This judgment was delivered in private. The judge has given leave for this version of the judgment to be published. In this case a Reporting Order has been made which continues in effect. All persons, including representatives of the media and legal bloggers must ensure that the terms of the Reporting Order, are strictly observed. Failure to do so may be a contempt of court.

Case No: FD23P00452

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
IN THE MATTER OF THE INHERENT JURISDICTION
IN THE MATTER OF INDI GREGORY (d.o.b. 24.02.2023)

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 2 November 2023

Before :

MR JUSTICE PEEL

- -

Between :

NOTTINGHAM UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Applicant

- and -

(1) INDI GREGORY (by her Children's Guardian)
(2) DEAN GREGORY
(3) CLAIRE STANIFORTH

Respondents

- -
- -

Scott Matthewson (instructed by **Browne Jacobson LLP**) for the **Applicant**
Katie Scott (instructed by the **Cafcass Legal**) for the **First Respondent**
Louis Browne KC and Bruno Quintavalle (instructed by **Andrew Storch Solicitors**) for the **Second Respondent**
The **Third Respondent** did not attend and was not represented

Hearing date: 31 October 2023

- -

Judgment

This judgment was handed down remotely at 10.30am on 2 November 2023 by circulation to the parties or their representatives by e-mail and by release to the National Archives

Mr Justice Peel

1. By a judgment handed down on 13 October 2023, after a hearing on 9 October 2023, I approved the Hospital Trust's care plan, and authorised the withdrawal of life sustaining invasive treatment in respect of IG, who is now a little over 8 months old. The approved order is dated 16 October 2023.

2. IG's father ("F") applied to the Court of Appeal for PTA, which was refused after an oral application heard on 23 October 2023.

3. A further application was made to the European Court of Human Rights, which declined to consider the case.

4. In accordance with the care plan, the Trust intended to proceed to extubation on Friday 27 October 2023, but extended that to 12pm on Monday 30 October 2023 to meet the parents' wishes for extubation to take place after a hospice transfer.

5. To the surprise of the Trust, at 10.28am on Monday 30 October 2023, F's newly instructed solicitors, Andrew Storch, sent an email to the parties, copying me in, which contained the following:
    a. A report from Dr Mark Walsh, a consultant congenital cardiologist at the CHI Crumlin and the Mater Hospital, Dublin, dated 23 October 2023 but, I was told, received by F's solicitors on or about 26 October 2023.
    b. A letter dated 29 October 2023 from a paediatrician and medical geneticist in Canada, Professor Khan.
    c. A letter dated 29 October 2023 from the Bambino Gesu Children's Hospital in Rome indicating that they would agree to IG being transferred to their care.
    d. A letter from F's solicitors to the Trust inviting them to agree to a transfer to Rome.

    The same day, a report by Dr Ross Russell dated 18 October 2023, a consultant in paediatric respiratory medicine, was circulated by F's solicitors.

6. By email I informed the parties that the matter would be listed the next day, i.e 31 October 2023, at 2pm.

7. Later on Monday 30 October 2023, a formal application was made, seeking permission for the care of IG to be transferred to other medical professionals; implicitly, although not explicitly, the intended team is at the hospital in Rome. I take the view that the application should be considered in the light of the proposed expert evidence upon which F relies, although I will also need to consider whether such evidence should be formally admitted into the proceedings.

8. The application is opposed by the Trust and the Guardian. The Guardian is particularly concerned, from IG's point of view, about the pain and suffering she is experiencing.

Legal principles

9. I accept that although I have delivered a final judgment and made a final order, which has been upheld by higher courts, there is no bar to a party (in this case F) from applying to the court to revisit the decision. The applicable principles seem to me to be accurately set out by Poole J in **An NHS Trust v AF (by his Litigation Friend the Official Solicitor) and SJ [2020] EWCOP 55** at para 22:

> "a. There is no strict rule of issue estoppel binding on the court.
> b. Nevertheless, the court should give effect loyally to a previous judicial finding or decision that is relevant to the determinations it has to make, and should avoid re-opening earlier findings that cannot be undermined by subsequent changes in circumstances. An example would be a finding that P lacked capacity at a particular point in time. Such findings, if not successfully appealed, should generally only be re-opened if new evidence emerges that might reasonably have led the earlier court to reach a different conclusion.
> c. Where there has been no material change of circumstances subsequent to a previous judgment, no new evidence that calls for a re-opening of the earlier findings, and the earlier evaluation of best interests clearly covers the decision that the new court is being asked to consider, appropriate case management might involve the court summarily determining the new application.
> d. Determinations of capacity and best interests are sensitive to specific decisions and circumstances, therefore the court will exercise appropriate restraint before making any summary determination.
> e. If the decision or circumstances that the new court is being asked to consider are not clearly covered by the earlier judgment, or there has been a material change of circumstances or new evidence that calls into question the previous findings, the court should manage the case in a way that is proportionate having regard to the earlier judicial findings and decisions.
> f. In dealing with the new application proportionately, the court's focus will be on what has changed since the previous ruling, and any new evidence. It should usually avoid re-hearing evidence that has already been given and scrutinised in the earlier proceedings."

10. I also remind myself that in respect of the proposed new expert evidence, the test remains one of "necessity".

11. The skeleton argument on behalf of F contained submissions on law which appeared to suggest that the parents' wish for IG to be treated in Rome cannot be overridden by the court, citing authorities about parental consent and human rights. In oral submissions, leading counsel for F did not press the argument to that extent. While reserving his position should the matter proceed to a higher court, he accepted that the ultimate test is one of best interests, albeit the views of parents who have a viable alternative is a powerful consideration.

12. To the extent that it is or may be submitted that the parents can give consent on IG's behalf to her being transferred to a different clinical team in Italy, and the court has no jurisdiction or power to override that consent being implemented, I cannot agree. The dispute between the Trust and the parents is about provision of ongoing invasive treatment. To seek a transfer to a different clinical team is all part of the issue before the court now (albeit not at the hearing before me on 9 October 2023), namely whether it is in IG's best interests for particular treatment to be administered or withdrawn.

13. Parental responsibility is defined in the Children Act 1989 s 3(1) as comprising "all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property." The concept of parental

responsibility describes the responsibility of a parent to secure the welfare of their child. This responsibility does not confer upon parents an unfettered right to make welfare decisions in respect of their children (see **Alder Hey Children's NHS Foundation Trust v Evans [2018] EWCA Civ 805).**

14. Pursuant to s 8(1) of the Children Act 1989 the court retains jurisdiction to determine questions which have arisen in connection with the exercise of parental responsibility by means of the exercise of its independent and objective judgment of the child's best interests. The Family Division of the High Court may also exercise its inherent jurisdiction to determine questions which have arisen in connection with the exercise of parental responsibility.

15. In **Re J (a minor)(wardship: medical treatment) [1990] 3 All ER 930** at 934, Lord Donaldson MR said:

> "The doctors owe the child a duty to care for it in accordance with good medical practice recognised as appropriate by a competent body of professional opinion (see *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118, [1957] 1 WLR 582). This duty is, however, subject to the qualification that, if time permits, they must obtain the consent of the parents before undertaking serious invasive treatment. The parents owe the child a duty to give or to withhold consent in the best interests of the child and without regard to their own interests. The court when exercising the *parens patriae* jurisdiction takes over the rights and duties of the parents, although this is not to say that the parents will be excluded from the decision-making process. Nevertheless in the end the responsibility for the decision whether to give or to withhold consent is that of the court alone. It follows from this that a child who is a ward of court should be treated medically in exactly the same way as one who is not, the only difference being that the doctors will be looking to the court rather than to the parents for any necessary consents. No one can dictate the treatment to be given to the child, neither court, parents nor doctors. There are checks and balances. The doctors can recommend treatment A in preference to treatment B. They can also refuse to adopt treatment C on the grounds that it is medically contra-indicated or for some other reason is a treatment which they could not conscientiously administer. The court or parents for their part can refuse to consent to treatment A or B or both, but cannot insist upon treatment C. The inevitable and desirable result is that choice of treatment is in some measure a joint decision of the doctors and the court or parents."

16. In **Re R [1992] 1 FLR 190** at 199C Lord Donaldson MR said that:

> "It is, however, clear that the practical jurisdiction of the court is wider than that of the parents".

At 199F he added that the court can override the consent of parents or guardians. These dicta are echoed by Staughton LJ at 203B. **Re W [1993] 1 FLR 1** was cited to me by counsel for F, but nothing in that judgment detracts from the proposition that the court, in the exercise of its parens patriae jurisdiction, has the power to make orders which override the wishes of the parents, and Lord Donaldson MR at 12D quoted his own observations in **Re R.**

17. Should there be any doubt about the matter, it was surely dispelled by the Court of Appeal in **Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and others [2018] 1 All ER 569**. Within his judgment, McFarlane LJ reviewed the authorities. At para 97, he said:

"Where, however, as in this case, the judge has made clear findings that going to America for treatment would be futile, would have no benefit and would simply prolong the awful existence that he found was the current state of young Charlie's life, he was fully entitled, on the basis of those findings to conclude as he did. The consequence of that conclusion is that the proposal for nucleoside therapy was not a viable option before the court".

18. At para 112 he continued:
"As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

19. In that case, the appeal against the judge's refusal to sanction a transfer to the United States for particular treatment was dismissed. Similarly, in **Alder Hey Children's NHS Foundation Trust v Evans [2018] EWHC 308 (Fam)**, Hayden J determined that it was not in Alfie Evans's best interests to be transferred to the Bambino Gesu hospital for treatment. By contrast, in **Raqeeb v Barts NHS Foundation Trust [2019] EWHC 2531 (Admin)** MacDonald J did not override the family's wish for the child to be transferred to Italy. The facts of that case were very different (not least because the child was not in any pain), but once again it is apparent that the court had the jurisdiction and power to make such decisions as part of a best interests analysis.

20. Finally, I have been referred to a useful checklist for what amounts to a relocation scenario contained at para 57 of **UR v (1) Derby City Council (2) NHS Derby and Derbyshire Clinical Commissioning Group [2021] EWCOP 10.**

21. F's human rights submissions were not pressed on me orally with as much emphasis as appeared in writing. The essence, as I understand it, is that the Trust's refusal to cooperate in IG's proposed move to a hospital in Rome constitutes a breach of IG's human rights as exercised by her parents. It seems to me that if the court declines to sanction a move to Rome, as it clearly has power to do, it would have to do so on the basis that any interference with human rights would be both necessary and proportionate to give effect to the best interests finding. I do not consider that the human rights submission goes further than that. Further, as the Guardian points out, the Supreme Court dismissed on 20 April 2018 an application for permission to appeal in the Alfie Evans case which included similar human rights arguments. Again, however, it did not seem to me that F's counsel were in fact challenging the long-standing proposition that the guiding principle in these cases is the best interests of the child.

22. In my judgment, where, as here, the proposed transfer for treatment elsewhere (in this case a hospital in Italy) is intrinsically bound up in the issue of treatment and best interests, the court has the power to make such determinations as may be appropriate, including sanctioning a course opposed by the parents. Of course, the court's powers must be exercised with the utmost care, informed by a holistic view of the evidence, and an evaluation of the child's best interests. The legal principles which I set out in my earlier judgment continue to apply.

<u>Findings in my previous judgment</u>

23. I will not repeat what is set out in my publicly available judgment of 13 October 2023. However, I refer to a number of matters which are of relevance to these applications:

    a. I heard evidence from one treating clinician, a nursing staff member a second opinion paediatric consultant, F and the Guardian. I read letters and reports from numerous other clinicians and medical professionals. I noted that the clinical team had sought assistance and information from a variety of national and international sources, and "no external clinician has suggested they should do anything different". I accepted the entirety of the medical evidence placed before me.

    b. I found that IG had deteriorated significantly since 6 September 2023, she showed no signs of recovery, she was on full life support, critically ill and extremely unstable. Her conditions were irreversible and untreatable, with no prospect of improvement. Her life expectancy was measured in days, if invasive ventilation were withdrawn, and a few months if it were maintained. I said at para 12: "There is no doubt in my mind that her presentation is on a rapid downward trajectory. She is now at the very limits of what is medically available for her". Nothing has been placed before me to suggest any indication of improvement.

    c. I had, at a hearing on 3 October 2023, refused F's application for expert evidence. I note that the two experts put forward to me in this application on behalf of F were not named among the pool of proposed experts at that time.

    d. I did, on 3 October 2023, permit F the instruction of a paediatric intensivist provided that such person could report by 10 October 2023. In the event, no report was provided by that date. On 18 October 2023, after the final hearing in front of me, Dr Ross Russell, a well-known expert in this field provided a report for F. I believe it was not in fact seen by the other parties until it was sent to them on Monday 30 October 2023.

    e. I found that IG's presentation is as a result of a constellation of factors, interlocking co-morbidities and complex entwined problems, "impacting across various conditions and disciplines, which cannot be compartmentalised". As Dr E said, "We know what is happening, even if the exact sequencing is uncertain".

    f. The second opinion doctor stated that there was no gap in the medical evidence which needed to be filled.

    g. I was satisfied that IG showed little awareness of the world around her, and had extremely limited quality of life.

    h. I was also satisfied that IG experienced frequent pain, multiple times a day, as a result of the various medical interventions, and displayed rection to painful stimuli with crying, increased heart rate, wincing and gasping.

24. Nothing I have seen or heard leads me to question those conclusions.

The new medical evidence

25. I bear in mind that I have already, on 3 October 2023, rejected the application by F for expert cardiological and metabolic/mitochondrial evidence (the expertise of Dr Walsh and Professor Khan). I note also that no application was made at the final hearing by F's counsel, after all the evidence had been collected, for such further evidence.

Dr. Ross Russell

26. In his recent report, Dr Ross Russell says:

> "…I can see no prospects for Indi to be able to enjoy or take pleasure in an independent life whilst she remains dependent on mechanical support for her ventilation…I am not able to support the institution of long term ventilatory support as I both see no prospects for significant recovery and at the same time would agree that interventions necessary to continue that respiratory support would be both burdensome and cause pain and suffering to her".

27. He raised the possibility of a cardiological cause for the desaturations, whilst acknowledging that (i) he is not an expert in paediatric cardiology, (ii) surgical options might be considered too risky, and (iii) "…this possibility does seem to have been considered by the hospital".

28. The lead treating clinician, Dr E, has spoken to Dr Ross Russell, who agrees with the Trust's care plan, and in particular that intensive care support should be withdrawn.

Professor Khan

29. Like Dr Ross Russell and Dr Walsh, Professor Khan has not seen IG. That is not a criticism of any of them, but it contrasts with those who gave written and oral evidence before me on 9 October 2023, and are deeply familiar with IG, her conditions and her symptoms.

30. Professor Khan comments that "While there are effects on the brain from Hydrocephalus, this does not mean that Indi, given some more time to recover from the immediate medical management, will not be able to continue to interact and have a positive quality of life".

31. That seems to me to be an expression of speculation, contrary to the evidence which I heard and the findings which I made about the irreversible nature of the condition, the lack of interaction with the world and the pain experienced by IG. Understandably, Professor Khan comments on one medical aspect, his area of expertise, whereas I had before me at the hearing a wide range of evidence which addressed IG's circumstances holistically. As already mentioned, the unanimity of the medical evidence was to the effect that her co-morbidities are incurable and leading inexorably to death in the near future. At the risk of repetition, this case is about the specific circumstances of this little girl for whom a range of complex conditions all come together, whereas Professor Khan is looking at the condition in a more abstract way.

32. Professor Khan refers to the ketogenic diet and other therapies, but I have already explained my findings on the impact of this for IG. He refers to improvement in July and August, but I heard plenty of evidence about the significant deterioration in early September. Professor Khan does not indicate that there is any further, or alternative, treatment, which has any prospect of altering the very bleak prospect of this child.

And, again, I remind myself that it is important to recall how IG experiences a whole range of related conditions, which militates against compartmentalisation of the medical evidence. It is understandably difficult for Professor Khan to appreciate the wider complexities inherent in IG's presentation.

33. Finally, I remind myself that at the substantive hearing I had before me written evidence from a paediatric consultant with expertise in inherited metabolic diseases, who confirmed there is no cure for Indi's D-2/L-2 condition, and that all realistic treatment options have been explored.

Dr. Walsh

34. Having read the report of Dr Walsh, who has not seen IG, I am of the view that, as with the evidence of Professor Khan, it does not amount to material new evidence justifying a reconsideration of my decision.

35. The report is expressly based on assumptions provided to him by F's solicitors. Those assumptions are:
    a. There is a reasonable chance that the experimental treatments for D2-/L-2 hydroxyglutaric aciduria (namely phenylbutyrate therapy, citrate therapy and the ketogenic diet) are being effective in neutralising the detrimental effects of that condition, including preventing any further damage to her brain, and possibly even improving her neurological function.
    b. For those treatments to have full effect, they need to be administered over a number of months or even years.
    c. The existing damage to Indi's brain is not such as to deprive her of a reasonable quality of life.

36. These assumptions were, I understand, based on what Professor Khan said. I have expressed the view that Professor Khan's opinion is undermined for a variety of reasons, which therefore in turn undermines Dr Walsh's report. I also consider that the provision of "assumptions" in this way by F's new solicitors to Dr Walsh was not appropriate. The stated assumptions are simply incorrect. They do not reflect my judgment, and my findings. There was nothing before me to suggest that these treatments are "neutralising" the detrimental effects of the condition. On the contrary, I found at para 8 of my judgment that "Recent therapies (medication, use of citrate and a ketogenic diet) have led to a reduction in the frequency of the desaturation episodes, but the overall prognosis is unchanged, and the plan is being implemented as a compassionate measure rather than in expectation that it will lead to improvement". For the avoidance of doubt, I was satisfied that there was no material benefit from these treatments to the progression of her conditions. They have been administered for several months, but she has deteriorated irreversibly. And to posit that the damage to her brain is not such as to deprive her of a reasonable quality of life is the opposite of what I found, namely that her various conditions have resulted in her being unable to engage with the outside world or experience any meaningful quality of life.

37. In any event, Dr Walsh comments that "[IG's] metabolic condition is outside my area of expertise" and "I don't think she is a candidate for surgery." He suggests that a catheter or stent might assist in palliative care but only if it was felt that IG would have a reasonable chance of survival with a meaningful quality of life, which I have

concluded she does not. He sensibly defers to other professionals as to the severity of IG's condition. He does not suggest that a catheter or stent would improve outcome. He opines nothing to contradict the evidence of the Trust, including two external hospital cardiological teams who would not be willing to offer cardiological treatment given her unstable condition and the futility of such treatment. Cardiac treatment was fully considered by the treating clinicians, and by me at the final hearing, and I accepted the evidence that it would not be appropriate (see for example paras 32(x) and 40 of the judgment).

38. Again, this seems to me to be compartmentalisation of one part of the medical history and diagnosis (cardiology), whereas I saw and heard all the evidence in the round which related to every aspect of her conditions, and not just the cardiological impact.

Conclusions on the medical evidence

39. I am satisfied that there is no compelling new medical evidence to justify revisiting my decision.

Transfer to Bambino Gesu

40. It is regrettable that the option of a transfer to Rome was not placed before me at the substantive hearing on 9 October. I appreciate that these cases are sometimes listed swiftly, but the Trust's original application was made on 7 September, about a month before. Had the option been on the table, (i) timely directions could have been given to deal with any matters requiring clarification, and (ii) oral evidence could have been given on the proposal. That would have avoided what has occurred in this case, namely a subsequent application to reopen which leads to additional litigation and pressures all round.

41. The short letter from Bambino Gesu is bereft of detail. It suggests that treatment would be paid for by the government of Italy, but the family would have to organise and fund the transfer. Although the hospital intends to prepare a detailed treatment plan, no Italian clinician has assessed IG, and it is therefore not possible to predict what their medical approach would in fact be in the event of transfer. The outline of their proposal is:
    a. A right ventricular outflow tract stent to manage her cardiological condition.
    b. Continuation of experimental therapies for D-2/L-2.
    c. Life sustaining treatment and palliative care.

42. My reading of 41c. above is that they might well continue to intubate IG and they do not rule out invasive treatment. Counsel for F accepted this is probably the case. Certainly, F would wish those options to be kept open. Given that I have found cardiac intervention (suggested at 41a.) and other invasive treatment (encompassed by, or at least not ruled out by, 40c.) to be inappropriate, what would be the benefit of transfer to Rome? The answer is that, on the evidence and my earlier judgment, there is none. On the contrary, continuation of such treatment would, on my findings, perpetuate a high level of pain and suffering for IG.

43. I have already commented on the proposal by the Rome hospital for cardiac intervention. The evidence before me was that cardiac intervention is inappropriate because of the severity of the underlying conditions, IG's instability and the lack of

prospect of any meaningful quality of life, and the ongoing burden and pain of invasive treatment. It will not cure her conditions. Nothing which I have seen since my judgment has given cause to re-assess that finding. As previously mentioned, the cardiological aspects cannot be considered in isolation from other aspects of her presentation, including D-2/L-2 and severe bilateral progressive ventriculomegaly. IG is an individual who is the subject of an array of complex, interlocking morbidities. No one treatment can unlock all the diagnoses and transform her prognosis. Any treatment for one condition has an impact on other conditions, and an impact on IG herself. It seems to me that to assert baldly that the insertion of a stent for her cardiological condition can improve the combination of all conditions and symptoms assailing her is somewhat simplistic and not consistent with the evidence I received, nor with my findings. The best interests decision on cardiac treatment has been reached, and F is unable to demonstrate that it should be reversed.

44. Similarly, I found that the experimental therapies do not alter the trajectory of IG's conditions. They are in the nature of palliative care.

45. Finally, I reached a clear conclusion that invasive life sustaining treatment is no longer appropriate for IG. The substantial burdens of such treatment significantly outweigh any perceived (but in my judgment negligible) benefit, in a context where her life expectancy is very short, and her conditions irreversible. Put another way, there is nothing to suggest that IG's prognosis would be beneficially altered by the Italian hospital's treatment. On the contrary, it may well prolong pain and suffering if and to the extent that it incorporates invasive procedures which in my judgment are not in IG's best interests, and should not be sanctioned.

46. I have in mind also the potential impact on IG of the logistics of the proposed move to Rome. This has not been explored in any detail, but it is acknowledged by leading counsel for F that the proposed transfer carries extra risk for IG, albeit on F's case that risk is outweighed by the potential benefit. I cannot discount the possibility that the process of transfer will increase the distress and suffering which IG experiences. She is highly unstable. To remove her from her current specialist clinical team for the transfer, and commit her into the care of the air ambulance doctor and nurse who have minimal knowledge of her immensely complex health issues, as a matter of common sense is not without risk. I have some doubt about whether the air ambulance would be willing to undertake this task once they carry out a full assessment and appreciate the complex specialist medical requirements, which is a pre-requisite before they commit to such a transfer.

47. It is open to me to adjourn this matter to enable such matters to be investigated (or indeed any matters which I consider require further exploration). But in my judgment, it is not necessary or appropriate to do so, for I have decided against the application in principle, and further delay is contrary to IG's welfare.

48. I am satisfied that the proposal for a transfer to Rome would not be in IG's best interests.

Conclusion

49. In my judgment, there is no material change of circumstances, or other compelling reason, to justify reconsideration of my original order. The application is dismissed.

In reaching this conclusion I have considered in the round my original judgment, the evidence before me at that hearing, and everything I have read and heard at this hearing.

50. If and insofar as F seeks to admit in evidence the reports/letters of Dr Ross Russell, Dr Walsh and Professor Khan, that application is dismissed, although I emphasise that I have had such evidence in mind when considering the specific application before me.