapy, so far as I am aware, N has not been told by anyone what the consequences are to her of not taking part in the CAR T cell therapy trial: in other words, the certainty of death.
39. N is not Gillick competent therefore and for a child such as she, the legal position is that she can be compelled to accept treatment either under the authority of a person with parental responsibility or the Court exercising its statutory or inherent jurisdiction.
40. In this case the father is not sanctioning the particular medical treatment proposed by GOSH and says it is not in N's best interests. It is the Court therefore which has the ultimate power to require treatment to be given, in accordance with a 'best interests' test.
41. The Court's duty is to weigh up the advantages and disadvantages of providing or withholding the treatment suggested by GOSH and to balance them in order to determine where N's best interests lie (*Re J (a minor) (wardship: medical treatment)* [1991] 2 WLR 140; 3 All ER 930; [1990] 2 Med LR 67).
42. When considering what is N's best interests, the Court must exercise independent and objective judgment on the basis of all the available evidence (*Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242).

43. The Court's approach to N's best interests will necessarily be highly fact-specific and the Courts have been slow to give definitive guidance on how to approach the 'best interests' test in this context.
44. I found Holman J's summary of the principles in an infant treatment case as set out in Mr Hallin's written submission particularly helpful. In *NHS Trust v MB* [2006] EWHC 507 Holman J said at [106] to [107]:

“(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 Lynton 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 Lynton 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."

45. I must consider N's wider best interests which are determinative and not just her medical best interests.

Discussion

46. As Miss Gollop QC for the Trust put it so clearly, in my judgment I have a stark choice between an experimental treatment which gives N a slim chance of a cure and a resumption of her childhood or no treatment and certain death. The mother, the Guardian and the doctors on balance support treatment.

47. The father opposes it on the basis that alternative remedies with few side effects have not been tried. In his evidence he relied on a book written by a cancer patient who had used diet as well as conventional medicine to be cured. At the father's request, the Consultant Paediatric Haematologist contacted the author who explained to him that her suggestions of starving the cancer were not to be approached as an alternative to conventional treatment but as a complimentary regimen.

48. The father said that he had conducted internet research and that there were examples of patients recovering from cancer using non-conventional therapies. As the Consultant Paediatric Haematologist said, if there was non-conventional treatment 'out there' which could cure ALL, he would be the first in the queue to obtain it for N.
49. The father had no firm proposals for an alternative therapy. His thinking had not progressed since the June 2021 hearing in front of Hayden J who said that the father "points vaguely to homeopathic remedies" ([14] A6 of the bundle) and "clings to the homeopathic hope" ([19] A7). The father has lost trust in conventional treatment which has failed and brought suffering to N. He desperately wants a cure for N but has no concrete alternative to the treatment suggested by GOSH.
50. I can hardly imagine the father's despair and his feelings of hopelessness and helplessness, the family are all close and he clearly loves N very much. He is clinging on to a forlorn hope that somehow out there, there is a natural cure for her leukaemia with no or few side effects which the hospital should discover and use. He is being unrealistic in my judgment.
51. From the evidence of the Consultant Paediatric Haematologist, a senior experienced doctor who has been committed to N for a very long time and indeed gave evidence before Hayden J in June 2021, there is no time for N to try a homeopathic or natural treatment. There is no specific alternative identified and in any event if there was one and it failed, as it would, it may then be too late for the CAR T cell therapy which is needed to start straightaway whilst N is relatively stable and it has a chance of working.
52. The decision is what is in the best interests of N. GOSH apply for the Court to make a declaration that the treatment should start tomorrow (15th September 2021) with N admitted tonight. N would start with debulking chemotherapy, leading, hopefully, to a CAR T cell therapy which, hopefully, would lead to a bone marrow transplant. I say hopefully because the father is right, this is an experimental process and I have set out above the Consultant Paediatric Haematologist's description of the potential side effects. I am conscious that this little girl has been through so much already.
53. I am clear that N at 11 $\frac{3}{4}$ lacks the capacity to make the decision herself. My job is to use an independent and objective judgement when considering the factors for and against the treatment.
54. Against the treatment is that N has had to endure years of side effects from the various treatments she has received. There is no doubt she will suffer during the treatment and her father who has no realistic alternative suggestion to the treatment and undoubtedly wants to find a cure for her, does not want to see her suffer further. That is an important factor for the Court. Of significance too is the fact that there is such a slim chance of a cure, about 10% to 20%. It is an experimental treatment and of the two children who have undergone it, one had died when his or her leukaemia returned. A neutral factor I find is that N does not want to spend long periods of time in hospital away from her close-knit family, I say neutral, because whatever decision I make she will be spending long periods of time in hospital.
55. In favour of the treatment, is the bald fact that she will die without it and very soon. If she does not have the treatment, she will suffer and have to enter hospital in an

attempt to control her pain in the weeks and months ahead. She will then too be away from her family and in great pain but in that situation she will have no chance of living. Another important factor is that her mother supports treatment as she recognises this is her daughter's last chance.

56. The doctors too have considered the options carefully. They have obtained a second opinion and gone to the bioethics committee to review the decision as to whether this treatment is in N's best interests. I was impressed by the Consultant Paediatric Haematologist's careful commitment to N, just one example of this was his willingness to speak to the author of a book on complimentary therapies when the father asked him to.
57. What of N's wishes and feelings? I find these are a factor in favour of treatment. As I have said above, N has not been told in bald terms what the alternatives are to the treatment. She has been described as having a zest for life, she has a positive sunny outlook which is remarkable in the circumstances. She wants to go to school and play with her friends and no doubt be with her family in the long term. In short, I find she wants to live.
58. The mother and the doctor have explained to her the risks of the treatment and the side effects in an age appropriate way and even though she does not know she will die without it she still wants to go ahead, she is between 50% and 80% sure of this.
59. I bear in mind too that N is an "experienced patient", an awful expression for the Court to hear, but it accurately describes the fact that N has gone through treatments for over five years, she has suffered a range of side effects and come out the other side. Despite all the pain and suffering from those treatments, she still wants to go ahead with this experimental study. Her views cannot determine the Court's decision but they are an important factor to consider.
60. The Guardian speculated too that if the Court did not make the declaration and N did not enter the study, she may find out later that her only chance at life was denied her. The Guardian's evidence was that N appreciated at some level that she needed to try anything to get better. The Guardian carefully picked her words and said N "would possibly find it quite difficult if she could not have treatment".
61. Weighing up the factors for and against, I find treatment is the only opportunity for this young girl to be cured and live the life she is longing for. It is a binary decision, a chance at life with lengthy hospitalisation which may lead to a cure or deterioration and hospitalisation in a few weeks until she dies. Alternative homeopathic and natural remedies were tried in Egypt and failed. I have heard this little girl's voice as expressed to her mother and the doctors and she wants to live.
62. The father relies on the side effects and the experimental type of treatment that is being suggested by GOSH as a reason for declining to approve the treatment. He has had his hopes raised before by suggestions of a conventional treatment most recently in June 2021, when it was thought N had 80% chance of a cure. His hopes have been dashed.
63. Dr Green suggested that the doctors would not somehow be able to monitor or control any side effects during the treatment but I disagreed with that view. GOSH had set

out the potential side effects (as quoted above) and had anticipated how they would be dealt with. They have explained they will monitor her throughout the process and are clearly aware of the risks. They have set out above what they will do if the side effects occur.

64. In my judgement N's best interests demand this Court make the declaration sought by the Trust. Contrary to the father's assertions, the benefits of the treatment outweigh the risks.
65. Due to the urgency of the application I gave an *ex tempore* decision straight after the hearing yesterday (14th September 2021) and this more detailed judgment today (15th September 2021).
66. The Guardian described N as an amazing child. Dr Green described her as remarkable. She is both those things and many more. She is a much loved child at the centre of a close and loving family who have been devastated by this illness for over five years. I noted the dignity of the mother when she gave her evidence and the commitment and love of her father who desperately wants his daughter to be cured. N and her family will have to go through yet more pain and suffering but at least they will know they have done their very best to give N a chance at life, whatever the outcome. There is no one in this Court who has not been moved by the struggle N and her family have had to endure and we all wish them the very best in the months ahead.
67. That is my judgment.