Neutral Citation Number: [2023] EWHC 2556 (Fam)

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: 13 October 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

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Emma Sutton KC (instructed by **Browne Jacobson LLP**) for the **Applicant**
Victoria Butler-Cole KC (instructed by the **Child's Guardian**) for the **First Respondent**
Bruno Quintavalle (instructed by **Moore Barlow LLP**) for the **Second Respondent**
The Third Respondent did not attend and was not represented

Hearing date: 9 October 2023

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Judgment

This judgment was handed down remotely at 2pm on 13 October 2023 by circulation to the parties or their representatives by e-mail and by release to the National Archives

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MR JUSTICE PEEL

Mr Justice Peel :

Introduction

1. Indi Gregory ("IG") was born on 24 February 2023 and is 7 ½ months old. She is a patient on the paediatric intensive care unit at the Queen's Medical Centre, Nottingham. IG is the much-loved child of devoted parents, and equally dearly loved by her siblings. Her parents are with her at her bedside as much as possible. I have seen photographs and videos of this beautiful child which are a reminder, if anybody needs one, that this case is about the precious life of a very young person, a family member and an individual in her own right.

2. Represented before me were the Hospital Trust, IG's father ("F") and the Guardian on behalf of IG. IG's mother ("M") is a party, but has not engaged in the proceedings, other than providing a witness statement in which she joins common cause with F.

3. In summary, IG's profound disorders, incorporating metabolic, neurological and cardiological aspects are:

   i) Combined D-2, L-2 hydroxyglutaric aciduria, a devastating metabolic disorder which causes progressive damage to the brain;

   ii) Severe bilateral progressive ventriculomegaly in which the brain ventricles are enlarged due to a build-up of spinal fluid;

   iii) Tetralogy of Fallot which affects normal blood flow through the heart;

   At the time of the hearing before me on 9 October 2023, there was also a diagnosis of central diabetes insipidus which is a lack of hormone made by the brain. Following a review by a Consultant in Paediatric Endocrinology and Diabetes on 11 October 2023 (before my judgment was handed down), it was confirmed that diabetes insipidus was no longer present. The Consultant had confidence in the previous diagnosis and stated that this is a picture frequently seen in children with progressive brain failure. The Consultant confirmed that IG's brain function continues to deteriorate.

4. The Trust applied on 7 September 2023 for declarations that it is not in IG's best interests to receive various forms of invasive procedures (including mechanical ventilation, high flow oxygen therapy, line access and CPR) in the event that she deteriorates to a point where such treatment is required to sustain life. Prior to determination of the application, these invasive procedures were in fact implemented following a deterioration in IG's condition during the course of these proceedings. Due to that deterioration in IG's presentation, the Trust, on 27 September 2023, amended its application, seeking authorisation to remove critical care. On the Trust's case, there is no prospect of recovery, her life expectancy is very limited, the multiple treatments she receives are causing her a high level of pain and suffering, and there is no discernible quality of life or interaction by IG with the world around her.

5. M and F oppose the application. They are loving parents who want everything possible to be done to treat IG and prolong life. They accept that she is fragile and has limited life expectancy, but they say that:

i) She has prospects of gaining a degree of autonomy, through being weaned from ventilation and reducing her medication;

ii) She is currently stable, and showing small signs of improvement;

iii) The precise causes of her presentation are unclear and require further time and investigation. Patience and further inquiry are required to be sure of what is the best treatment for her;

iv) She interacts meaningfully with those around her, particularly her family to whom she brings great joy, and derives pleasure from her surroundings albeit in a limited way. She shows no sign of serious pain, and accordingly the benefits of life outweigh the burdens of her treatment.

6. The Guardian supports the application brought by the Trust.

The background

7. IG was known antenatally to have a hole between the two main chambers of her heart, as well as fluid in the brain. She was born in good condition, needing no resuscitation. She was almost immediately found to have a tetralogy of Fallot which is a combination of heart defects. She developed oxygen requirement and bilious vomiting, and was diagnosed with intestinal malrotation where the gut is not twisted correctly, for which she underwent a corrective surgical procedure. An MRI of her brain revealed congenital hydrocephalus, a build-up of fluid in the brain. A shunt was fitted. She went on to develop seizures. Further inquiries led to a diagnosis in June 2023 of Combined D-2, L-2 hydroxyglutaric aciduria, which is characterised by epileptic encephalopathy, respiratory insufficiency, abnormalities in the brain, developmental arrest, and early death.

8. After birth, frequent episodes of profound desaturation (that is to say, insufficient oxygen in the blood) and bradycardia (drop in heart rate) occurred and required bag mask ventilation for increasingly long periods of time, measured in hours. These took place sometimes several times a day (1-7 is referred to in the evidence). Until her recent deterioration, she on 8 occasions required PICU or NICU ventilation. On three occasions, she had cardiac arrests and needed CPR. No clinical way has been found to avoid these episodes. 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. She was last extubated on 31 August 2023, and a semi-permanent Hickman line was inserted.

9. She has challenging IV access, which is problematic in an intensive care setting where lines are required for life sustaining treatment. Apart from the Hickman line, other IV access has been required via needle insertion into veins. These processes, I am satisfied, cause pain and risk infection. On 10 occasions she has needed the drilling of a needle into her bones, often when awake, which again is a painful experience. She has a triple lumen line into her neck.

10. On 6 September 2023 she was once more intubated after a desaturation episode, and has been fully intubated and invasively ventilated since then. She has two nasal tubes, one for ventilation and one for feeding. Pain medication has increased; she is on eight medications for her comfort. She had further major episodes on or around 8 September and 25 September, each lasting 3 to 4 days, characterised by multiple desaturations and significant blood pressure support. She has fever spikes which are indicative (as I find) of brain deterioration, and are not markers of infections as the parents suggest. On 10 September 2023, and again on 7 October 2023, she required a blood transfusion. As outlined above, she had a diagnosis of central diabetes insipidus on 9 October 2023 when the matter was heard. A subsequent review of IG on 11 October 2023 confirmed that this was no longer present, but that her brain function was continuing to deteriorate.

11. The parents' suggestion that IG's presentation (including the desaturation episodes) since the end of August is due to infection is not supported by the evidence. Other than E-Coli detected on one occasion on 28 August 2023, there has been no detection of any infection. Over the past few days, antibiotic treatment (which might have suppressed an infection) has been withdrawn and there are no markers of infection. Multiple tests have been carried out, including by a specialist microbiological team. I am satisfied that for over a month she has not had any infection which has caused or contributed to her presentation.

12. She has been on full life support for about a month, critically ill and extremely unstable. She is intubated, ventilated, with multi-organ support, and sedated. She has the highest level of intensive care support and shows no sign of recovery. Her conditions are untreatable. It is of note that whereas her previous intubations lasted 3 to 4 days, this one has lasted a month, indicating the extent of her deterioration. Sadly, she is not, as the parents suggest, showing signs of improvement. 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 achievable for her.

The proceedings

13. The first hearing of this case was before me on 15 September 2023. IG's mother ("M") did not attend either in person or remotely. She preferred, entirely understandably, to be at IG's bedside. That has been the case at every hearing. F attended in person. I adjourned the application to 27 September 2023, and gave directions to enable the family to obtain legal representation. It has been scandalous that, until recently, parents of children in these immensely difficult serious medical treatment cases have not been entitled to public funding. Fortunately, by a change to the regulations which came into force on 3 August 2023, it is now available on a non-means-tested basis for parents faced with applications for the withdrawal or withholding of life-sustaining treatment in respect of their child.

14. F instructed solicitors on 20 September 2023. On 25 September 2023, a letter was sent by solicitors on behalf of the parents, seeking an adjournment. They indicated that public funding should be available by the end of that week. The solicitors' letter also suggested that there would be a need for expert medical evidence, and that there should be a directions hearing in early October, followed by a further (probably lengthy) adjournment to a 3-day final hearing.

15. On 27 September 2023, I adjourned the case again, so as to allow the lawyers to obtain public funding, and enable the parents to be represented. I listed further hearings on 3 October and 9 October. It seemed to me that it might be possible to conduct a final hearing on either of those dates. I gave further directions on a tight timetable to at least leave open the possibility of determining the case on the first of the two dates.

16. On 29 September 2023, public funding was approved, and solicitors came on the record for F, but not for M.

17. Prior to the hearing on 3 October 2023 (at which F was represented), F filed an application for leave to adduce experts in 4 disciplines:

    i) A mitochondrial expert;

    ii) A neuroradiological expert;

    iii) A consultant cardiologist;

    iv) A paediatric intensivist.

18. A tentative query was raised from the Bar as to whether the proceedings before me were and are family proceedings, such that the test for expert evidence under Part 25 of the FPR 2010 is whether such evidence is "necessary". By contrast, the test under Part 35 of the CPR is whether such evidence is "reasonably required". I would, in fact, have reached the same conclusion under either test. I did not hear any submissions on the point. However, I am quite sure that the FPR apply to these proceedings:

    i) By FPR 2.1 the rules apply to "…family proceedings in

        a) the High Court; and

        b) the family court".

    ii) By s32 of the Matrimonial and Family Proceedings Act 1984:

        a) "family proceedings" means "proceedings which are family business";

        b) "family business" means "business of any description which in the High Court is for the time being assigned to the Family Division and to no other Division by or under section 61 of (and Schedule 1 to) the Senior Courts Act 1981".

    iii) S3 of Schedule 1 of the Senior Courts Act 1981 provides that:

        "To the Family Division are assigned –

        b) all causes and matters relating to:

            ii) the exercise of the inherent jurisdiction of the High Court with respect to minors….."

iv) The application before me is for declaratory relief under the inherent jurisdiction.

v) Finally, I note that by the President's Guidance issued on 24 May 2021, at Part A thereof, applications for declaratory relief (other than under Part III of the Family Law Act 1986) must be brought in the Family Division, as must (by Part B) applications in medical treatment cases e.g., for novel medical treatment or lifesaving procedures.

19. The test for expert evidence is that which is "necessary". Sir James Munby P in **Re: H L (A Child) [2013] EWCA Civ 655** defined "necessary" as: "Lying somewhere between 'indispensable' on the one hand and 'useful', 'reasonable' or 'desirable' on the other hand", having "the connotation of the imperative, what is demanded rather than what is merely optional or reasonable or desirable". I had regard to **St George's University Hospitals NHS Foundation Trust v Casy [2023] EWCA Civ 1092**, in which the Court of Appeal (albeit in a case where the CPR test of "reasonably required" applied) rejected the submission that the first instance judge was wrong to refuse an application for further expert opinion.

20. Save in one respect, at the hearing on 3 October 2023, I refused the application for expert evidence, and gave reasons in an ex-tempore judgment. In summary:

i) The application suggested that evidence would not be obtainable until 20 October, and that the proceedings should be adjourned to a date on or after 30 October. I did not consider that to fit within this child's timescale, given the urgency of the situation.

ii) The medical evidence is extensive. There were three (now five) statements from IG's lead consultant in paediatric critical care, a statement from a consultant in paediatric respiratory medicine, and a statement from a paediatric consultant with specialist interest in inherited metabolic disease; all are clinicians at the hospital where IG is an in-patient. In addition, there are exhibited statements or letters from the cardiology teams at two nearby hospitals. The Trust has also commissioned a second opinion from a paediatric intensivist at another hospital in the form of two letters which are before the court.

iii) The entirety of the medical evidence is unanimous. The medical evidence is that IG is now almost certainly permanently intubated. Her conditions are irreversible and untreatable. The current treatment causes IG pain, exposing her to harmful procedures and therapies which provide no long-term benefit. Life expectancy is severely limited and there are no curative therapies.

iv) There was no medical evidence to the contrary offered by the parents. They said that IG has an infection, but there was no evidence of that. All cultures were negative. In any event the parties agreed that IG would cease to receive antibiotics, and further tests over the following few days should establish the position definitively.

v) The application for expert evidence did not suggest what was incorrect, or might be incorrect, about the medical evidence currently before the court. There was no evidence of any alternative treatment which is theoretically possible, let alone

practicable. There was nothing to indicate a gap in the evidence in any of the fields suggested.

vi) I took the view that the application for expert evidence was somewhat speculative.

21. I did, however, accede the application for a paediatric intensivist provided that they could report by no later than 7 October 2023. In truth, I did not really consider that the threshold of "necessity" was reached, but it seemed fair to the parents to permit them to explore the case with another pair of eyes. In the event, it was not possible to commission an expert report in the time available, not least because public funding was not approved.

22. At the outset of the hearing before me on 10 October, there was no application on behalf of F to adjourn the case to allow time for the proposed expert to report. Nor was such an application made at the end of the hearing, after the evidence had been given. Nevertheless, throughout the hearing I bore in mind the possibility that the unfolding evidence might raise points or queries which would justify additional expert input. In the event, having heard the case, I am quite satisfied that there is no need for any additional expert evidence.

The Law

23. I bear in mind that the human rights of IG, M and F are fully engaged, in particular Articles 2, 8 and 14 of the ECHR. Any interference with those rights must be necessary and proportionate.

24. The parents rely upon the UN Convention on the Rights of Persons with Disabilities, and UN Convention on the Rights of the Child. However, neither Convention is incorporated into the law of this country (unlike the ECHR). It seems to me that neither is therefore directly applicable, as has been clearly set out by the Court of Appeal in **Dance v Barts Health NHS Trust [2022] EWCA Civ 1106** and the Supreme Court in **R (on the application of SC, CB and 8 children) v Secretary of State for Work and Pensions and others [2021] UKSC 26.**

25. In **Manchester University NHS Foundation Trust v Fixsler and others [2021] EWHC 1426; [2021] 4 WLR 95** at para 56, MacDonald J said this:

> "The court may grant a declaration declaring that treatment in accordance with the recommendation of the child's doctors can take place, on the grounds that it is in the child's best interests (see *Re B (A Minor) (Wardship: Medical Treatment)* (1982) 3 FLR 117). The jurisdiction of the court to make such an order arises where a child lacks the capacity to make the decision for him or herself, in the context of a disagreement between those with parental responsibility for the child and those treating the child (*An NHS Trust v MB* [2006] EWHC 507 (Fam)). The court has no power to require doctors to carry out a medical procedure against their own professional judgment."

26. In **Aintree University Hospital NHS Foundation Trust v James [2013] UKSC 67; [2014] AC 591** Baroness Hale said at para 22:

"Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it."

And at paragraph 35:

"The authorities are all agreed that the starting point is a strong presumption that it is in a person's best interests to stay alive. As Sir Thomas Bingham MR said in the Court of Appeal in *Bland*, at p 808, "A profound respect for the sanctity of human life is embedded in our law and our moral philosophy". Nevertheless, they are also all agreed that this is not an absolute. There are cases where it will not be in a patient's best interests to receive life-sustaining treatment."

And at para 39:

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

27. At para 57 of **Manchester University NHS Foundation Trust v Fixsler (supra)** MacDonald J summarised the applicable principles:

"The following key principles can be drawn from the authorities, in particular In *Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:

i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.
ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be.
iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and

instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening [2005] 1 FLR 21 should be recalled: "This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism."

iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests

v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.

vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.

vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.

viii) Each case is fact specific and will turn entirely on the facts of the particular case.

ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB* Holman J, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

> "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."
>
> "The views of the child must be considered and be given appropriate weight in light of the child's age and understanding."

28. This decision was upheld by the Court of Appeal in **Fixsler v Manchester University NHS Foundation Trust [2021] EWCA Civ 1018** and no part of MacDonald J's analysis of the law was disapproved.

29. There is no requisite minimum pain threshold which must be found by the court; **Re A [2016] EWCA Civ 759**. Whether IG experiences pain, and the degree of any such pain, is part of the overall circumstances, inter dependent with all the other factors.

30. In respect of parental views, in **Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust [2017] EWCA Civ 410**, McFarlane LJ observed that: "…the sole principle is that the best interests of the child must prevail, even to cases where parents, for the best of motives, hold on to some alternative view".

The oral evidence

31. I heard evidence from Dr E, consultant in paediatric critical care and IG's named consultant. He was sensitive, thoughtful and compassionate in his evidence. I am quite sure that he wants the very best for IG; it is just that his view of what is best for her differs from the view of IG's parents. Indeed, the clear impression I have of the treating team as a whole (including Dr E) is one of the utmost skill and dedication devoted to the care of IG.

32. Summarising his written and oral evidence, Dr E says:

    i) IG's case is extremely complex, and the status quo is unsustainable, as it involves multiple recurring life-threatening desaturation episodes. Her presentation has deteriorated significantly in recent weeks. She is very unstable, requiring highly skilled interventions.

    ii) There are no curative therapies. Her conditions are irreversible and untreatable. There is no prospect of an improved prognosis. An updated metabolic opinion has been given in a witness statement by Dr Q (who was not required for cross examination), a paediatric consultant with a particular interest in inherited metabolic diseases, who confirms that there is no cure for combined D-2/L-2, and all realistic treatment options have been exhausted.

    iii) Invasive ventilation, coupled with the full range of critical care, might prolong life by a few weeks or months, whereas without such treatment her life expectancy can be measured in days, perhaps a week or two. The life expectancy is not a result of one particular diagnosis per se, it is a consequence of interlocked conditions and causes. Her problems are entwined, impacting across various conditions and disciplines, and cannot be compartmentalised.

    iv) He and the team have consulted widely, nationally and internationally, on how best to treat her, and have followed suggestions where appropriate, for example administering citrate and placing IG on a ketogenic diet. No external clinician has suggested they should do anything different.

    v) D-2/L-2 affects every cell in the body. The brain is the most energy hungry and most affected organ. Sadly, IG's brain is highly abnormal. The most recent MRI scan is from June 2023; it has simply been too dangerous to do another MRI scan since then. The severe hydrocephalus had not meaningfully improved since the insertion of the shunt, which means that the underlying problem is one of brain development rather than a fluid blockage. Compared to a healthy child of

the same age, IG has a large volume of fluid, and a severe lack of brain tissue. The brain tissue which remains is severely compromised. Any updated scan would be unlikely to show any material difference. A paediatric neuroradiologist from the Trust has explained these matters to the parents.

vi) Currently IG shows little awareness of the world around her. She has very poor neurological functioning, falling far short of motor development milestones. She does not fix or follow with her eyes, or smile. She is able to wriggle arms and legs spontaneously but not purposefully. She does not engage meaningfully with the world. IG has been observed holding her mother's finger, which Dr E describes as a reflex movement. She has extremely limited quality of life.

vii) Dr E has himself observed episodes of distress and agitation, which the bedside team see multiple times a day. The current treatment causes IG pain, exposing her to harmful procedures and therapies which provide no long-term benefit. She displays signs of distress during interventions (such as handling, suctioning, use of IV lines, blood tests) and reacts to painful stimuli, including crying (tears well up in her eyes), increased heart rate and mottled skin, wincing and gasping. These episodes of distress can last up to 10 minutes.

viii) He was cross examined about an academic article. It was suggested that because the specific genetic mutations are not known, one cannot tell with any certainty where on the scale of severity and life expectancy she lies. However, that line of questioning rather falls away:

a) The diagnosis report from the geneticist in June 2023 was provided after cross examination (nobody was aware of this point until it emerged during the evidence) and shows IG's specific two mutations, as well as markers referable to the most severe end of this condition.

b) In IG's case, there are multiple co-morbidities. In the research, none of the cases referred to any conditions other than D-2/L-2.

ix) What matters is the holistic presentation of the child, not necessarily the specific cause. She was born with D-2/L-2, and has multiple linked conditions, affecting all her organs. She is one of the most severely ill children Dr E has ever dealt with, and has to be regarded in the context of a constellation of medical factors. Put another way, Dr E said that "We know what is happening, even if the exact sequencing is uncertain". The co-morbidities, arrested development and presentation must all be viewed together**.**

x) There is no practical treatment for her cardiac condition. CPR is highly traumatic, and would be very distressing; it is, moreover, futile, as the problem is not pumping of blood, it is the way blood is pumped. The cardiology team at a nearby hospital unanimously agree that no intervention for her tetralogy of Fallot should be offered as the risks considerably exceed any long-term benefit. Her chances of tolerating and surviving anaesthesia and/or cardiopulmonary bypass are very low; it is unlikely the operation could be safely performed. A cardiology team at a different nearby hospital (asked to provide a further opinion) has concluded that "…we would not be willing to offer any treatment for her heart condition in our institution. We do not think this would be in her

best interests". It further stated: "Our opinion is that any cardiac intervention would not meaningfully alter IG's prognosis and so we do not think that cardiac surgery is indicated".

xi) There is no evidence of any infection which is causative of, or contributory to, her presentation. All cultures are negative. IG's fevers are not due to an underlying infection; that indicates the cause is likely to be abnormality in the central brain stem.

xii) Tracheostomy ventilation is not practical, for reasons set out in a witness statement by Dr R (who was not required for cross examination), a consultant in paediatric respiratory medicine, and unlikely to provide any benefit. It might prevent immediate death due to a desaturation episode, but other organ systems would in turn be affected and death could be a long, drawn out, uncomfortable process.

xiii) This case falls within the Royal College of Paediatrics and Child Health's 2015 guidance in that IG has a progressive condition which is known to be fatal, she has severe neurological deficit, and she is not showing developmental progress.

33. I heard from Dr S, from the Paediatric Intensive Care team at a different hospital. He was asked by the Trust to provide a second opinion. His written evidence concluded: "Very sadly, further ventilation, painful procedures, or resuscitation is not appropriate. This is on the basis that physiological deterioration is occurring regardless of treatment, and that the severity of her progressive neurological condition is such that she can no longer benefit from continued life". He said orally that having heard the evidence of Dr E, his view remained the same. In answer to a question from me, he stated that in his view the treating team has tried everything possible for IG, and that there is no gap in the medical evidence before me which needs to be filled.

34. F in his evidence was composed, dignified and clear. One can only imagine the strain he and M are undergoing. I detected a sense of frustration with the treating team (particularly Dr E) who he believes could and should be doing more. He described IG as a fighter, who interacts with them. He believes she experiences pleasure, and he was adamant that she does not experience any significant pain. His view is that any minor distress is outweighed by the benefits of prolonging life. He would like more clinicians to look at her, different treatments to be considered, and for IG to be afforded time to try and undertake some form of recovery. In his view, she is showing signs of improvement.

35. The Guardian orally confirmed her written analysis which support's the Trust's application. Specifically, in answer to questions from me, she told me that, when visiting IG, she observed her wincing in pain during an intervention. She told me that the nursing staff regularly see IG in distress, multiple times a day.

36. I asked to hear from one of the nursing staff who was present in court, but had not provided a witness statement. Nobody objected. She told me that IG is distressed by the various interventions. She struggles to breathe, winces, coughs and her eyes fill with tears. This takes place several times a day, often lasting several minutes, in response to medical interventions.

Conclusions

37. I turn now to consider my assessment of the evidence and analysis of the case. I have not compartmentalised the evidence, but have taken it into account holistically, guided throughout by the best interests of IG. I have looked at the totality of the evidence. Albeit in a different context the dictum of Dame Elizabeth Butler-Sloss P in **Re T [2004] EWCA Civ 558, [2004] 2 FLR 838** at para 33 resonates:

> "Evidence cannot be evaluated and assessed in separate compartments. A judge in these difficult cases must have regard to the relevance of each piece of evidence to other evidence and to exercise an overview of the totality of the evidence……"

38. The devotion of the family to IG is palpable. Their pain is almost unimaginable. Nobody could fail to be moved by their concern for their child, and their belief in IG's resilience, courage and fortitude is a testament to their fierce determination to do the best for her.

39. The wishes of the family are a powerful consideration. They all have a right to a family life, although that is not an absolute. I readily accept that IG brings them joy. IG's life has an inherent value in itself, and there is a presumption that to stay alive is in her best interests, although that too, is not an absolute.

40. As against that, the medical evidence is unanimous and clear. I accept what I was told by Dr E, Dr S and the nurse. I am satisfied there is no gap which needs further inquiry. Tragically, IG has an incurable condition which, combined with her other morbidities, will lead to a fatal deterioration within, at the most, a few months even if she receives ongoing full critical care, and probably a few days if invasive interventions are withdrawn. Beyond prolonging life, which in itself has a value and to which I pay high regard, treatment is futile. There are no curative therapies. IG is progressively deteriorating, and highly unstable. She has reached the limit of what medicine can achieve. She will not recover from, or even have minor improvement to, her life-limiting conditions. Her short life has consisted of cycles of stability, punctuated by episodes of acute care associated with painful stimuli, leading to the most severe episode of all in early September from which she has not recovered. Physiological deterioration is occurring regardless of treatment. Cardiac treatment will not address the underlying incurable disease. Nor, on the evidence, is it a feasible option as it is clear no cardiological treating team would be willing to provide any cardiac intervention. CPR would be without any purpose for the reasons outlined by Dr E. The parents' belief that her presentation has been caused by infections since early September is not supported by the evidence. The current fever spikes are not symptoms of infections, but a consequence of the progression of the mitochondrial disorder and evidence of ongoing damage to the brain. The reality in this case is that infection is not a cause of IG's multiple diagnoses, but a consequence thereof. Tracheostomy ventilation is not practical or realistic. Whilst the ketogenic diet and administration of citrate may have some effect on reducing the number of desaturation episodes, they are still occurring.

41. Although F's case, as presented through counsel, advanced the proposition that the causes of IG's presentation are unclear, how the various morbidities interlink is unclear, and whether alternative treatment may provide better results is unclear, I do not agree. The medical evidence about this little girl is compelling. All her issues are interlinked,

and her diagnoses and conditions, viewed in the round, lead to her current presentation. I am satisfied that there is nothing more than can be realistically done by the treating team. Similarly, on occasion questions were put to witnesses about the hypothetical treatment for a child not suffering from IG's particular conditions, but ultimately the clinicians, and the court, are concerned with this particular child with this range of presentations.

42. I accept that, at least in theory, IG may have some level of awareness of the world around her, but in my judgment, if so, it is at the barest minimum. At her best, she is stable, but that is far from a settled state. She seems to derive comfort from M stroking her hair, but I accept the clinical observations that she does not follow with her eyes, does not respond to stimuli, and her limb movements are not purposeful. I do not think she experiences any meaningful quality of life, and sadly she never will.

43. I take the view that the parents do not recognise the pain she is suffering, perhaps because, as the Guardian put it, they see IG through their own lens. That is completely understandable. They are hoping against hope for something positive to emerge. However, the evidence clearly establishes that she experiences significant pain and distress several times a day, and each painful episode lasts up to ten minutes. It has been observed by Dr E, other clinical team members, the nursing staff and the Guardian, all of whose evidence I accept. The descriptions of her wincing, struggling to breathe, gasping and developing tears in her eyes are vivid. Such pain is caused by her multiple treatment interventions including invasive ventilation, suctioning, use of IV lines, blood tests and the like. It will continue for as long as the interventions continue.

44. With a heavy heart, I have come to the conclusion that the burdens of invasive treatment outweigh the benefits. In short, the significant pain experienced by this lovely little girl is not justified when set against an incurable set of conditions, a very short life span, no prospect of recovery and, at best, minimal engagement with the world around her. In my judgment, having weighed up all the competing considerations, her best interests are served by permitting the Trust to withdraw invasive treatment in accordance with the care plan presented. That plan envisages weaning her off intubation within 1 week, and facilitating the use of a bag mask for up to a week after extubation. I am quite sure that the Trust will, as they say, do everything they can to care for IG with compassion, providing her with treatment to alleviate pain, and making her as comfortable as possible. That can take place at home or at a hospice, as the parents may elect.

45. I therefore grant the application, and make the declarations sought, with sorrow but on the basis that it is clearly in IG's best interests to do so. I know that this will come as a heavy blow to the parents. I know that they love IG dearly and want the very best for her. I sincerely hope that they will be able to spend as much time as possible with IG.