Neutral Citation Number: [2019] EWHC 2531 (Admin) and [2019] EWHC 2530 (Fam)

IN THE HIGH COURT OF JUSTICE
QUEEN'S BENCH DIVISION (ADMINISTRATIVE COURT)
AND FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 03/10/2019

Before:

THE HONOURABLE MR JUSTICE MACDONALD
(Sitting in Public)

- -

Case No: CO/2767/2019

Between:

TAFIDA RAQEEB **Claimant**
(By her Litigation Friend XX)

-and-
BARTS NHS FOUNDATION TRUST **Defendant**

-and-
SHALINA BEGUM and MUHHAMED RAQEEB **Interested Parties**

Case No: FD19P00378

Between:

BARTS NHS FOUNDATION TRUST **Applicant**

- and -
SHALINA BEGUM and MUHHAMED RAQEEB **First and Second Respondents**

-and-
TAFIDA RAQEEB **Third Respondent**
(By her Children's Guardian)

-and-
XX **Fourth Respondent**

Ms Katie Gollop QC and Mr Eliot Gold (instructed by **Kennedys LLP**) for the **Applicant in FD19P00378 and Defendant in CO/2767/2019**
Mr David Lock QC and Mr Bruno Quintavalle (instructed by **Sinclairs Law**) for the **First and Second Respondents in FD19P00378 and Interested Parties in CO/2767/2019**
Mr Vikram Sachdeva QC, Ms Nicola Kohn and Mr Alan Bates (instructed by **Irwin Mitchell LLP**) for the **Claimant in CO/2767/209 and the Interested Party in FD19P00378**
Mr Michael Gration (instructed by **CAFCASS Legal**) for the **Third Respondent in FD19P00378**

Hearing Dates: 9 to 13 September 2019

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.

Mr Justice MacDonald:

INTRODUCTION

1. The dilemma presented by cases concerning, as this case does, the withdrawal of life sustaining treatment from a child rests on the fact that they address what many see as an appalling present, but a present that for many also remains sanctified morally or as an article of religious faith because life subsists. For the treating doctors involved in such cases, seen through the prism of medical best interests life is at best a barely wakeful shadow burdened by futile medical treatment or, at worst, mere oblivion. For parents, seen through the prism of abiding love and fierce devotion and the amplifying effect on those emotions of the flattering voice of hope, life is still a faded jewel that has not yet been robbed away from the body and one that may yet regain its lustre. Within this context, the decision for this court in these concurrent proceedings is a grave, multifaceted and complex one.

2. I recognise at the outset of this judgment that such cases, touching as they do on the very nature, purpose and value of human life, raise emotive, complex and contentious issues that generate strong feelings on both sides of the litigation and in the wider public and professional sphere. Be that as it may, it is important to state at the beginning that the duty of this court is to decide the applications before it by reference to the law. The court must, and does disregard the urging of media and social-media campaigns, petitions, and pressure groups and the views of informed and uninformed commentators and opinion writers. The court does so not because the views and opinions of those diverse constituencies are in any way unwelcome or invalid, but rather because the decisions of the High Court in these most challenging of cases are determined solely by application of the law, in order to reach a decision on the seminal question of best interests.

3. Within the foregoing context, the court has before it two sets of proceedings concerning Tafida Raqeeb, a little girl born on 10 June 2014 and now aged five years old. The first set of proceedings, issued on 16 July 2019, concerns an application by Tafida for judicial review of what is said to be the decision by the Barts Health NHS Trust (hereafter 'the Trust') not to agree to Tafida being transferred to a hospital in Italy for continued medical treatment pending the determination of an application to the High Court for a declaration regarding her best interests. The second set of proceedings, also issued on 16 July 2019, concerns an application by the Trust for a specific issue order pursuant to s. 8 of the Children Act 1989, and an application for a declaration pursuant to the inherent jurisdiction of the High Court, that it is in Tafida's best interests for her current life-sustaining treatment now to be withdrawn, a course of action that will lead inevitably to her death.

4. In the application for judicial review Tafida acts through her litigation friend, XX. On 5 September 2019, I dismissed an application by the Trust to remove XX as the litigation friend for Tafida. My reasons for so doing will be set out in a separate judgement. Tafida is represented in the application for judicial review by Mr Vikram Sachdeva, Queen's Counsel, Ms Nicola Kohn and Mr Alan Bates of counsel. The Trust is the defendant to the application for judicial review and is represented by Ms Katie Gollop, Queen's Counsel. Tafida's parents, Shelina Begum and Mohammed Abdul Raqeeb are interested parties in the application for judicial review, represented by Mr David Lock, Queen's Counsel and Mr Bruno Quintavalle of counsel. The

Trust is the applicant in the applications made pursuant to the Children Act 1989 and the inherent jurisdiction and the parents and XX are respondents to those applications, each party with the same legal representation as set out above. Tafida is a party to the application under the inherent jurisdiction and is represented by Mr Michael Gration of counsel through her Children's Guardian, Kay Demery.

5. In this case I have also had the benefit of written representations from the Bangladesh High Commissioner to the United Kingdom (the parents each also being citizens of the People's Republic of Bangladesh), and a *fatwa* (being a ruling on Islamic law given by a recognised authority) from the Islamic Counsel of Europe, obtained and filed and served by the parents. In addition, the parents obtained, and I admitted into evidence with the consent of the parties, a legal opinion authored by Dr Giacomo Rocchi, a Judge of the Italian Supreme Court of Cassation, provided in his capacity as an acknowledge expert in Italy on issues of the type with which this court is concerned. This court extends its gratitude to those who have provided the aforesaid documents, to which it has given careful consideration.

6. In this case Tafida and her parents argue that, before any issue of best interests is considered, Tafida is entitled to what has been termed an "anterior procedural ruling" in the claim for judicial review that the decision of the Trust to refuse her transfer to Italy is unlawful and that, accordingly, the decision of the Trust should be quashed, a mandatory order made requiring the Trust to retake the decision or a mandatory order made requiring the Trust to permit the transfer of Tafida with a declaration that the Trust may not prevent that transfer, following which decision the court would be *functus* as to Tafida's wider best interests. Within this context, with respect to the order of proceedings, over the first two and a half days of the final hearing, I heard the submissions in the application for judicial review. Having been satisfied that it was necessary and appropriate to do so, I then moved to hear the oral evidence of the mother and submissions in the application under the Children Act 1989 and the inherent jurisdiction in respect of Tafida's best interests. Given the gravity, complexity and range of the issues engaged in this case, I thereafter reserved my judgment and now set out the decisions I have made, and the reasons for those decisions, in each set of proceedings before me. Given the court has heard and determined *two* sets of proceedings in one hearing and given the gravity, complexity and range of the issues engaged in each set of proceedings, this judgment is, of regrettable necessity, lengthy.

BACKGROUND

7. Tafida was born on 10 June 2014 and is the daughter of Shelina Begum and Mohammed Abdul Raqeeb. Each parent holds parental responsibility for Tafida. Tafida has a brother and a large extended family, many of whom live on the same street as Tafida and her parents. The parents are committed Muslims and were raising Tafida in the Islamic religious tradition. The applications before the court concerning Tafida arise in what all parties acknowledge is a truly mournful situation. The brevity with which the genesis of that situation can be stated articulates starkly the sudden and devastating manner in which it arose early on the morning of 9 February 2019.

8. Prior to that date, Tafida was a happy, joyful little girl, as is so evident from the description of her provided to me by her parents and relatives and in the videos of Tafida I have seen from before February 2019. She was the helping hand monitor in

her class, her favourite film was 'Frozen', she attended ballet lessons and she was always running everywhere. She was bilingual in English and Bengali, had learnt some verses from the Quran and was due to attend Arabic classes in September 2019. She had already, at her young age, travelled widely across the world. At approximately 5.15am on 9 February Tafida woke her mother and complained of a headache. Shortly afterwards Tafida stopped breathing. The mother immediately summoned an ambulance, which arrived promptly and conveyed Tafida to Newham University Hospital. Examination revealed a large blood clot on Tafida's brain considered to be life threatening and requiring urgent surgical intervention. Some three hours later an operation was carried out at Kings College Hospital. The cause of the bleeding in Tafida's brain was identified as a ruptured arteriovenous malformation (hereafter AVM). This is a rare condition and was undetected and asymptomatic in Tafida. The ruptured AVM has resulted in extensive and irreversible damage to Tafida's brain.

9. Following surgery on 9 February 2019 Tafida was treated in the paediatric intensive care unit of Kings College Hospital for nearly two months before being transferred to the Royal London Hospital on 3 April 2019. I pause to note that in his report of 10 July 2019, Dr H, paediatric neurologist from Kings College Hospital, states as follows (emphasis added):

> "At the nadir of her illness in March 2019, myself, Mr Z and Dr S, consultant in paediatric intensive care and PICU senior nurses jointly spoke to the parents and counselled them that Tafida was extremely unlikely to survive her illness and that if she did she would be profoundly disabled and ventilator dependent, needing permanent intensive care inputs for a short few months ahead. We recommended that Tafida's care was redirected to palliative care and that she was not given invasive treatment inputs that would of no benefit to her on futility grounds. Parents could not bring themselves to withdrawal of treatment *under any circumstances*. They wanted all active treatments for her."

10. Save for a short period of further treatment at Kings College Hospital between 12 and 25 April 2019 to deal with a build-up of fluid on Tafida's brain, Tafida has remained at the Royal London Hospital to date. She is provided with artificial ventilation, which artificial ventilation is keeping her alive. Tafida's mother has demonstrated unerring and conscientious dedication to her care during this time, giving up her career as a solicitor and remaining in the hospital to meet Tafida's day to day care needs, assisted at times by the father, Tafida's nanny and members of the extended family. Whilst there is a dispute about whether a further cerebral insult occurred between 2 and 10 June 2019, which dispute it is not necessary for the court to determine for the purposes of these twin proceedings, all parties accept that Tafida has been left with catastrophic damage to her brain.

11. Within this tragic context, two key issues of fact came into focus during the course of submissions. First, whether the parents at any point prior to this hearing consented to the withdrawal of life sustaining treatment from Tafida (the Trust contending that this question is relevant to the courts assessment of the weight to be accorded to the strength of the religious objections to the withdrawal of treatment in this case). Second, the precise nature of the decision made by the Trust in relation to the question of whether Tafida could be transferred to the Gaslini Hospital in Italy. Whilst the

submissions on each of these issues were extensive, each issue can be dealt with shortly.

12. In relation to the question of whether at any point consented to the withdrawal of life sustaining treatment from Tafida, the answer is plainly ‘no’ on the Trust’s own evidence. In her statement, Dr D, Tafida’s treating paediatric intensivist, makes clear that “The family never consented to the withdrawal of treatment and of course we never acted without parental consent.” Within the documentation before the court, there is clear evidence that the mother in particular, but also the father stated on more than one occasion that the active withdrawal of treatment from Tafida was against their personal and religious beliefs. There is evidence that in late June 2019 the mother in particular was struggling with the question of the right course of action and agreed that should Tafida deteriorate *whilst on life support*, she should not be resuscitated. However, as Dr D makes clear in her evidence, at no point does the evidence suggest that the parents consented to the withdrawal of the life-sustaining treatment itself. Within this context, I am also satisfied that there was never a point where the Trust intended to withdraw treatment from Tafida without her parents’ consent. Within the context of conversations taking place with the parents in late June, and the treating teams firm view that continued life sustaining treatment was not in Tafida’s interests, it is apparent that at one point the doctors believed they had reached a consensus with the parents and a date for the withdrawal of treatment was set subject to the outcome of the parents’ enquiries of other hospitals. Once again however, it is clear that the parents at no point gave their informed consent and the plans were, accordingly, never enacted. In any event, matters were subsequently overtaken by the outcome of parental enquiries of the Gaslini Hospital.

13. In light of the firm medical opinions being expressed by the treating team in London, the parents commenced contact with a number of hospitals around the world, to see whether they would be in a position to assist Tafida. As part of this process they contacted a team of doctors from the Gaslini Paediatric Hospital in Genoa, Italy (in which hospital the child of a family friend of the parents was being treated). By 5 July 2019 the parents had obtained, and the Gaslini had been provided with, a complete set of medical records for Tafida. The team from the Gaslini Hospital who considered Tafida’s case comprised Dr Armando Cama, Professor of Paediatric Neurosurgery, Dr Carlo Minetti, Professor of Child Neurology, Dr Luca Ramenghi, Honorary Professor of Neonatology and Dr Andrea Rossi, Honorary Professor of Neuroradiology. Following the receipt of the report dated 6 July 2019 from these doctors, and in circumstances where the opinion of the experts from the Gaslini Hospital did not state that they believed that Tafida should have all medical care removed, on 7 July 2019 the parents made a request to the Dr Paolo Petralia, Director-General of the Gaslini Hospital, to transfer Tafida from the Royal London Hospital to the Gaslini Hospital for care and treatment. By a letter to the parents dated 7 July 2019, Dr Petralia accepted this request subject to the parents being responsible for all costs associated with Tafida’s transfer to and treatment at the Gaslini Hospital.

14. Once again, whilst during the course of submissions the precise nature of the decision made by the Trust in response to the parents’ request for the transfer of Tafida to Italy was the subject of some dispute, the position is, again, tolerably clear on the documentary evidence before the court. It is plain from an email sent by the mother on 7 July 2019 to Dr D that on that date that the parents requested that the treating

team in London agree to the transfer of Tafida to the Gaslini Hospital. In her statement of 6 September 2019, Dr D confirmed that she understood the mother, by her email of 7 July 2019, to be asking for this once the necessary transfer arrangements had been put in place. It is further clear from the documentary evidence before the court that by 8 July 2019 the treating team had indicated to the parents that they would *not* agree to the transfer of Tafida to the Gaslini hospital because, in circumstances where the treating team considered that such a transfer would not be in Tafida's best interests, and hence there was a dispute as to best interests between the parents and the doctors, the court would have to decide that issue.

15. On 12 July 2019 two further clinicians from the Gaslini Hospital, Professor Lino Nobili, Chief of Paediatric Neurology and Paediatric Psychiatry at the Gaslini Hospital, and Andrea Moscatelli, Honorary Professor of Paediatric Intensive Care, examined Tafida via a video-link arranged by the Royal London Hospital. Exhibited to Dr D's statement is a record of this video-link which records as follows:

> "The team at Gaslini were asked the purpose of accepting the parents (*sic*) request to take over the care of Tafida. Based on the assessment they were able to make from the documentation sent to them by RLH, they thought it was highly unlikely that they could do anything to treat Tafida and lead to an improvement. They explained however that they would be able to offer palliative care, which would consist of ensuring Tafida was comfortable and not suffering. It may also entail performing a tracheostomy, so that Tafida could go home on long-term ventilation. As Tafida does not fulfil the criteria for brain-stem death, Italian law does not allow active withdrawal of care. The parents had no further questions. Following the call with the Gaslini team, the parents said they would reflect on this, discuss with family and give us their views at a meeting on Monday 15 July."

16. On 15 July 2019, following the examination by the clinical team at the Gaslini Hospital, that team confirmed as follows in a letter to Tafida's parents which is contained in the bundle:

> "This letter aims to corroborate all the points discussed during our video conference last Friday, from 1.30 to 2.30pm, Italian time and the previous email correspondence. We confirm we can take care of Tafida Raqeeb including potential palliative care and without any limitation of length of staying. We also add under Italian laws Tafida does not fulfil the criteria for active withdrawal of care as she cannot be judged as "brain dead".
>
> We have already given our clinical judgment based on the exhaustive clinical documents received from London, nevertheless we cannot exclude that in order to get the best standard of care for Tafida may receive tracheostomy and gastrostomy once Tafida will be under our clinical responsibility. Having consulted the full medical records again, discussed her condition with her treating clinicians and observed the patient's conditions by video link, we can confirm that such transportation can be effected safely without undue risk to the patient as we can guarantee during transport the same level of care that Tafida is currently undergoing in the

> PICU. In conclusion, although we may be not able to cure Tafida, we will take care of her to the best of our abilities."

Within this context, the parents continued to seek Tafeeda's transfer to Italy. On 19 July 2019 the Gaslini Hospital provided a detailed "Transport Plan" for Tafida detailing the Gaslini Critical Care ECMO and Transport Team's proposals for conveying Tafida to the Gaslini Hospital and the medical care that will be made available to her on arrival at that institution, which plan, as I have noted, Dr Playfor considers appropriate. The parents have secured private funding for Tafida's transfer to, and continued treatment at the Gaslini Hospital. It became clear during the course of submissions that the parents will, if it proves possible to move Tafida to a position where she can be maintained on ventilation at home, contemplate a return to this jurisdiction with Tafida in order to care for her at home with family support.

17. As noted above, this court has also had additional documentation in the form of a *fatwa* from the Muslim Council of Europe, a legal opinion on authored by Dr Giacomo Rocchi provided in his capacity as an acknowledge expert in Italy on issues of the type with which this court is concerned and a written representation from the Bangladesh High Commissioner to the United Kingdom. No party has sought to press during this hearing the representations from the Bangladesh High Commissioner, in part because it remains unclear whether they are yet in their final form. The essential thrust of the representations is that any Bangladeshi national, including doctors, who consented to, or participated in the withdrawal of treatment from Tafida would be guilty of a criminal offence under the law of Bangladesh and liable to prosecution in that jurisdiction. Whilst grateful to the High Commissioner for this information, I have not held it necessary to investigate these matters further or to place reliance on them in reaching my decision.

THE MEDICAL POSITION

18. In this case the court has the following medical opinions and evidence on Tafida's medical condition and prognosis:

    i) A report dated 1 July 2019 from Dr T, Tafida's treating consultant paediatric neurologist at the Royal London Hospital.

    ii) A report dated 10 July 2019 from Dr H, Tafida's treating paediatric neurologist at Kings College Hospital.

    iii) A report secured by the parents dated 20 August 2019 from Dr Andrea Moscatelli, anaesthesiologist and intensivist paediatrician, Professor Lino Nobili, Professor of Child Neuropsychiatry and Dr Michele Torre, paediatric surgeon, each of the Gaslini Hospital.

    iv) A report dated 21 August 2019 secured by the Litigation Friend in the judicial review proceedings from Dr Stephen Playfor, consultant paediatric intensivist at the Royal Manchester Children's Hospital dealing with the question of transfer.

    v) A report dated 30 August 2019 secured by the Trust from Dr Martin Smith, consultant in paediatric neurology at the Oxford John Radcliffe Hospital.

vi) A note of the experts meeting that took place on 6 September 2019 between Dr D, Dr Martin Smith, Dr Stephen Playfor and Professor Lino Nobilli.

vii) A supplementary medical report dated 8 September 2019 secured by the Litigation Friend in the judicial review proceedings from Dr Stephen Playfor dealing with the question of medical best interests.

Tafida's Overall Medical Condition

19. With respect to Tafida's medical condition, there is no dispute that on 9 February 2019 she suffered a catastrophic rupture of a previously undetected and asymptomatic congenital AVM, resulting in a bleed into the right side of her posterior fossa, causing brain stem compression, displacement of the midline structures of the brain and obstruction in the flow of cerebrospinal fluid. As I have noted, whilst their remains a dispute as to whether Tafida suffered the totality of the damage to her brain on 9 February 2019, or sustained further damage at a point thereafter between 2 and 10 June 2019, it is common ground that the hypoxic ischaemic damage now extends to her right cerebellar hemisphere, vermis, two thirds of her left cerebellar hemisphere, her cerebellar peduncles, midbrain, pons, nearly one third of the medulla, the fronto-parietal, temporal and occipital lobes, caudate nuclei and globus pallidi. No party seeks to dispute that the proposition that, as a result, Tafida has extensive disabilities. Dr Smith considers Tafida's condition to be exceptionally complex.

20. During his examination, Dr Smith was able to elicit ongoing breathing effort by Tafida without mechanical ventilation for a period of 10 minutes maintaining good oxygen saturations but with instances of pauses of nearly 40 seconds, associated with a slowing of her heart rate, a rise in her end tidal CO_2 levels without change in her respiratory rate. The Italian doctors state that, subject to further assessment, they are and were comfortable with an assumption that the motor neurones are activating the respiratory muscles. However, whilst Tafida has regained some breathing after the initial cerebral insult, the consensus of medical opinion is that this is currently insufficient by itself to sustain her breathing independent of the ventilator and she remains ventilator dependent. Tafida does not exhibit episodes of pronounced muscle spasm although she has episodes believed to be epileptic in nature and treated with Levetiracetam. Within this context, it is agreed between the doctors that Tafida is otherwise medically stable.

Level of Awareness

21. With respect to current level of awareness, on 27 June 2019 an EEG demonstrated very severe generalised cerebral dysfunction with no reactivity to external stimulation. Somatosensory evoked potentials the same date showed response in the cervical region to stimulation of the median nerve, but no cortical response. On 1 July 2019 Dr T reported that on neurological examination Tafida had a sleep/wake cycle with eye opening and closing. Dr T reported no brainstem function save for pupillary response and some breathing drive. In their report of 20 August 2019 the Italian team consider that Tafida has a severe alteration in her state of consciousness, that they were unable to verify the parents' reports of motor responses related to verbal stimuli and nor could they themselves elicit any responses that could be unequivocally be interpreted as awareness, although they did note that Tafida opened her eyes spontaneously several times, that her eyes could sometimes be maintained

fixed in axis and she had a direct and consensual pupillary light reflex. Dr Smith concludes that during his assessment he noted no signs of volitional spontaneous movement in Tafida's arms and legs but noted a video (also shown to the court) where Tafida appeared to life her arm and turn it outwards to place rolled up bandage into the hand of her nanny. Dr Smith could identify no evidence of visual function, although in respect of Tafida's "doll's eye response", the absence of which is one of the features of brain stem death, Dr Smith considered the results to be equivocal, he not being confident that a response was entirely absent. With respect to awareness of touch and of voices, Dr Smith records as follows:

> "36. I asked mother to stimulate Tafida by voice and touch whilst positioned on her left side. It appeared to me that Tafida's eyes slowly moved to the left side. I then asked mother to move to the opposite side of the bed and repeat the exercise. Once again it appeared to me that Tafida's eyes moved to the right side where mother was now positioned. Finally I asked mother to return to the left side. On this occasion there was no obvious eye deviation to the left. I repeated this task at the end of the assessment and on the second occasion there was no convincing response in terms of eye deviation to stimulation.
>
> 37. If this was a genuine sign of responsiveness, my instinct is that Tafida was responding to her mother's voice and touch, but was probably not visually aware of her mother."

22. Within the foregoing context, there is a consensus of medical opinion that if Tafida is aware, she is minimally so. During the meeting of doctors on 6 September 2019 Dr D stated that she is "reasonably certain she has no or minimal awareness". At the same meeting Professor Nobili stated they were not able to detect any level of awareness but cannot exclude the possibility of some level of conscious awareness. Dr Playfor considered he had seen no convincing evidence of awareness. Dr Smith repeated the view as set out in his report in which, having noted that distinguishing between a vegetative state (VS) and a minimally conscious state (MCS) is very challenging and, in children, most paediatric neurologists do not attempt the distinction in routine practice, he concludes as follows:

> "54. It is very difficult to accurately state whether Tafida is in a vegetative state or a minimally conscious state. I would be very wary of the risk of misinterpreting the absence of responses in Tafida as VS because of the inevitable limitations on the accuracy with which medical science is able to test for awareness in a child like Tafida who has no useful vision, no speech, impaired or no pain sensation and a sever movement disorder."

And, within this context, and in common with the clinicians at the Gaslini Hospital:

> "59. Bearing in mind the limitations of medical science in assessing and categorising between VS and MCS, I am inclined to adopt the approach advocated by Wade (2017), that the distinction between VS and MCS is somewhat artificial. Whilst I feel Tafida's condition is consistent with VS, I am reluctant to exclude the possibility of some minimal awareness."

Tafida's Ability to Feel Pain

23. With respect to Tafida's ability to feel pain in the context of the possibility that she retains some minimal awareness, in early July 2019 Dr T reported that Tafida "flexes to pain". In his report on 10 July 2019 Dr H relates that Tafida shows no facial grimace to deep pain and does not cough or gag to endotracheal tube suction. On examination, the Italian team likewise noted no facial grimace to pain and only intense pain stimulation elicited flexion of the legs or arms, further noting that no EEG changes after painful stimulation are visible. Within this context, the Italian team concluded that:

> "Tafida does not seem to perceive pain in her resting state and reacts only to intense painful stimulations with flexion. The suggests she feels no pain under her standard condition."

24. In the meeting of doctors held on 6 September 2019 Dr D stated she had not seen a response to pain such as in increase in heart rate or a facial grimace or withdrawal from pain. Dr Smith concurred, having stated in his report as follows:

> "79. Tafida's experience or lack of experience, of pain has to be considered. Accurate and reliable assessment of ability to experience pain, like assessment of awareness, is fraught with difficulty in a patient as severely neurologically impaired as Tafida. We cannot ask her, she cannot speak or communicated, and her ability to move is so impaired that it is difficult to interpret any movement she may make, or an absence of movement, after the application of a stimulus that would cause pain in a child not neurologically impaired. The absent SSEP responses suggest that sensory information from the rest of the body is not perceived within the sensory processing areas of the brain, although this test does not necessarily imply total absence of the ability to feel pain.
>
> 80. There is no evidence that Tafida's everyday life causes her pain. I have not seen any evidence to suggest to me that she does experience pain in painful stimulus is applied. However, as to both her everyday life and response to stimulus it is impossible to prove a negative, and in the same way I cannot exclude some limited awareness I cannot exclude the ability to perceive some pain. It may be that her brain stem damage protects painful stimuli connecting to higher cortical centres that are in any event so damaged that pain could not be experienced in a conventional sense event if the brain stem was intact, but because of the difficulties of testing and interpretation, it is difficult reliably to say more."

Future Options for Treatment and Care

25. With respect to future treatment and care options, there is agreement between all doctors, including the team from the Gaslini Hospital, that Tafida will not substantially recover and cannot, accordingly, be "cured". Within this context, there is consensus that any continued medical intervention will be aimed at sustaining Tafida's life in or very near to her current condition. Two key issues emerge from the medical evidence in this context.

26. First, the question of whether it will, ultimately, be possible to wean Tafida off mechanical ventilation. Whilst there is consensus that Tafida is currently unable to breath without mechanical support, and the doctors in this jurisdiction are sceptical that this position will ever change, the Italian doctors consider that the question of whether Tafida could be weaned off a ventilator following a tracheostomy requires further, detailed evaluation.

27. Second, the question of whether, even if she is required to remain on mechanical ventilation, Tafida could return, and be cared for at home. In this respect the Italian doctors commented in their report on 20 August 2019 that "a possible scenario is to discharge her at home on mechanical ventilation with a tracheostomy, since she is not oxygen dependent" if this was ultimately assessed to be proportionate to her clinical status. They went on to observe that:

> "Tracheostomy could be managed safely at home by well trained family caregivers. In our experience, we have been following plenty of tracheostomised children cared at home by parents with no major accidents (life threatening). The same experience is reported in the medical literature. There are risks related to the management of a child with tracheostomy at home (e.g. obstruction, displacement of the tracheostomy tube) that should be taken into consideration and must be overweighted by the benefits given by the tracheostomy itself. In the case of Tafida, the tracheostomy could be life sustaining, because of the tendency of airway obstruction. Our centre, being the site of tracheal team, is used to train parents to tracheostomy management at home".

28. In their report dated 20 August 2019 the Italian team complete a comprehensive risk analysis regarding a tracheostomy and conclude that the risks are well known and do not contraindicate the procedure in Tafida, albeit they recognise that there is an ethical component in that:

> "Tracheostomy imposes a relevant burden to the family, since a trained caregiver should always look after Tafida 24/7. The life expectancy of Tafida would increase, even if withdrawal of care could always be possible, if indicated, through weaning from mechanical ventilation, and appropriate sedation."

The Italian team also consider that a gastrostomy would be advantageous and that a PEG would improve Tafida's quality of life. Within the foregoing context, in the meeting of doctors on 6 September 2019, Dr D expressed herself to be reasonably confident that, with a care package and training, Tafida will be able to go home. Professor Nobili agreed, as did Dr Playfor and Dr Smith.

29. Within this context I pause to note that, during the course of submissions, the approach to the treatment of other children in this jurisdiction in a similar situation to Tafida was raised in circumstances where both Dr Playfor and Dr Smith deal with that issue in their respective reports. A degree of caution is required in respect of these submissions as the court does not have precise details of the conditions of other such children. However, in his unchallenged report dated 21 August 2019, Dr Playfor notes, in the context of observing that PICU has transitioned from a speciality that

deals with acute illness in the mostly previously well, to one that is part of a multidisciplinary team that cares for children with chronic illness, as follows:

> "[3.10] With these changes, and with the increase in numbers of children dependent on technology to survive living at home, there has been a steady increase in the proportion of children admitted to PICU for whom the clinical team consider treatment to be inappropriate.
>
> [3.11] To give the court some perspective of TR's neurological status in the context of current PICU practice: In a PICU the size of the Royal Manchester Children's Hospital unit, a child in a clinical condition broadly similar to TR will be admitted for mechanical ventilation at least once every 3 or 4 months. Such children will typically be supported on some form of long-term ventilatory support either at home or in another part of the hospital and suffer an acute deterioration, most commonly pneumonia. In the majority of cases these children will recover to their baseline status and be discharged from PICU to another ward, or home, without the issue of withdrawal of life-sustaining therapy being addressed.
>
> [3.12] There is no practical reason evident why TR could not be managed at home on long-term ventilatory support assuming the necessary pre-conditions can be satisfied.
>
> [3.13] Although no specific data have been published, in my experience, given the increased duration of admission associated with complex chronic disorders, on any given day there will be several children in a clinical condition broadly similar to TR being mechanically ventilated in UK PICUs."

Dr Smith agrees with Dr Playfor's observation that there are other children in most other UK centres with severe neurodisability maintained on long term ventilation at home. Likewise, in her statement of 30 August 2019, Dr D says as follows with respect to Dr Playfor's observations in this regard:

> "I agree with him that there are children with a similar level of damage to Tafida whose lives are sustained long term sometimes in hospital and sometimes at home, sometimes on a tracheostomy alone and sometimes on a tracheostomy plus a ventilator and that sometimes the issue of whether continued treatment is in a child's best interests has not been considered. This can happen for lots of different reasons and in my experience, can sometimes depend on how the injury arose. Whether it is right that there is no consideration of whether more treatment is right for the child is debateable. I have tried to focus on Tafida".

30. Finally in respect of options for future medical care, there is no dispute that, should the court consider that it is in her best interests, the transfer of Tafida to Italy can be effected with minimum risk. In his report considering the efficacy of the proposed transfer, Dr Playfor concludes that the 'Transport Plan' proposed by the Gaslini Hospital in one that is entirely reasonable and that the proposed transfer of Tafida to the Gaslini Hospital is "extremely unlikely to have any medical or welfare impact" on Tafida.

Prognosis

31. With respect to prognosis, as I have noted above, there is no dispute that the catastrophic rupture of the AVM on 9 February 2019 resulted in hypoxic ischaemia that has caused irreversible damage to Tafida's brain. All the doctors concur however that, if maintained on mechanical ventilation, Tafida will live, as Dr Smith puts it, for a substantial period of time. The temporal range given by the medical professionals being between ten and twenty years.

32. Within this context, as to the chances of their being an improvement in Tafida's level of neurological functioning, Dr Smith concludes in his report that:

> "61. It is certainly possible that Tafida could show some small improvements over time if she remains alive. As discussed above, the adult literature contains examples of late improvement from VS and MCS, although almost without exception these individuals were still left with severe neurodisability. The adult literature also emphasises the distinction between traumatic and non-traumatic mechanisms of brain injury, the former having the possibility of some recovery of consciousness for as long as 12 months, whereas the latter are unlikely to improve substantially after 3 months. Tafida's injuries are non-traumatic, and therefore the adult literature would suggest the chances of any substantial improvement at this stage is very small."

And, in the context of considering the concept of brain plasticity:

> "Therefore, whilst the concept of neuroplasticity is entirely valid, the said reality is that the chance of substantial recovery is unfortunately very slim, and there can be no reasonable doubt that Tafida will remain with severe neurodisability for the remainder of her life."

33. Within this context, in the meeting of doctors on 6 September 2019 Dr Smith stated as follows:

> "I am not a dogmatic physician and prefer not to box myself in with absolute statements where possible, but for the purposes of this situation, I have to be as clear as possible that, whilst a further 12 months might see some slight changes, it would nevertheless leave Tafida with a profound neurodisability. I do not consider a further 12 months will transform her situation in any meaningful way which will improve her quality of life."

At the meeting on 6 September 2019, Dr D considered it "incredibly unlikely" that Tafida's neurological function would improve. Professor Nobili considered that there is a "very, very low possibility" of Tafida improving neurologically. Professor Nobili said he could not exclude the recovery of some awareness. Whilst Professor Nobili could not say whether this would be better for Tafida or not, having heard Dr Smith's view, he stated that any change could not be considered as an improvement given the severity of her clinical situation. Dr Playfor stated that, if pressed, he would say Tafida's neurological function will change but not in a way that could be described as an improvement.

34. The question raised by Professor Nobili and Dr Playfor as to whether any change in awareness would be an improvement arises in the context of a further aspect of Tafida's prognosis that is the subject of medical consensus, namely the development of conditions that, were she to develop a greater level of awareness could be burdensome to her. In addition to the continuation of a severe movement disorder and immobility comprising combination of spasticity and dystonia and severe cognitive impairment, those conditions will likely include drug resistant epilepsy, scoliosis with associated cardio-respiratory impairment, which may require surgery, partial or full hip dislocation, pneumonia with worsening respiratory failure, bone disease due to osteopaenia associated with pathological fractures, the development of renal stones, pressure sores, hypertension and malignancy.

Medical Best Interests

35. Tafida's treating doctors are now clear in their opinion that further life-sustaining treatment is not in Tafida's best interests. Dr D considers that such treatment "is a continuing burden for Tafida" and should be discontinued and Tafida palliated. Dr H is of the view that the proposition that because Tafida does not feel pain or distress further treatment will not cause pain or distress is an "artificial semantic construct" as *if* she had a "sentient" brain she would feel pain and distress and considers that she should be allowed "the dignity of dying peacefully."

36. With respect to the experts instructed in this matter, Dr Smith recognises that the legal concept of Tafida's best interests is wider than medical considerations and that that is an issue for the court to decide. Within this context, he states that:

> "After very careful and lengthy consideration and reflection, and with a heavy heart having personally observed and been affected by the devotion of her parents, I have come to the conclusion that the only medical benefit that continued ventilation (whether with or without a tracheostomy) could provide Tafida is the continuation of life. I think any chance of regaining any level of awareness or increased awareness is negligible. With awareness or greater awareness would come awareness of the burdens of her severe neurodisability and these will only increase if ventilation continues."

37. Dr Playfor considers the burdens of ongoing mechanical ventilation, if present at all, are currently modest. However, in light of a lack of convincing evidence that Tafida has any awareness and therefore lacks the ability to derive benefit from continued life, Dr Playfor considers that Tafida's clinical situation meets the RCPCH criteria under which withdrawal of life-sustaining treatment may be ethically permissible. Within this context, Dr Playfor considers that ongoing life sustaining treatment is not in Tafida's best interests, primarily because it is difficult or impossible for her to derive benefit from continued life.

38. The Italian team take, within the framework of Italian law and the ethical framework they apply, the following view regarding the question of best interests:

> "In this ethical and normative frame, the clinical picture of Tafida could not be completely defined. Even if Tafida's brain damage is extensive and irreversible to a great extent, according to recent guidelines, precise

> prognostication after severe brain injury might require up to one year from the acute event in adults. Disorders of consciousness lasting longer than 1 month post injury may still attain functionally significant recovery after 1 year post injury. The natural history and prognosis of children with prolonged disorders of consciousness is not well-defined, with a greater uncertainty about definitive outcome compared to adults. Parents feel that Tafida is occasionally respondent to their stimulation and still hope for possible improvement. Withdrawing care at this stage seems to them unacceptable. Tafida does not seem to respond to pain, if not to very deep stimulation, and she is cared for by parents with extreme dignity and compassion. As suggested by recent guidelines, in case of uncertainty about prognosis and different positions between caring physicians and family, we wonder if it might be advisable to give Tafida more time. Provisional intensive care could be continued until a better prognostic definition is achieved, allowing the development of a plan of care tailored to Tafida's definitive clinical condition. Such plan could include, if appropriate, palliation and end of life care. This approach might also facilitate acceptance and elaboration of grief by the family. Tracheostomy and gastrostomy could be careful taken into consideration to improve Tafida's quality of life, aiming at home care for chronic respiratory support or palliative care, according to her definitive neurological outcome. Tracheostomy should not exclude an eventual future withdrawal of care by weaning of mechanical ventilation, with the necessary sedation to alleviate discomfort. A better prognostic definition might require serial standardised neurological and neurophysiological evaluations in addition to MRI functional studies. With the available date, we do not foresee any specific therapies which might contribute to improve Tafida's neurological outcome other than standard support of vital functions and homeostasis. We will be honoured to take care of Tafida at the best of our professionalism and compassion. Treatments deemed to be disproportionate according to Italian laws, the Italian physician's ethics code, and the available national and international guidelines will be avoided."

The Views of the Parents

39. Finally, and importantly, the court has the views of the parents as to Tafida's current medical condition, level of progress they contend she has made to date and what they contend would be Tafida's wishes and feelings regarding her current situation. In considering and weighing this evidence, the court must have regard *both* to the fact that the parents spend a great deal of time with Tafida *and* the fact that, for parents, the flattering voice of hope can, in cases of this nature and entirely understandably, provide a distorting lens through which the child's presentation is viewed by those who love her.

40. The parents have provided the court with a memory stick containing a series of video clips that they submit demonstrate examples of Tafida's progress and level of awareness. In oral evidence, the mother did not accept the doctors assessment of the latter and considers that Tafida is aware to an extent, and in particular is aware the presence of her parents and family. Within this context, the parents contend that Tafida has defied her initial fatal prognosis, is in a serious but stable condition,

continues to improve on a daily basis and make the following points in their written and in the mother's measured and dignified oral evidence:

i) Following the initial insult, and medical advice that Tafida would die imminently, she started making small but definite progress, opening her eyes and moving her limbs. She has a sleep/wake cycle;

ii) Tafida has demonstrated a level of ability to control urinary functions for a period of time;

iii) Tafida now tries to come forward when her parents sit her up in bed, and moves her head from side to side in response to touch and voice (as also witnessed on one occasion by Dr Smith), which she was not previously doing (in her report the Children's Guardian records witnessing the mother asking Tafida to raise her arm and that Tafida moved her arm, although the Guardian could not say for certain this was in response to her mother's request);

iv) Tafida stretches her feet, legs and whole body when her splint boots are removed and in response to physiotherapy;

v) Tafida removes her hands from under the covers and flings them behind her head, which she was not doing previously;

vi) Tafida reacts to painful stimuli but shows no sign of pain or distress in her resting state.

vii) Tafida "knows" that her mother is present and wakes to her mother's voice.

41. Finally, and importantly, as to Tafida's wishes and feelings were she to be able to express a view on the issues that fall to be decided by this court, in her oral evidence the mother stated that prior to her injury Tafida demonstrated herself to greatly value all life, reiterating a story of Tafida becoming upset at the death of a ladybird and of a goldfish, and of Tafida's gentle, accepting and non-judgmental approach to another child with serious disabilities.

42. Whilst the mother was measured in her evidence regarding Tafida's conception of religion and its consequences (conceding of her own volition, for example, that Tafida is too young to have developed an understanding of end of life issues), she also emphasised the fact that Tafida had begun to follow Islamic practices, showing the court a video of Tafida with her small prayer mat, encouraging her brother to come and pray with her. Within this context, the mother contended that Tafida had a clear understanding that "if you kill or do harm you will be in trouble with Allah" and that Tafida would wish to live whatever life is left to her notwithstanding her current condition. In emotional testimony, the mother also contended that Tafida would ask the court why she is being treated differently to other children in her position in this country who are maintained at home on ventilation.

SUBMISSIONS

Application for Judicial Review

(i) Claimant and Interested Parties

43. It is convenient to deal in summary with the submissions in the judicial review on behalf of Tafida as Claimant, by Mr Sachdeva, and on behalf of the parents as interested parties, by Mr Lock, together, as they advance, essentially, the same case.

44. Tafida and her parents submit that it is plain on the evidence that the Trust made a decision to refuse to permit Tafida to be transferred to the Gaslini Hospital, relying on the Trusts own summary of a discussion with the parents on 8 July 2017 which records Dr D as saying that taking Tafida to Italy would not be possible, which account Dr D confirms in her statement of evidence. Tafida and her parents further rely on the report of a meeting with the parents on 10 July 2019 at which Dr F is recorded as stating "we could not allow the transfer of Tafida as we do not believe it is in [Tafida's] best interests." Tafida and her parents contend that the Trust took the decision it did not on the basis of Tafida's best interests, but rather by reason of the philosophical or ethical differences as between England and Italy regarding best interests decisions concerning continued provision of medical treatment and the fact that Tafida is an English national.

45. In the context of the Trust contending otherwise, Tafida and her parents further submit that the decision of the Trust to refuse to permit Tafida to be transferred to the Gaslini Hospital is a decision amenable to judicial review in circumstances where the Trust is a public body and exercises its public functions under the National Health Service Act 2006, and where the NHS Constitution stipulates that patients have the right to challenge NHS decisions by way of judicial review.

46. As to the lawfulness of the decision, Tafida and her parents submit that as a citizen of the United Kingdom and, therefore a citizen of the EU, Tafida enjoys the full benefit of EU free movement rights and, accordingly the rights Art 56 of the Treaty for the Functioning of the European Union (hereafter TFEU) relating to the provision and receipt of services. Mr Lock also made comprehensive and helpful submissions regarding the impact in this case of the right to freedom of movement under Art 21 of TFEU. I am satisfied however, in the context of this case being, at its heart, about the provision and receipt of services in the form of medical treatment, that it is Tafida's EU rights under Art 56 of TFEU that fall to be considered and it on those rights that I shall concentrate when dealing with the claim for judicial review.

47. Within this context, Mr Sachdeva and Mr Lock contend that the corollary of the freedom to provide services enshrined in Art 56 TFEU is the freedom to *receive* those services in another Member State. Within this context, Tafida and her parents further submit that the provision of intensive care, palliative care and end of life care by a hospital in another EU Member State constitute services for the purposes of Art 56 of TFEU read with EU Directive 2011/24. In this context, Tafida and her parents submit that choice of provider of medical services is a function of parental responsibility and that, where a parent makes a choice for their child to be treated at a particular medical institution in the EU in accordance with orthodox medical practice, the choice made

by parents on behalf of a child who is too young, or otherwise unable to make a decision for herself constitutes an exercise of the child's directly effective EU rights.

48. Accordingly, Tafida and her parents further submit that, where a child has a right under Art 56 to receive healthcare services in another Member State as a function of her EU rights, public authorities in this jurisdiction may not restrict the right to receive such services *unless* there an imperative public policy reason for the purposes of Art 52 of TFEU read with Art 24 of the EU Charter of Fundamental Rights (hereafter the CFR). Within this context, Tafida and her parents submit that the NHS Trust should have recognised that its decision to refuse to permit Tafida's transfer to the Gaslini Hospital interfered with Tafida's right to receive services under Art 56 of TFEU. Further, having regard to Art 52 of TFEU read with Art 24 of the CFR, Tafida and her parents submit that the Trust should then have asked itself whether, having regard to Tafida's best interests as a primary consideration, that interference amounted to a proportionate public policy justification under Art 52 of TFEU such that the Trust was justified in refusing to comply with the instruction of Tafida's parents given in the exercise of their parental responsibility. Tafida and the parents further submit in this context that where, having undertaken this analysis, an NHS Trust objects to a transfer request by parents, that Trust is bound to apply to the court for injunctive relief to provide a proper legal basis for the continued interference in the Art 56 rights that the objection constitutes by demonstrating to the court that the decision is justified by reference to Art 52.

49. Within this framework, Tafida and her parents submit that not only was this analytical process not followed by the Trust in reaching its decision, the Trust failed to consider Tafida's rights under Art 56 of TFEU *at all* when reaching its decision. In the circumstances where this is accepted by the Trust, Tafida and her parents submit that the Trust's decision *must* be held to have been unlawful on public law principles.

50. Further, Tafida and her parents submit that, even had it considered Tafida's EU rights, the Trust could not in this case have discharged the burden of demonstrating that the interference in Tafida's Art 56 rights was justified by a proportionate public policy justification under Art 52 of TFEU. Accordingly, they submit that the decision of the Trust to refuse to permit the parents to transfer Tafida to the care of a specialist medical team in another Member State ready and able to treat her would have been unlawful even had Art 56 been properly considered.

51. As to the contended for absence of a proportionate public policy justification under Art 52 of TFEU, Tafida and her parents submit that in this case, (a) the Trust had determined that it was no longer in a Tafida's best interests to continue life sustaining treatment, (b) a hospital in another EU Member State had agreed to the transfer and continued treatment of the Tafida, (c) the parents had requested such transfer, (d) it was clear that the transfer could be effected without risk to Tafida and (e) no best interests decision had been made by the domestic court. In these circumstances, they submit that there was no basis for asserting a proportionate public policy justification under Art 52 of TFEU for restricting Tafida's EU rights under Art 56 of TFEU and that the Trust was therefore bound to give effect to the child's rights under Art 56 and accede to the parents' request, in the exercise of their parental responsibility, to effect the transfer of Tafida to another EU Member State for continued medical treatment, which would also be consistent with the parents right to change doctors.

52. Further, in circumstances where any justification must be compatible with EU law, Tafida and her parents submit that the decision of the Trust could not have been justified by any philosophical or ethical differences as between EU Member States regarding best interests decisions concerning continued provision of medical treatment, as this would fail to recognise the principles of comity, equivalence and mutual respect that underpin free movement across the EU and would act to prevent Tafida from receiving services that are lawfully available to other EU citizens in another Member State. Nor, it is submitted, could the fact that Tafida was an English national being treated in England be a basis for justification, as underscored by the constitutional right to non-discrimination under Art 18 of TFEU and Art 2 of the EU Charter of Fundamental Rights (hereafter CFR).

53. Finally, Tafida and the parents submit that the fact that there is an extant dispute in this jurisdiction as to Tafida's best interests that the Family Division of the High Court is given jurisdiction to determine pursuant to Art 8 of Council Regulation (EC) 2201/2003 (hereafter BIIa), could also not have amounted to a justification for the decision made by the Trust because (a) EU law takes primacy over UK law, (b) such a situation would be incompatible with the need to establish "overriding reasons of general interest" as required by EU Directive 2011/24, (c) such a situation would be discriminatory as it would apply only to UK nationals and would prioritise a UK approach to best interests over different approaches in other EU Member States and (d) such a situation would impose a substantial obligation on parents to become involved in court proceedings in order to exercise their EU rights.

54. In support of the primary ground of breach of EU rights under Art 56 of TFEU, it is further submitted on behalf of Tafida and her parents that the following further matters further render unlawful the decision of the Trust not to accede to the requested transfer of Tafida to Italy:

    i) On behalf of the parents, Mr Lock submits that in making its decision the Trust acted unlawfully for the purposes of the Equality Act 2010 ss 19(1) and 19(2) in adopting an entirely secular, medically based analysis based on the essentially secular RCPCH Guidelines which failed to take any, or any proper account of the parents to manifest their religion pursuant to Art 9 of the ECHR and Art 10 of the CFR by continuing the life of their child. Hence, it is submitted that the Trust discriminated against the parents where the Trust was on notice that the withdrawal of treatment was profoundly against the parents' religious views and preventing the transfer to a country that will care for her in a manner that accords with those views is not a proportionate means of achieving a legitimate aim. Mr Lock further submits that in deciding to refuse the request to transfer Tafida to Italy the Trust also acted unlawfully in that it discriminated against Tafida as compared to a child of Italian nationality in circumstances where the latter would have been returned to Italy by the Trust at the request of his or her parents following initial treatment if he or she fell ill in London, which discrimination was not a proportionate means of achieving a legitimate aim.

    ii) Mr Sachdeva submits that the decision of the Trust unlawfully deprived Tafida of her liberty contrary to in Art 5 of the ECHR (right to liberty and security) as read with Art 8 of the ECHR (right to respect for private and family life), Art 9 (right to freedom of thought, conscience and religion) and Art 14 (prohibition of discrimination) in circumstances where her retention in hospital was not for the purposes of keeping her alive but rather to prevent her transfer to Italy, which purpose does not fall within any exception provided by Art 5(1) of the ECHR, and in particular not for the purposes of educational supervision nor bringing her before a competent legal authority. Mr Sachdeva contends that this case is to be distinguished from *R (Ferreira) v HM Senior Coroner for Inner South London* [2018] QB 487 and *Alfie Evans No.2* [2018] 4 WLUK 624.

iii) The parents submit through Mr Lock that in making its decision, the Trust failed to engage in the rights of Tafida and her parents under the NHS constitution. Mr Lock submits that in failing to give serious regard to an acceptable, albeit in the Trust's view not optimal, treatment plan proposed by the parents, offered by the Gaslini and which did not offend against the conscience of the doctors where it was a course accepted by Dr D should the court determine it was in Tafida's best interests, meant that the Trust failed to recognise and consider the NHS Constitution as a factor in its decision to refuse transfer.

55. In the circumstances, Tafida and her parents invite the court to quash as unlawful the decision of the Trust to refuse to comply with the parents request to transfer Tafida to the Gaslini hospital, to grant a mandatory order requiring the Trust to retake the decision or a mandatory order requiring the Trust to permit the transfer of Tafida to the Gaslini Hospital with a declaration that the Trust may not prevent that transfer. As noted above, in this context, Tafida and her parents submit that this court is *functus* in respect of Tafida's wider best interests.

(ii) Defendant Trust

56. In its amended Grounds of Defence, the Trust contended that it had not made a decision to prevent, block or prohibit Tafida's transfer to Italy. However, in its Skeleton Argument, the Trust characterises it decision in slightly different terms. Namely, a decision taken on 8 July 2019 not to agree to the parents request to take Tafida to Italy pending a resolution by the High Court of the question of what medical treatment is and is not in Tafida's best interests; the Trust contending that there is a plain distinction between advising the parents that the hospital would not agree to transfer because it does not consider the transfer to be in the patients best interests and seeking a determination from the court in accordance with the recognised procedure and physically preventing removal of the patient.

57. With respect to whether the decision of the Trust, so characterised, is amenable to judicial review, in its amended Grounds of Defence the Trust contends that it has not made any decision amenable to judicial review because:

i) Where a dispute as to Tafida's best interests had arisen it is well established that it is for the court to determine the issue and not for doctors to impose their opinion on the parents and the child, per *Gard v United Kingdom* (2017) 65 EHRR at [96] and *Evans v Alder Hey Children's NHS Trust* [2018] 4 WLUK 624 at [13], necessitating an application to the court for a decision on whether transfer was in Tafida's best interests, which the court granted the Trust permission to make on 16 July 2019.

ii) The Trust was statutorily obliged to bring the application before the Family Division of the High Court in circumstances where a dispute had arisen between doctors and parents as to the child's best interests, having regard to its obligation under s 11(2) of the Children Act 2004 to safeguard and promote the welfare of children, in the absence of clarity on consent with respect to medical treatment.

iii) An application under s 8 of the Children Act 1989 is the appropriate statutory mechanism by which a public authority may ask the court in the jurisdiction of the child's habitual residence to determine the child's best interests where a dispute has arisen. In making its decision to apply to the Family Division of the High Court the Trust itself exercised no statutory power but rather followed the proper procedure for determining a dispute as to best interests.

iv) The Family Division of the High Court is the plainly appropriate forum for the determination of the best interests dispute and there is no remedy available in the Administrative Court that is not also available in the Family Division.

58. Within the foregoing circumstances, and accepting that Tafida has rights under Art 56 of TFEU to access medical treatment in another EU Member State, the Trust submits there is no right or requirement to an antecedent ruling as to the child's EU rights prior to a best interest decision being made by the court where the issue is not *where* the treatment takes place but whether that treatment is in the child's best interests *per se*. In addition to submitting that the TFEU provides no basis for the claimed right to a procedural ruling on EU rights prior to the court's determination of best interests, the Trust submits that if such a right existed it would act to introduce a threshold before the court could embark on deciding the dispute as to the child's best interests in cases of this nature, a situation expressly deprecated by the Court of Appeal in *Great Ormond Street v Yates and Gard* [2018] 4 WLR 5 at [94]. Within this context, the Trust contends that, once a disagreement as to what is in a child's best interests has coalesced, it is for the court in the EU Member State of the child's habitual residence at the time the court is seised to determine that issue under the jurisdiction conferred by Art 8 of BIIa, without first having to cross any procedural or other threshold for intervention, the child's EU rights falling as one factor for consideration in the best interests evaluation.

59. Further, if Tafida does have the right to an antecedent ruling on her EU rights, the Trust denies that by its decision it imposed restrictions on Tafida's accepted rights under Art 56. In the alternative, the Trust submits that if it has imposed restrictions, the same are justified by a legitimate and proportionate objective, namely the discharge of a requirement to seek a determination from the court as to Tafida's best interests in circumstances where a dispute as those best interests had arisen, per *Gard v UK* (2017) at [96] and *Evans v Alder Hey Children's NHS Trust* [2018] at [13].

60. Within this context, the Trust submits that its actions in declining to agree to Tafida's transfer and applying to court for a best interests declaration were, in circumstances where EU Member States have an area of discretion as to what amounts to public policy, justified by powerful reasons of public interest, namely (a) the public interest in the protection of a child's best interests where the best interests of children are one of the fundamental interests of society and must be taken into account as *at least* a primary consideration in any decision, (b) the equal treatment of all children where a

dispute as to their best interests arises, (c) the public interest in the courts and not doctors determining the outcome of a dispute between parents and doctors as to a child's best interests, (d) the public interest in ensuring that a child has an independent voice in the determination of a dispute between parents and doctors as to the child's best interests, (e) the public interest in doctors having a legally certain route available to them to determine what the law requires of them in cases where there is a dispute as to the child's medical treatment. Accordingly, the Trust submits that the public interest demands that where there is any dispute between a child's doctors and parents regarding whether medical treatment is in a child's best interests that is more than minimal in nature (the Trust contending that the choice between continuing and withdrawing life sustaining treatment constitutes the gravest of disputes) and which they are unable to resolve, that dispute be determined by a court of the child's habitual residence on the basis of the child's best interests broadly construed, pursuant to the jurisdiction conferred by EU law in the form of Art 8 of BIIa.

61. The Trust contends that further support for this submission is derived from the fact that Art 24 of the CFR and Art 3 of the United Nations Convention on the Rights of the Child mandate that Tafida's best interests are treated as a primary consideration. The Trust submits that, in circumstances where Tafida's EU rights are hers and separate to those of her parents, these provisions require that Tafida's best interests are therefore a primary consideration when considering whether any interference in her Art 56 rights is justified, that her best interests are not compartmentalised by separate consideration of travel for treatment and the treatment itself and are not made subordinate to a procedural ruling of the court or other imposed threshold. The Trust also submits that the international instruments mandating the child's best interests be a primary consideration demonstrate further the propriety of it applying to the court for a determination of best interests where a dispute has arisen within a legislative framework that ensures the child's best interests are paramount and contends that to do otherwise would breach Tafida's rights under CFR Art 24 and Art 8 of the ECHR.

62. As to the further grounds relied on by the Claimant and the Interested Parties in the claim for judicial review in support of the contended for breach of Art 56 of TFEU:

i) The Trust denies it has acted in a discriminatory manner by its decision to bring an extant dispute as to a child's best interests before the court as mandated by its domestic and international legal obligations. The Trust submits that that decision was not taken on the grounds of nationality *per se* or on the basis of differences amongst EU Member States in respect of withdrawal of life sustaining treatment. Further, the Trust submits that insofar as Tafida and her parents are alleging unlawful indirect religious discrimination, (a) this court has no jurisdiction to determine a claim of unlawful indirect discrimination by reason of Equality Act 2010 s 114, (b) that in any event Tafida and her parents fail to identify the provision, criterion or practice the Trust is said to have applied in making its decision, (c) that in making its decision all Trust did was to take an individual decision in relation to medical treatment of a specific patient in a specific set of circumstances rather than applying a neutral criteria or rule applied by the Trust to all persons and (d) that, in any event, its decision caused no disadvantage to Tafida by having her best interests considered brought before the court and in so far as it disadvantaged the parents it was proportionate means of protecting Tafida's best interests.

ii) The Trust likewise denies that it has infringed Tafida's Art 5 rights, relying on *Evans v Alder Hey Children's NHS Trust* [2018] 4 WLUK 624 at [12] and *Gard* [2017] 4 WLR 131. Further, the Trust submits that if Tafida's position does constitute an interference with her rights under Art 5(1) of the ECHR, that interference is justified for the purposes of brining Tafida before a competent legal authority for the determination of her best interests, the *Travaux Préparatoires* for the Convention making clear that such exception was intended to cover the detention of a minor prior to civil or administrative proceedings, and that her detention is neither arbitrary nor unjustified but rather to ensure that the court is in a position to determine her best interests. Further, the Trust submits that had it discharged Tafida against her best interests it would itself have been in breach of her ECHR rights, the parents not being able to waive her ECHR rights.

iii) The Trust further submits that is has not contravened the NHS constitution, the legal obligation on the Trust being to have regard to it, with the decision maker being permitted to depart from it where there are good reasons for doing so. The Trust further submits that nothing in the constitutions confers on a parent the right to remove a child from an NHS hospital and take them abroad for treatment that is not in their best interests. Rather, the Constitution imposes a duty on doctors not to provide treatment they assess not to be in the patients best interests or which they consider may be degrading, requires preferences to be reflected only where possible and that, within this context, doctors did all they could to assist parents to explore their preference but ultimately came to conclusion that the same was not in Tafida's best interests. In the circumstances, the Trust submits that it complied with its duties under the NHS Constitution.

63. The Trust accordingly invites the court to dismiss the judicial review proceedings and adopt the ordinary process in the Family Division of considering Tafida's best interests pursuant to its applications under the Children Act 1989 s 8 and the inherent jurisdiction of the High Court.

Application under the Children Act 1989 and the Inherent Jurisdiction

(i) The Trust

64. Ms Gollop submits that whilst human rights are engaged, including the Art 9 right to freedom of thought, conscience and religion, this case is about best interests, per *Re T (A Minor)(Wardship: Medical Treatment)* [1997] 1 WLR 242. The Trust submits that it is in Tafida's best interests for life sustaining treatment now to be withdrawn and for her to be palliated and, accordingly, it is not in Tafida's best interests for the court to conclude she should continue to receive life sustaining treatment in Italy or otherwise. Trust submits that the best interests question in this case is dominated by health issues.

65. The Trust invites the court to prefer the opinion of Dr Smith, which opinion it contends is that Tafida is in the equivalent of VS. Within this context, the Trust

submits that the evidence demonstrates that Tafida cannot survive without mechanical ventilation and will now always be dependent on the same, with no hope of recovery or only a minimal level of recovery that will be adverse to her welfare. The Trust further submits that the evidence demonstrates that Tafida now has no vision and very altered sensation such that she maintains only a limited ability to feel and *may* retain some ability to process sound. She is described by Ms Gollop as having "animation without experience". The Trust accepts that the evidence suggests that Tafida's existence is not painful, but reminds the court that there is evidence that she can feel pain if a painful stimulus is applied and that the possibility of pain cannot be excluded completely which, the Trust contends, is significant in terms of some of the future conditions prognosticated in respect of Tafida. The Trust submits that it is not possible to determine whether Tafida experiences pleasure.

66. With respect to the question of the benefit and burden of continued treatment, within the foregoing context, the Trust submits that, within the context of the difficult question of how to treat those with little or no awareness, absence of awareness and pain does *not* mean an absence of harm in circumstances where, it submits, there is plainly now *no* benefit to be gained by Tafida from continued medical treatment given the prognosis of no significant improvement in her condition, the lack of ability to derive benefit being an aspect of the assessment of quality of life under the RCPCH Guidance. Within this context, the Trust submits that years in her current condition are not in Tafida's best interests, in particular were she to regain slightly more awareness but remain in a very minimally conscious state given the anticipated development of further severely disabling conditions.

67. As to Tafida's wishes and feelings, when seeking to divine Tafida's views the Trust invites the court to be cautious in accepting that Tafida was raised by parents who take an absolute position on the religious prohibition of the course of action advocated by the Trust in circumstances where the evidence, so submits the Trust, indicates that the mother was prepared at least to contemplate the same. In any event, with respect to the extent to which the court can derive Tafida's wishes and feelings from the religious environment in which she has been raised, and evidence of her consequential attitude to end of life questions, the Trust again cautions the court as what can be *properly* be drawn from such evidence.

68. Whilst accepting that the evidence demonstrates that Tafida had knowledge of her religion and participated in aspects of it, including prayer, the Trust submits that at the age of 4 she can have had no real concept of her mortality or of the possibility of her current situation. Ms Gollop accordingly submits that whilst the court can infer what Tafida thought of her religion generally, it has no information from which to infer he wishes and feelings regarding existing for many years with no or minimal awareness, with the possibility of physical deterioration and the ever present risk of infection. Ms Gollop further submits that in circumstances where her condition is consistent with VS but with the possibility of minimal awareness, compelling evidence would be required to demonstrate she would have wanted a ventilated existence. There is, submits the Trust, in fact no evidence she gave thought to what she would have wanted for herself in this situation. Accordingly, the Trust submits that it is difficult in those circumstances for the parents to make out a submission that Tafida's understanding and commitment to her faith would have meant she subordinated any wish not to endure such an existence to her religious beliefs, there being no evidence

she contemplated and understood that possibility. Moreover, the Trust submits that prior to her injury, all the evidence points to the fact that Tafida understood life as a situation of feeling, communication and experience.

69. With respect to Tafida's Art 9 right to freedom of thought, conscience and religion *per se*, the Trust submits that she is not now capable of manifesting religion in belief, practice or observance, not being able to exercise these freedoms because she is not free but rather trapped by the small amount of her brain that survives. Within this context, Ms Gollop further invited the court to engage in a detailed analysis of the *Fatwa*, including inviting the court to question whether it properly applied to the situation in this case. Ms Gollop submits that Tafida's situation in fact falls out with the prohibitions contained in the *Fatwa* as she cannot consent, and is not consenting to the termination of her own life and accordingly, as a matter of logic, cannot commit the act that is prohibited by her religion as explained in the *Fatwa* (and neither are or could her parents). Neither Tafida nor her parents are asking for her life to be ended. It is the Trust that makes the request and the court which will decide. In all the circumstances, the Trust submits that the relief it seeks does not constitute an unlawful interference with the Art 9 rights engaged.

70. With respect to the question of the parents' religious convictions, the Trust submits that those convictions, and the rights that protect them, are one factor to be considered in the best interests analysis and do not confer on the parents the right to access medical treatment that is not in Tafida's best interests. Within this context, the Trust submits that for the parents to claim a 'right' to have Tafida treated in a way which accords with their religious views is an position that is unsustainable within the context of the international provisions which provide for Tafida's best interests to be a primary consideration and the domestic statutory provisions that require her best interests to be paramount. Further, the Trust submits that where the parents' religious views conflict with Tafida's best interests, the conflict must be resolved in favour of the latter.

71. With respect to the sanctity of life, Ms Gollop submits that Tafida's right to life under Art 2 of the ECHR falls to be considered in the context of her current state. Within this context, Ms Gollop submits that the State, in the form of the court, should not concern itself with teleological or ontological arguments concerning the meaning of life (such as whether a life without awareness or experience is properly consistent with conceptions of being) but rather consider the quality of Tafida's current existence as measured against the principle that sanctity of life is of the highest importance. Within this context, and in circumstances where the Trust submits that Tafida derives no benefit from life and any change of circumstances for Tafida will only be negative, this is a case in which the sanctity of life is outweighed by other considerations.

72. The Trust acknowledges that there is a fully worked out care plan for the transfer of Tafida the Gaslini Hospital, that the evidence demonstrates that such the transfer could occur with minimal risk to Tafida and that the evidence demonstrates that Tafida benefits from the round the clock care from a loving and dedicated family (the Trust further conceding the Tafida continues to benefit from Art 8 right to respect for family life). However, the Trust submits that geography is not the issue in the case. Ms Gollop contends that the antecedent question is whether further mechanical ventilation is in Tafida's best interests. If it is not, then the Trust submits that that

answer holds for Tafida wherever such treatment is available. As the question of dignity, contending that this is a concept that means many different things to many different people, Ms Gollop submits that what would certainly not be dignified for Tafida is being transported across international borders in a moribund state to be kept alive in a moribund state.

73. Finally, with respect to the evidence of Dr Playfor, Dr Smith and Dr D that there are children in a similar situation to Tafida currently ventilated long term both in hospital and at home, Ms Gollop submits there is, in fact, no sufficiently cogent evidence in respect of other children ventilated in this position in the United Kingdom, and in particular no evidence of how similar or otherwise their situations are to that of Tafida.

(iii) The Parents and Interested Party

74. The parents and the maternal aunt contend that it is in Tafida's best interests to continue to receive life sustaining treatment and, on the evidence available, that the court should so declare. Emphasising that each case must be decided on its own facts and that there is no agreed "touchstone of intolerability" per *In re B (A Minor)(Wardship: Medical Treatment)* [1981] 1 WLR 1421 at 1424, the parents and the maternal aunt submit that there is no evidence that Tafida suffers pain and, in this respect, her case is "unique". In any event, the parents and interested party submit that the treatment is not overly burdensome for Tafida.

75. Within this context, the parents and the maternal aunt submit that it is further important in this case for the court to have regard to the medical consensus that brain stem death has not occurred, that Tafida's death is not imminent subject to continued life sustaining treatment (with which Tafida could live a further 10 to 20 years) and that Dr Playfor, Dr Smith and Dr D all acknowledge that children in a similar position to Tafida (to use Dr D's formulation) are treated long term both in hospital and home and that the latter is an available and fully funded option for Tafida in Italy. The parents and the maternal aunt also pray in aid evidence that whilst the chance that Tafida will make improvements in her level of awareness is low, the same cannot be ruled out and rely on their own observations of what they contend are improvements over the significant period of time they have spent with Tafida. Within this context, and reminding the court that the RCPCH Guidance has no force in law and does not purport to replace the best interests requirements under the law, Mr Sachdeva submits that in the absence of pain and suffering, the question of inability to derive benefit becomes a *heavily* value laden factor, with the best evidence as to 'benefit' in those circumstances coming from the wider perspective of the family, and the religious and cultural context in which they live, rather than the narrower, entirely medical perspective of the doctors.

76. Within this context, the parents and the maternal aunt submit that, in her current condition, Tafida's wishes and feelings regarding continuing to receive life-sustaining treatment can be derived from the religious and cultural context in which she was raised and from the evidence before the court that demonstrates that not only was Tafida has been brought up in accordance with the tenets of Islam and but that, on what is submitted to be compelling evidence that prior to her injury she understood the concept of religion and had expressed a clear desire to adhere closely to the Islamic faith, she was developing her own religious identity and value system in this

context. Mr Sachdeva acknowledges that Tafida's capacity to understand the true nature and extent of her religious and cultural background must be limited by her age, but he submits the evidence shows she had a prior understanding and relationship with her Muslim faith. In these circumstances, the parents and the maternal aunt submit that the court can be certain that Tafida *would* have wanted to live in her current circumstances where the withdrawal of treatment causing death would not be in accordance with the beliefs and values of the religion with which she identified and the community to which she belongs. Accordingly, the parents and maternal aunt submit that the benefit that accrues to Tafida from continued life is in part a spiritual one and is protected by her Art 9 right to freedom of thought, conscience and religion. Within this context, it is submitted that in this case the concept of autonomy (as embodied in the child's wishes and feelings) and the sanctity of life point to the same result.

77. The parents further submit that the sanctity of life means that the continuation of Tafida's life is itself inherently a good and that Tafida was growing up in an Islamic community where, although she cannot have realised it in detail, the sanctity of life is of the highest importance. Within this context, they submit that there is a substantial inherent benefit to Tafida of continuing to be alive because the continuation of her life is both an inherent good and accords with the tenets of the belief system of which she was part. Within this context, the parents and the aunt submit that whilst, from a narrow medical perspective, life-sustaining treatment might be considered futile, to Tafida and those who share the belief system in which she grew up, rather than being futile life sustaining treatment confers the benefit of protecting the sanctity of life. The parents and the aunt submit that this conclusion is reinforced by the fact that a life with a severe disability is held, in both domestic and international law, to be of equal value to all the other myriad lives in the world. Within this context, they submit that where she is medically stable and effectively ventilated, where she is not suffering pain and where there is no conflict in this case between sanctity of life and autonomy as articulated by her ascertained wishes and feelings, the sanctity of her life requires that Tafida be allowed live out the remainder of life notwithstanding the severity of her disability.

78. The parents and the aunt further contend that the best interests justification for this course is, in this case, reinforced by the fact that a team of doctors at an internationally renowned paediatric centre of excellence, with more than sufficient medical expertise to meet Tafida's ongoing medical needs, are prepared to treat Tafida and have provided to the court a fully worked up care plan for Tafida, which plan is also full funded. The parents and the aunt further rely on Dr Playfor's evidence that it is very unlikely that Tafida would suffer any pain or discomfort during transfer and that the transfer plan is entirely reasonable and appropriate for Tafida. They further point to the dedication the parents and wider family in caring for Tafida and their willingness to continue to do so. Within this context, the parents and the maternal aunt submit that in this case the court must have regard to the fact that the continuation of life-sustaining care they submit is in Tafida's best interests is care that a European centre of paediatric excellence is prepared to give.

79. Within the foregoing context, the parents and the aunt further point out that the care plan formulated by the team from Gaslini, and fully funded, reflects the evidence from Dr Playfor, Dr Smith and Dr D regarding the approach taken towards other

children in the United Kingdom in a similar situation to that of Tafida. Accordingly, they submit that the continuation of life-sustaining care that they submit is in Tafida's best interests, and that is offered by the Gaslini and fully funded, is care that is regularly provided to other children in like clinical situation and is accordingly care that falls within the mainstream body of medical opinion on the treatment of children in conditions similar to that of Tafida. In these circumstances, the parents submit that all that they seek for Tafida is simply that which is already a well-recognised approach in this jurisdiction to providing long-term care for children in her position, which does not involve the withdrawal of treatment and death.

80. With respect to the question of dignity, the parents and aunt submit that, given her particular situation and levels of awareness, all judgments regarding Tafida's dignity are, by definition, extrinsic, with no evidence before the court to demonstrate that Tafida *herself* would consider her position to be undignified or that living with profound disabilities would render her position so, there being no indignity in disability, even where severe. Within this context, they submit that the court must be astute to avoid holding the life of a severely disabled child to be inherently undignified or as having less dignity than the life of a person without disability.

81. Within the foregoing context, and in circumstances where a team of doctors at a prominent paediatric centre of distinction are prepared to treat Tafida in a manner in which other children in this jurisdiction in a similar condition to Tafida can be treated, the parents and the aunt submit that whilst her quality of life may not be high by the standards of many, it is in Tafida's best interests to continue to receive life sustaining treatment, which treatment will, in the circumstances of this case, deliver to Tafida a life that is pain free with limited awareness and which confer benefits upon her by reference to her cultural and religious heritage, the sanctity of her life and the love and dedication of her family.

(ii) The Child

82. Having completed her investigations, the Children's Guardian contends that it is now in Tafida's best interests for life sustaining treatment now to be withdrawn and her Tafida to be palliated. In her final report dated 3 September 2019 Ms Demery states that:

> "...it is difficult to see how it could be in her best interests for her to have to endure the life that she currently leads devoid of any quality and beleaguered by the burden of illness and procedures that keep her alive. Whilst it is thought that she is no experiencing any pain, the evidence is that she is unable to experience any pleasure or comfort from her environment because of lack of awareness that is a feature of the damage her brain has experienced."

And

> "From all the information currently available to me, it is with great sadness I say that I do not now see how it can be in Tafida's best interests to continue with life sustaining treatment. The current regime is an inevitable burden upon Tafida, regardless of whether she experiences the pain or discomfort that would otherwise be associated with these procedures, such

> as deep suctioning and nasogastric feeding. It is not intended and will not provide any respite from the underlying cause of her disability and, according to medical evidence, is therefore futile."

83. With respect to the burden and benefit of treatment, during his oral submissions Mr Gration contended that if Tafida's treatment is maintained the burden of that treatment upon her will be significant in that her life will be, for ten to twenty years, one that is mechanically sustained, one of no or minimal awareness, with an inability to derive comfort or to interact and with developing conditions set out in prognosis that, if she does recover some awareness, will make her aware of her very difficult situation, more aware of treatment and more aware of these consequential problems and illnesses. Mr Gration submits that whilst modern science can sustain Tafida's life, it will only do so without pleasure, comfort, joy, experience of the love of her family or "anything else that makes life a pleasurable and rich experience for most people". This burden is not, he submits, in Tafida's best interests.

84. With respect to Tafida' ascertainable wishes and feelings, Mr Gration told the court that the Guardian accepts that the evidence regarding Tafida can amount to evidence of her wishes and feelings insofar as she understood her religion. Mr Gration further makes clear that in her assessment the Children's Guardian took account of Tafida's caring and non-judgmental approach to a child with severe disabilities, in so far as it can be said to demonstrate a realisation in Tafida of the sanctity of life and the recognition that people lead full lives notwithstanding challenges to their disability, as well as having regard to Tafida's evident love of life itself. However, Mr Gration submits that this does not provide a complete answer to the best interests question before the court as, with respect to Tafida's wishes and feelings, the proper question is whether she had a concept of the situation she is currently in bearing in mind her age in order to form a view about it.

85. In this respect, Mr Gration submits that this is not at all likely and that Tafida would not have understanding of end of life or of the nature of a life lived with profound illness or disability. Within this context, Mr Gration further submits that, at best and whilst not devaluing the significance of her religious upbringing, the court has evidence of her general views based on her childhood understanding of religious tenets. In the circumstances, the Children's Guardian has not able to accord this significant weight, given that the nature of the situation Tafida would be required to take a view on was one beyond her childhood conception.

86. Within the foregoing context, and making clear that the Children's Guardian has paid due respect to the sanctity of life, Mr Gration indicates that the Guardian comes to the view that continued life sustaining treatment leading to a life of no suffering but no pleasure is not in Tafida's best interests. However, Mr Gration was also at pains to make clear that the Guardian accepts that the case is not one that has an obvious answer and that the court may reach a different conclusion.

THE LAW

EU Law

87. As I have noted, the Trust does not dispute that Tafida, as a citizen of the EU has directly enforceable rights under Art 56 of TFEU to receive medical treatment in

another Member State. The issue in this case is whether the Trust, in refusing to agree to Tafida's transfer to Italy pending a decision by this court as to best interests, breached those EU rights and, if so, whether that derogation from EU rights that have direct effect was justified. In the circumstances, the following legal provisions and jurisprudence are relevant.

88. Art 56 of the TFEU provides as follows regarding the right to provide services within the EU:

> "Within the framework of the provisions set out below, restrictions on freedom to provide services within the Union shall be prohibited in respect of nationals of Member States who are established in a Member State other than that of the person for whom the services are intended.
>
> The European Parliament and the Council, acting in accordance with the ordinary legislative procedure, may extend the provisions of the Chapter to nationals of a third country who provide services and who are established within the Union."

89. Within the foregoing context, I pause to note that Directive 2011/24/EU on the application of patients' rights in cross-border healthcare provides as follows in paragraph 4, 7 and 12 of the recitals to the Directive:

> "(4) Notwithstanding the possibility for patients to receive cross-border healthcare under this Directive, Member States retain responsibility for providing safe, high quality, efficient and quantitatively adequate healthcare to citizens on their territory. Furthermore, the transposition of this Directive into national legislation and its application should not result in patients being encouraged to receive treatment outside their Member State of affiliation.
>
> .../
>
> (7) This Directive respects and is without prejudice to the freedom of each Member State to decide what type of healthcare it considers appropriate. No provision of this Directive should be interpreted in such a way as to undermine the fundamental ethical choices of Member States.
>
> .../
>
> (12) The concept of 'overriding reasons of general interest' to which reference is made in certain provisions of this Directive has been developed by the Court of Justice in its case-law in relation to Articles 49 and 56 TFEU and may continue to evolve. The Court of Justice has held on a number of occasions that overriding reasons of general interest are capable of justifying an obstacle to the freedom to provide services such as planning requirements relating to the aim of ensuring sufficient and permanent access to a balanced range of high- quality treatment in the Member State concerned or to the wish to control costs and avoid, as far as possible, any waste of financial, technical and human resources. The Court of Justice has likewise acknowledged that the objective of maintaining a balanced medical and hospital service open to all may also fall within one of the derogations,

> on grounds of public health, provided for in Article 52 TFEU, in so far as it contributes to the attainment of a high level of health protection. The Court of Justice has also held that such provision of the TFEU permits Member States to restrict the freedom to provide medical and hospital services in so far as the maintenance of treatment capacity or medical competence on national territory is essential for public health."

90. Art 52 of the TFEU provides as follows with respect to the circumstances in which derogation from the rights set out in Chapter 2 of Part 3, Title IV of the TFEU, which includes the EU rights under Art 56, are permitted:

> "1. The provisions of this Chapter and measures taken in pursuance thereof shall not prejudice the applicability of provisions laid down by law, regulation or administrative action providing for special treatment for foreign nationals on grounds of public policy, public security or public health.
>
> 2. The European Parliament and the Council shall, acting in accordance with the ordinary legislative procedure, issue directives for the coordination of the above mentioned provisions."

91. Art 2 of the Treaty of the European Union provides that the EU is founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities. In addition to the fundamental rights set out in the schema of the Treaties, pursuant to Art 6 the Treaty of the European Union, Art 56 must be read subject to rights enshrined in the EU Charter of Fundamental Rights (hereafter CFR). The CFR itself falls to be interpreted in line with the provisions of ECHR, which in turn must be interpreted having regard to the provisions of the UNCRC. Within the context of the judicial review proceedings, the following provisions of the CFR are relevant:

> "**Article 21**
>
> **Non-discrimination**
>
> 1. Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.
>
> 2. Within the scope of application of the Treaty establishing the European Community and of the Treaty on European Union, and without prejudice to the special provisions of those Treaties, any discrimination on grounds of nationality shall be prohibited."

And:

> "**Article 24**
>
> **The rights of the child**

> 1. Children shall have the right to such protection and care as is necessary for their well-being. They may express their views freely. Such views shall be taken into consideration on matters which concern them in accordance with their age and maturity.
>
> 2. In all actions relating to children, whether taken by public authorities or private institutions, the child's best interests must be a primary consideration.
>
> 3. Every child shall have the right to maintain on a regular basis a personal relationship and direct contact with both his or her parents, unless that is contrary to his or her interests."

92. Within the context of the foregoing legal framework, I was referred to a large number of authorities during the course of submissions law on the issue of the nature and extent of derogations from EU rights that are permitted. However, six key authorities fall for consideration.

93. Dealing first with the question of public policy as a justification for derogating from fundamental EU rights, in *Van Duyn* (Case 41/74) [1974] ECR1337 at [18] the ECJ considered the interpretation of the public policy exception in the context of freedom of movement for EU Citizens and observed as follows:

> "It should be emphasized that the concept of public policy in the context of the Community and where, in particular, it is used as a justification for derogating from the fundamental principle of freedom of movement for workers, must be interpreted strictly, so that its scope cannot be determined unilaterally by each Member State without being subject to control by the institutions of the Community. Nevertheless, the particular circumstances justifying recourse to the concept of public policy may vary from one country to another and from one period to another, and it is therefore necessary in this matter to allow the competent national authorities an area of discretion within the limits imposed by the Treaty."

94. Staying with the question of public policy restrictions on fundamental EU rights, in *Ministerul Administraţiei Şį Internelor – Direcţia Generala De Paşapoarte Bucureşti v Jipa* (Case C-33/07) [2008] CMLR 23 the ECJ held at [28] that the question of whether the derogation in issue is properly founded on reasons of public policy, or public security, is one for the *national* court to answer on the basis of the matters of fact and law said to justify such derogation. Within this context, the court went on to hold that:

> "[29] When making such an assessment, the national court will have also to determine whether that restriction on the right to leave is appropriate to ensure the achievement of the objective it pursues and does not go beyond what is necessary to attain it. According to Art.27(2) of Directive 2004/38 and the Court's settled case law, a measure which restricts the right of freedom of movement may be justified only if it respects the principle of proportionality (see, for example, to that effect *Alluè v Universita degli Studi di Venezia* (C-259/91, C-331/91 & C-332/91) [1993] E.C.R. I-4309 at [15]; *Baumbast v Secretary of State for the Home Department* (C-413/99)

> [2002] E.C.R. I-7091; [2002] 3 C.M.L.R. 23 at [91]; and *Ministre de l'Intérieur v Oteiza Olazabal* (C-100/01) [2002] E.C.R. I-10981; [2005] 1 C.M.L.R. 49 at [43])."

95. Within the foregoing context, in *Society for Protection of Unborn Children Ireland Limited v Grogan and others* Case C-159-90 [1991] 3 CMLR 849 at [37] the Advocate General dealt with the question of national rules that may actually or potentially restrict the freedom to receive services under Art 56 of TFEU on the basis of public policy as follows:

> "(21) ... that national rules which, albeit not discriminatory, may, overtly or covertly, actually or potentially, impede intra-Community trade in services fall in principle within the scope of Articles 59 and 60 EEC. I say 'in principle' advisedly, because such national rules may nevertheless be compatible with those Treaty provisions where they are justified by imperative requirements of public interest (see section 22 et seq., below)...
>
> (22) The Court has consistently held, in particular in its judgment in Case 279/80, *Webb* [1981] E.C.R. 3305, [1982] 1 C.M.L.R. 719 (in paragraph 17, which refers to the judgment in Joined Cases 110-111/78, *Van Wesemael* [1979] E.C.R. 35, [1979] 3 C.M.L.R. 87, that regard being had to the particular nature of certain services, specific requirements imposed on the provider of the services cannot be considered incompatible with the Treaty where they have as their purpose the application of rules governing such activities. However, the freedom to provide services is one of the fundamental principles of the Treaty and may be restricted only by provisions which are justified by the general good [intérêt général] and which are imposed on all persons or undertakings operating in the said State in so far as that interest is not safeguarded by the provisions to which the provider of the service is subject in the member-State of his establishment.
>
> .../
>
> (24) It is in the light of this frame of reference (which is similar for trade in goods and trade in services) that the national rule at issue must, in my opinion, be considered. The questions arising in this connection are whether the rule pursues an objective which is justified under Community law, that is to say whether it can rely on imperative requirements of public interest which are consistent with or not incompatible with the aims laid down in the Treaty provisions, and whether that rule has no effects beyond those which are necessary and, in particular, is not disproportionate, that is to say whether it satisfies the test of the principle of proportionality."

96. Staying with restrictions on the Art 56 rights, in *Gebhard v Consiglio dell'ordine degli avvocati eprocuratori di Milano* C55/94 EU:C:1995:411 the ECJ, in a case concerned with the freedom to provide services, observed as follows regarding measures taken by EU Member States that hinder the exercise of fundamental freedoms under the EU Treaty:

> "...national measures liable to hinder or make less attractive the exercise of fundamental freedoms guaranteed by the Treaty must fulfil four conditions:

> they must be applied in a non-discriminatory manner; they must be justified by imperative requirements in the general interest; they must be suitable for securing the attainment of the objective which they pursue; and they must not go beyond what is necessary in order to attain it (see Case C- 19/92 *Kraus v Land Baden-Württemberg* [1993] ECR I - 1663, paragraph 32)."

The passaged in *Kraus v Land Baden-Württemberg* at [32] referred to by the court reads as follows:

> "Consequently, Articles 48 and 52 preclude any national measure governing the conditions under which an academic title obtained in another Member State may be used, where that measure, even though it is applicable without discrimination on grounds of nationality, is liable to hamper or to render less attractive the exercise by Community nationals, including those of the Member State which enacted the measure, of fundamental freedoms guaranteed by the Treaty. The situation would be different only if such a measure pursued a legitimate objective compatible with the Treaty and was justified by pressing reasons of public interest (see to that effect, judgment in Case 71/76 *Thieffry v Conseil de l'Ordre des Avocats à la Cour de Pans* [1977] ECR 765, paragraphs 12 and 15). It would however also be necessary in such a case for application of the national rules in question to be appropriate for ensuring attainment of the objective they pursue and not to go beyond what is necessary for that purpose (see judgment in Case C-106/91 *Ramrath v Ministre de la Justice* [1992] ECR I-3351, paragraphs 29 and 30)."

97. With respect to the domestic application of these principles in a claim for judicial review involving the right to receive medical services in another EU Member State, in *R v Human Fertilisation and Embryology Authority ex parte Blood* [1999] Fam 151, [1997] 2 WLR 806, [1997] 2 FLR 742 the Court of Appeal considered the terms of Art 56 (formerly Art 49 of the Treaty of the European Community and referred to as such in the judgment of the Court of Appeal). In that case the Court of Appeal held that preventing a person from receiving treatment in another Member State (in that case by prohibiting the export of the sperm of the claimant's late husband for the purposes of fertility treatment in another Member State) constituted a restriction on the freedom to receive services, which restriction had to be justified by the challenged State, for example on public policy grounds, if it was to be lawful. Within this context, the Court of Appeal at [47] identified a two stage process for the application of EU law having direct effect:

> "This illustrates the two-stage process in the application of Community law where it has direct effect: first, the court or decision taker must consider whether the challenged actions or decisions are an infringement of the relevant cross-border rights of the affected Community citizen, and then whether they are justified by the legitimate requirements of the state whose actions or decisions are challenged."

98. The question of infringement falls to be evaluated on a practical basis. Thus, in *Blood* the Court of Appeal noted that were a decision has the practical effect of withholding the provision of treatment in another EU Member State, from a functional point of

view the ability to provide and to receive those services is not only substantially impeded but made impossible.

99. As to the second question of whether, if there has been a practical interference in the claimant's EU rights, the interference is justified by the legitimate requirements of the state whose actions or decisions are challenged, in *Blood* the Court of Appeal noted as follows at [53] and [54]:

> "[53] However the fact that there is interference with the freedom to provide services does not mean that Article 59 is infringed. It means no more than the second stage has been reached and the interference has to be Justified in accordance with the well-established principles if it is not to contravene Article 59. Those principles are correctly summarised by Lord Lester in the case of an administrative decision as being that the decision must be non-discriminatory, it must be justified by some imperative requirement in the general interest, it must be suitable for securing the attainments of the objects which it pursues and it must not go beyond what it is necessary to attain that objective...
>
> [54] Furthermore the provision of services in relation to artificial insemination raise difficult ethical and moral considerations which Member States can appropriately feel it is necessary to protect by imposing regulations to prevent abuse and undesirable practices occurring."

100. In the circumstances, in evaluating the behaviour of the decision maker in a claim for judicial review in the foregoing context, the Court of Appeal in *Blood* concluded as follows:

> "[56] Article 59 cannot therefore be relied upon as preventing the Authority from imposing any restriction on the export of sperm, where a particular direction is sought, and in each case it is a question of degree whether the restriction is justified by the considerations to which reference has already been made. This in the first instance is a question for the Authority. The Courts will only intervene in one of two situations. First where the Authority does not comply with the usual administrative law standards which are enforced by judicial review, including directing themselves correctly as to the law. Secondly where the Authority's decision wrongly evaluates the considerations Lord Lester identified to an extent which goes beyond the margin of appreciation European law allows in the case of administrative decisions of this sort."

Within this context, I further note that in *Blood* the Court of Appeal was clear at [59] that a failure by an authority to take into account that its decision would act to impede the right under Art 56 to receive treatment in another EU Member State and to ask itself whether in the circumstances the interference is justified, renders the decision unlawful.

101. Finally, I note that the question of whether denying or otherwise preventing parents from moving a child from the United Kingdom to another EU Member State to receive continued life-sustaining treatment constitutes an unjustified interference in EU rights under Art 56 has been raised before the domestic courts on two recent

occasions in the same case. As Mr Sachdeva and Mr Lock point out, when the point was taken before the Court of Appeal in *Evans v Alder Hey Children's NHS Foundation Trust* [2018] EWCA Civ 984 at [29] it was not fully argued and, in any event, that decision of the Court of Appeal was concerned only with permission to appeal. However, the arguments were attempted at an earlier stage before the Court of Appeal, and in more detail, in the first appeal in *Evans v Alder Hey Children's NHS Foundation Trust* [2018] 2 FLR 1269, which appeal was heard and determined on the merits. Within this context, at paragraph [53], whilst not deciding the point, the Court of Appeal observed as follows regarding the arguments concerning contended for breach of EU rights under Art 56 of TFEU:

> "The other rights to which Mr Diamond has referred – the rights of the parents; the right to free movement; the right to access medical treatment – are not unlimited rights. This is apparent from the authorities relied on by Mr Diamond. For example, in *R v Human Fertilisation and Embryology Authority ex parte Blood* [1999] Fam 151, [1997] 2 WLR 806, [1997] 2 FLR 742 the court made clear that the right to receive medical treatment in another Member State could be limited if justified."

Medical Disputes and Parental Responsibility

102. 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).

103. Within this context, 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 Hight Court may also exercise its inherent jurisdiction to determine questions which have arisen in connection with the exercise of parental responsibility. Within this context, with respect to the interrelationship between role of parents with parental responsibility, the role of treating doctors and the role of the court in relation to the medical care of children, in *Re J (a minor)(wardship: medical treatment)* [1990] 3 All ER 930 at 934, [1991] Fam 33 at 41, Lord Donaldson MR observed as follows:

> "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."

104. Dealing in more detail with the role of the court, whilst in some contexts a statutory threshold of harm must be met before the court can make orders with respect to the care of children by the State, it is now established that no such threshold applies in disputes concerning the *medical* care of children by the State. The sole criteria to be applied by the court in determining disputes of that nature is that of the child's best interests. In *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and others* [2018] 1 All ER 569 the Court of Appeal made clear that this proposition holds good even where the parents have identified alternative options for continued treatment, McFarlane LJ (as he then was) making stating at [112] that:

> "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."

105. Within the context of the application for judicial review, and relevant to its determination, I also heard submissions regarding the proper procedure to be adopted domestically where a dispute arises between a parent with parental responsibility and treating doctors as to the medical treatment of a child and in particular, whether an NHS Trust is *required* to apply to court for a determination where such a dispute arises. In *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and others* McFarlane LJ described an application of the type with which I am concerned as "conventional", with the decision as to where the child's best interests lie being a choice falling to be made by a judge following a child-focused, child-led evaluation and not by the hospital forcing its views on the parents. Later, at [119] McFarlane LJ stated that "The system *requires* any dispute to be determined by a judge" (emphasis added and see also *Airdale NHS Trust v Bland* at 859 E-F per Lord Keith).

106. Within this context, I further note that in *Gard v United Kingdom* (2017) 65 EHRR 65, the ECtHR recapitulated the principles regarding the withdrawing of life sustaining treatment from the stand point of the State's positive obligations under Art 2 of the ECHR, a key aspect of compatibility being held to be the possibility of approaching the courts in the event of doubts as to the best decision to take in the patient's interests, following *Lambert v France* (2016) 62 EHRR 2 at [143]. In this context, in *Gard v United Kingdom* at [96] the ECtHR stated that:

> "The third element is the possibility to approach the courts in the event of doubts as to the best decision to take in the patient's interests. It is evident from the domestic proceedings that there was not only the possibility to approach the courts in the event of doubt but, in fact, a duty to do so (see [39]–[45] above). The Court also recalls that in its judgment in *Glass* (2004) 39 EHRR15, this Court criticised the treating hospital for failing to approach the courts in similar circumstances. The facts of the present case are wholly different, GOSH quite properly applied to the High Court under the relevant statute and the inherent jurisdiction of that court to obtain a legal decision as to the appropriate way forward."

And at [106]:

> "On the question of state interference where there is a conflict between a parent's desire concerning medical care for their child and the opinion of medical professionals treating the child, the Court has found that it is appropriate for the medical professionals involved to bring such conflicts before a court for resolution (see *Glass* (2004) 39 EHRR 15 at [83])."

And at [117]:

> "It is therefore clear that it was appropriate for the treating hospital to turn to the courts in the event of conflict"

107. That the proper route for an NHS Trust to take, in the event of a dispute between a parent with parental responsibility and treating doctors as to the medical treatment of a child, is an application to the court in this jurisdiction under the Children Act 1989 and/or the inherent jurisdiction of the High Court is reinforced by a number of further factors.

108. First, and most fundamentally, EU law confers jurisdiction to determine a dispute between a parent with parental responsibility and treating doctors as to the medical treatment of a child on the courts of the Member State of the child's habitual residence pursuant to Art 8 of BIIa, which provides as follows:

> "**Article 8**
>
> **General Jurisdiction**
>
> 1. The courts of a Member State shall have jurisdiction in matters of parental responsibility over a child who is habitually resident in that Member State at the time the court is seised."

Having regard to the independent and uniform interpretation given to the term 'habitual residence' throughout the EU for the purposes of Art 8 of BIIa, no party to these proceedings has sought seriously to suggest that this court does not have jurisdiction in respect of questions of parental responsibility concerning Tafida. Within this context, the ECJ has made clear in *Detiček v Sgueglia* C-403/09 PPU, EU:C:2009:810 that where there is a dispute (in that case in the context of Art 24(3) of the CFR) as to the child's best interests (emphasis added):

> "...a balanced and reasonable assessment of all the interests involved, which must be based on objective considerations relating to the actual person of the child and his or her social environment, *must* in principle be performed in proceedings before the court with jurisdiction as to the substance in accordance with the provisions of [BIIa]."

In addition to Art 8, Art 20 of BIIa provides that in urgent cases the provisions of the Regulation will not prevent the courts of a Member State from taking such provisional, including protective, measures available under the law of that Member State. As I will come to, when considering the application for judicial review it is important to bear in mind that EU law thus confers jurisdiction on the domestic court to determine the dispute between the parents and the treating doctors as to the medical treatment of Tafida in the proceedings under the Children Act 1989.

109. Second, I accept Ms Gollop's submission that the duty of an NHS Trust under s.11(2)(a) of the Children Act 2004 to ensure that its functions are discharged having regard to the need to safeguard and promote the welfare of children require it, where there is a dispute between a parent with parental responsibility and treating doctors as to the medical treatment of a child, to give consideration to and if necessary to make an application to the domestic court for the determination of the dispute. To do otherwise in such circumstances is to leave a void in relation to consent. This cannot be consistent with the duty on the NHS Trust to ensure that its functions (in this case, the medical treatment of a child) are discharged having regard to the need to safeguard and promote the welfare of children, nor with the best interests of the individual child concerned. It would also have the effect, if no such application were made, of conferring on the parents an unimpeachable authority to make welfare decisions in respect of their children notwithstanding countervailing medical advice, which is not the position in law.

110. Third, in cases that raise sensitive moral and ethical issues the EU recognises that different Member States will take different views concerning such issues and, in the circumstances, accord Member States a margin of appreciation in the manner in which it deals with such issues. Thus, in the context of life sustaining treatment, in *Gard v United Kingdom* at [84] the ECtHR observed as follows:

> "Accordingly, the Court considers that in this sphere concerning the end of life, as in that concerning the beginning of life, states must be afforded a margin of appreciation, not just as to whether or not to permit the withdrawal of artificial life-sustaining treatment and the detailed arrangements governing such withdrawal, but also as regards the means of striking a balance between the protection of patients' right to life and the protection of their right to respect for their private life and their personal autonomy (see, mutatis mutandis, *A v Ireland* (2011) 53 EHRR 13 at [237]). However, this margin of appreciation is not unlimited (at [238]) and the Court reserves the power to review whether or not the state has complied with its obligations under art.2 (*Lambert (*2016) 62 EHRR 2 at [148])."

And further at [122]:

> "The Court also recalls that where there is no consensus within the Member States of the Council of Europe, either as to the relative importance of the

> interest at stake or as to the best means of protecting it, particularly where the case raises sensitive moral or ethical issues, the margin of appreciation of the domestic authorities will be wider (see *Dubská* (2015) 61 E.H.R.R. 22 at [178] and *Parrillov Italy* (2016) 62 E.H.R.R. 8 at [169]). The Court has previously considered in the context of art.8 that in respect of the lack of consensus on access to experimental medical treatment for the terminally ill, the margin of appreciation is wide (see *Hristozov* (47039/11 and 358/12) 13 November 2012 at [124]). Moreover, it is clear that the case before it raises sensitive moral and ethical issues."

111. Fourth, the need for EU Member States to have a mechanism for resolving disputes between parents with parental responsibility and treating doctors as to the medical treatment of a child according to law is reflected in Art 6(2) of the Council of Europe's Convention on Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine which provides that:

> "Where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law."

112. During his submissions, Mr Sachdeva also sought to persuade the court that where the parents and a body of reputable medical opinion are in agreement as to the treatment of the child, this negates the need for the court to be involved at all, notwithstanding that a different body of reputable medical opinion disagrees. Mr Sachdeva relied for support on the decision of the Supreme Court in *An NHS Trust v Y* [2018] UKSC 46 at [102] to [113] that in cases where it is proposed to withdraw life-sustaining treatment from a patient lacking capacity for the purposes of the Mental Capacity Act 2005, and there is a consensus between a body of medical opinion and the family that this should be done, the permission of the court is not required. I am not persuaded by that submission.

113. First, *An NHS Trust v Y* concerned the Mental Capacity Act 2005 as applied to a man in his fifties who had capacity until her suffered a cardiac arrest, and not the Children Act 1989. In the circumstances, the Supreme Court was not required to consider the applicability to children of the principles it formulated. Second, *An NHS Trust v Y* concerned a consensus between the family and the only doctors treating the patient. The Supreme Court was not required to give consideration to the position that pertains in this case, namely different teams of reputable clinicians take contrasting views as to the appropriate way forward and offering different options (which, of course, by definition, would denote a dispute). Finally, and in the context of the matters I have set out above regarding the proper course of action where matters *are* in dispute, I also note that Lady Black made clear in *An NHS Trust v Y* at [109] that (emphasis added):

> "The opportunity to involve the court is available whether or not a dispute is apparent, and is of particular benefit where the decision is a finely balanced one. No one would discourage an application in any case where it is felt that the assistance of the court would be valuable. And if a dispute has arisen and cannot be resolved, it *must inevitably be put before the court*."

114. Having regard to the matters set out in the foregoing paragraphs, I am satisfied that in the event of a dispute between a parent with parental responsibility and treating doctors as to the medical treatment of a child habitually resident in this jurisdiction which is not capable resolution by agreement, that dispute requires to be put before the court, either by the parents or the treating doctors, for determination by a judge. In this jurisdiction, that course will be achieved by means of an application to the Family Division of the High Court for a specific issue order under s.8 of the Children Act 1989 or by an application for declarations under the inherent jurisdiction. I will come later to the significance of this conclusion regarding this 'national' procedure for the application for judicial review.

Best Interests in the Context of Medical Disputes

115. Where a dispute arises between parents and treating doctors regarding the proper course of treatment for a seriously ill child, 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.

116. As regards the application by the court of best interests principle in the context of the provision of medical treatment to children who are not 'Gillick' competent, this is well settled. The following key principles can be drawn from the authorities, in particular *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, *Re Ashya King* [2014] 2 FLR 855, *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 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."

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

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) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patients attitude to treatment is or would be likely to be. Within this context, the views of the child must be considered and be given appropriate weight in light of the child's age and understanding.

vi) 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 (see *Airedale NHS Trust v Bland* [1993] ACR 789 at 825). 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. Within this context, as I noted in *Re Y (No 1)* [2015] EWHC 1920 (Fam) at [37], the right to life under Art 2 of the ECHR imposes a positive obligation to provide life sustaining treatment, but that that obligation does not extend to providing such treatment if that treatment would be futile in nature and where responsible medical opinion is of the view that the treatment would not be in the best interests of the patient concerned (see *R (Burke) v The General Medical Council* [2005] EWCA 1003).

vii) 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 Waite LJ, in *Re T (A Minor)(Wardship: Medical Treatment)* [1997] 1 All ER 906 at 916 to 917 stated:

> "In this instance, however, in agreement with Butler-Sloss LJ, I consider that the judge was betrayed into an error of law by his concern with the need to form a judgment about the reasonableness of the mother's approach. An appraisal of parental reasonableness may be appropriate in other areas of family law (adoption, for example, where it is enjoined by statute), but when it comes to an assessment of the demands of the child patient's welfare, the starting point—and the finishing point too—must always be the judge's own independent assessment on the balance of advantage or disadvantage of the particular medical step under consideration. In striking that balance, the judge will of course take into account as a relevant, often highly

> relevant, factor the attitude taken by a natural parent, and that may require examination of his or her motives. But the result of such an inquiry must never be allowed to prove determinative. It is a mistake to view the issue as one in which the clinical advice of doctors is placed in one scale and the reasonableness of the parent in the other."

And later:

> "All these cases depend on their own facts and render generalisations— tempting though they may be to the legal or social analyst—wholly out of place. It can only be said safely that there is the scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare, widely accepted by the generality of mankind; and at the other end lie highly problematic cases where there is genuine scope for a difference of view between parent and judge. In both situations, it is the duty of the judge to allow the court's own opinion to prevail in the perceived paramount interests of the child concerned, but in cases of the latter end of the scale, there must be a likelihood (though never, of course, a certainty) that the greater the scope of general debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature."

viii) 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.

ix) Regard must be paid to the rights of the child, in particular her right to life under Art 2 and her right to respect for private and family life under Art 8. Regard must also be paid to the parents rights, in particular their right to respect for private and family life under Art 8. In this case, the right of Tafida and her parents to freedom of thought, conscience and religion under Art 9 of the ECHR is also engaged and must be considered.

x) 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.

117. Within the foregoing context, as I also noted in *Kings College Hospital NHS Foundation Trust v Haastrup*, in *Re A (A Child)* the Court of Appeal confirmed once again that, whilst requiring great sensitivity and care of the highest order, the task of the court in cases concerning disputes in respect of the medical treatment of children can be summed up by reference to two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, namely:

> "[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

> "[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."

118. The court has heard a number of detailed submissions regarding the manner in which the foregoing principles should be interpreted and applied, both generally and in the particular circumstances of this case. These submissions concentrated on (a) the nature and application of the best interests test, (b) the weight to be given to ascertainable wishes and feelings of the child, (c) the weight to be attached to the human rights engaged in this case and (d) the significance of an absence of pain and/or awareness to the best interests evaluation. I will deal with each of them in turn.

119. As to the nature and application of the best interests test, within the context of the evidence that Tafida is likely to develop in the future further and potentially discomforting or painful sequalae as a result of her cerebral injuries, Mr Lock submits the court cannot, in determining Tafida's best interests, look into the future but rather must evaluate best interests at the point the decision falls to be made. Whilst this is the position under the Mental Capacity Act 2005, the Children Act 1989 s 1(3)(e), under which this court proceeds, provides *expressly* for consideration of risk of future harm when determining a child's best interests. In the circumstances, I accept Mr Gration's submission that, contrary to the proposition advanced by Mr Lock, Tafida's extended prognosis falls to be considered under s 1(3)(e) of the 1989 Act, including areas of physical deterioration that are covered in the medical evidence, when her best interests are being considered.

120. With respect to wishes and feelings, on behalf of the maternal aunt in the Children Act proceedings, Mr Sachdeva sought to establish that, in cases of this nature, the court should give something like pre-eminent weight (the exact starting weight Mr Sachdeva sought to articulate remained unclear) to the ascertainable values and beliefs of the child in its best interests analysis. To make good this submission, Mr Sachdeva sought to draw an equivalence between s 1(3)(a) of the Children Act 1989 and s 4(6) of the Mental Capacity Act 2005, submitting that the latter demonstrates

that when considering the best interest of the child in a case of this nature, the beliefs and values that the child would be likely to influence the child's decision must be a consideration. Mr Sachdeva also prayed in aid s 4(7)(b) of the 2005 Act, which requires the court to have regard to the views of others as to the patients beliefs and values.

121. Within this context, Mr Sachdeva further submitted that as the jurisprudence with respect to the Mental Capacity Act 2005 has grown, the extent to which an individual's values and wishes have shaped the assessment of their best interests have also grown in importance, to the point where 'substituted judgment' informed by the beliefs and values of the patient, as informed by others who know the patient is now the key driver of the court's best interests decision. Mr Sachdeva submits that this is the effect of the seminal the decision of the Supreme Court in *Aintree University Hospital NHS Foundation Trust v James* [2014] AC 591, a case concerning the treatment of a 68 year old man who had lost capacity. Mr Sachdeva accordingly submits that, whilst the child's views have always been a material factor in cases of this nature, the consequence of *Aintree* is that in cases concerning children, whilst not determinative or a legally magnetic factor, the child's beliefs and values must be given something like pre-eminent weight (again, the exact starting weight Mr Sachdeva sought to articulate remained unclear). To further support this submission, Mr Sachdeva also draws the court's attention to Art 12(4) of the UN Convention on the Rights of Persons with Disabilities, which provides that measures relating to the exercise of legal capacity respect will and preferences of the disabled person. Mr Sachdeva further contends that the equivalence he seeks to draw between the operation of the Children Act 1989 s 1(3)(a) and the Mental Capacity Act 2005 s 4(6) was recognized by Hayden J's citing of *Aintree* in *Manchester CC v M* [2019] EWHC 468 at [28]. I am not persuaded by these submissions.

122. It is clear that the starting point of the court's analysis is to consider the matter from the assumed point of view of the child. The court must ask itself what the child's attitude to treatment is or would be likely to be. Within this context, in accordance with s 1(3)(a) of the Children Act 1989, the ascertainable wishes and feelings of the child on this question, which will include his or her values and beliefs, must be considered and be given appropriate weight in light of the child's age and understanding. But that is a very different to the proposition that the child's values and beliefs must start with elevated importance or some pre-assigned weight in the balance. Whilst I accept that paragraphs [22] and [39] of judgment of Baroness Hale in *Aintree* are often cited in cases concerning children as conveniently encapsulating the overall approach to best interests in medical cases (and were used in this way by Hayden J in *Manchester CC v M*), I do not read those passages as *requiring* the court to give preferential weight to the values and beliefs of the child in the balancing exercise. As Mr Gration submits, the position under s 1(3)(a) of the Children Act 1989 is clear. The wishes and feelings of the child do not carry any presumption of precedence over any of other the other factors in the welfare checklist. The child's wishes and feelings are only one factor in the case and the court is not bound to follow it. Having regard to the words of section 1(3)(a), what governs the weight to be attached to any ascertainable values or beliefs of the child in each case is the principle of the evolving capacity of the child, expressed as a function their age and understanding. The weight to be attached to the child's wishes and feelings will depend on the particular circumstances of each case and the final decision is that of

the court and not of the child (see *Re P (Minors)(Wardship: Care and Control)* [1992] 2 FCR 681). At all times, the child's best interests are the court's paramount consideration and this demands that other factors, including the wishes and feelings of the child, may, in a given case, outweigh the ascertained beliefs and values of the child. Thus, whilst in an individual case, the child's values and beliefs may attract the most weight, in all cases they start with an equal value to that of all other relevant factors.

123. Within the context of the foregoing submissions by Mr Lock and Mr Sachdeva, I agree with Ms Gollop that in cases under the Children Act 1989, and in particular those cases concerning the medical treatment of younger children and infants, it is not helpful to seek to import, wholesale, principles from the Mental Capacity Act 2005. To take Mr Sachdeva's submission regarding values and beliefs as an example, beyond the obvious fact that children below the age of 16 are outwith the jurisdiction of the 2005 Act, that Act deals with a fundamentally different constituency of people to that of the Children Act 1989. Within this context, the emphasis placed on beliefs and values by s 4(6) and the views of others in respect of the same by s 4(7) is consistent with the fact that those with whom the Mental Capacity Act 2005 is concerned, namely adults and children over the age of 16, are more likely to have developed sophisticated religious, moral or philosophical beliefs and values before losing capacity and to have discussed them with others than are the young children or infants that the Children Act 1989 is often concerned with. Given the fact of evolving capacity, the sophistication of the values and beliefs of those children vary widely in accordance with their age and understanding, the concepts of thought, conscience and religion implying a developing capacity to understand, appreciate and engage rationally with competing ideas and beliefs and, ultimately, the fully formed capacity to exercise choice in respect of those ideas and beliefs. These matters explain the wider wording of s 1(3)(a) of the Children Act 1989 and why it is well suited to evaluating the proper weight to be attached to the widely differing sophistication of children's values and beliefs (see *Re P (Section 91(14) Guidelines)(Residence and Religious Heritage)* [1999] 2 FLR 573) and highlight the undesirability of placing a gloss on s 1(3)(a) by using s 4(6) of the 2005 Act.

124. To use ss 4(6) and 4(7) of the Mental Capacity Act 2005 to add a gloss to s 1(3)(a) of the 1989 Act risks imputing to a young child matters beyond their comprehension and failing to take account of principle of evolving capacity (which is nowhere mentioned in s 4(6) of the 2005 Act), contrary to the express requirement by s 1(3)(a) of the 1989 Act. This is a particular risk where one is dealing with the complex area of religious belief, where the child's age and understanding is key to determining the weight to be attached to any such belief. Within this context, I again note the terms of Art 6(2) of Council of Europe's Convention on Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, which stipulates that "The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity."

125. Turning to the legal submissions regarding the rights engaged in this matter, during the course of her submissions, Ms Gollop appeared to suggest that were the Trust to continue treating Tafida it may or would breach her rights under Art 3 of the ECHR. This argument was raised only during the course of the hearing and was not pressed in detail. Indeed, at this stage the argument amounts to the contention that if the court

refuses the Trust's application the court will act to breach Tafida's Art 3 rights by compelling the continuation of inhuman or degrading treatment. In the circumstances, I do not consider it necessary to address this argument in detail. Within its best interests analysis the court is required to 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 and will do so. Likewise, it is expressly required to consider the benefits and burdens on the child. If having undertaken that exercise, the court considers that treatment should continue in Tafida's best interests, it is difficult to see how that decision could simultaneously amount to a breach of Art 3.

126. The parents and the maternal aunt also submit that Tafida is being unlawfully deprived of her liberty pursuant to Art 5 of the ECHR. In this regard, I need only note the following observations of the Court of Appeal in *Evans v Alder Hey Children's NHS Foundation Trust* [2018] 2 FLR 1269 at [60] to [62]:

> "[60] In *R (Ferreira) v Inner South London Senior Coroner (Intensive Care Society and Others Intervening)* [2017] EWCA Civ 31, [2017] 3 WLR 382, the Court of Appeal decided that a person is not being deprived of their liberty where they are receiving treatment and are physically restricted by their physical infirmities and by the treatment they are receiving: para [10]. In reaching this conclusion the court referred to *Nielsen v Denmark* in which the European Court of Human Rights had concluded that the hospitalisation of the child in a child psychiatric ward did not amount to a deprivation of liberty. A critical part of the court's assessment was that (at para 72):
>
>> '… the restrictions to which the applicant was subject were no more than the normal requirements for the care of a child of 12 years of age receiving treatment in hospital. The conditions in which the applicant stayed thus did not, in principle, differ from those obtaining in many medical wards where children with physical disorders are treated.'
>
> [61] In *Ferreira* Arden LJ adopted the expression used in the European Court of Human Rights' decision of *Austin and Others v United Kingdom* (Application Nos 39692/09, 40713/09 and 41008/09) [2012] ECHR 459, (2012) 55 EHRR 14, [2012] Crim LR 544, 32 BHRC 618 when excepting from the scope of Art 5 'commonly occurring restrictions on movement'. Arden LJ concluded, at paras [88]–[89], that restrictions resulting from the administration of treatment, because they are the 'well-known consequences of a person's condition, when such treatment is required', do not amount to a deprivation of liberty. [62] This clearly applies to Alfie's situation. We see no basis for any submission that he is being deprived of his liberty in terms either of Art 5 or the doctrine of habeas corpus."

127. The parents place their religious faith and practices, and Tafida's contended for understanding of and belief in the same at the heart of their objection to the course of action proposed by the Trust. Art 9 of the ECHR provides as follows:

> **“Article 9**
>
> **Freedom of thought, conscience and religion**
>
> 1. Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief and freedom, either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance.
>
> 2. Freedom to manifest one’s religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others.”

128. The right to freedom of thought, conscience and religion has been described as a far reaching and profound right encompassing freedom of thought on all matters, personal conviction and the commitment to religion or belief, whether manifested individually or in community with others (see Human Rights Committee General Comment No 22 1993 HRI/GEN/1/Rev 8, p 194, para 1). In *Grzelak v Poland* (2010) Application No 7710/02 at [8] the European Court of Human Rights reiterated that:

> “… freedom of thought, conscience and religion, as enshrined in Article 9, is one of the foundations of a ‘democratic society’ within the meaning of the Convention. It is, in its religious dimension, one of the most vital elements that go to make up the identity of believers and their conception of life, but it is also a precious asset for atheists, agnostics, sceptics and the unconcerned. The pluralism indissociable from a democratic society, which has been dearly won over the centuries, depends on it. That freedom entails, inter alia, freedom to hold or not to hold religious beliefs and to practise or not to practise a religion.”

129. International law does not establish a minimum age above which a person may enjoy freedom of thought, conscience and religion. Further, a person’s right to freedom of thought, conscience and religion will often, as in this case, exist in the context of beliefs embedded within the values of local communities, which communities themselves have a cohesive ethical, moral, spiritual, cultural and social framework. Within this context, Mr Sachdeva refers the court to the decision in *IH (Observance of Muslim Practice)* [2017] EWCOP 9 in which Cobb J considered at [40] that P derived benefit from his family feeling that he was being enabled to follow Muslim custom to the fullest possible extent. Mr Sachdeva also cites *IH (Observance of Muslim Practice)* as an example of the court taking into account religious belief and practice even where P had limited or no understanding of it and of cultural and religious beliefs, including those held by parents and community, having a significant impact on the assessment of best interests.

130. Against this, Art 9(2) makes clear that derogations from the right to freedom of thought, conscience and religion are permitted in certain narrowly defined circumstances. Whether a particular act constitutes interference in the rights enshrined in Art 9(1) will depend on all the circumstances of the case in question, including the extent to which in the circumstances an individual can reasonably be

expected to be at liberty to manifest his or her beliefs in practice (see *Kalac v Turkey* (1997) 27 EHRR 552 cited in *R (Williamson) v Secretary of State for Education and Employment* [2005] 2 AC 286 at [38]). In the circumstances, the right to freedom of thought, conscience and religion may be circumscribed where this conflicts with the child's best interests assessed by reference to the terms of s 1 of the Children Act 1989. In *Prince v Massachusetts* (1944) 321 US 158 the US Supreme Court held that parents' rights to manifest their religion are necessarily circumscribed by the interests of the child in that:

> "… neither rights of religion nor rights of parenthood are beyond limitation. Acting to guard the general interest in youth's well-being, the state as *parens patriae* may restrict the parent's control by requiring school attendance, regulating or prohibiting the child's labor [*sic*] and in many other ways. Its authority is not nullified merely because the parent grounds his claim to control the child's course of conduct on religion or conscience. Thus, he cannot claim freedom from compulsory vaccination for the child more than for himself on religious grounds. The right to practice religion freely does not include liberty to expose the community or the child to communicable disease or the latter to ill health or death … [T]he state has a wide range of power for limiting parental freedom and authority in things affecting the child's welfare; and that this includes, to some extent, matters of conscience and religious conviction …"

131. Finally on the submissions as to the law, in circumstances where the medical consensus in this case is that Tafida does not feel pain in her resting state and has with no awareness or a minimal current level of awareness, the parties made submissions regarding the significance of these factors, and the question of dignity, for the best interests analysis.

132. Ms Gollop submitted that in *Re J (A minor) (wardship: medical treatment)*[1991] Fam 33 at page 46 and in *Re A* [2016] EWCA Civ 759 at [58] the Court of Appeal made clear that the absence of pain does not prevent, in an appropriate case, the court concluding that life-sustaining treatment should nonetheless not be continued. Within this context, I further note that in the Court of Appeal in *Airedale NHS Trust v Bland* [1993] AC 806 at 829, Hoffman LJ observed as follows with respect to the argument of the Official Solicitor that Anthony Bland felt no pain or awareness and therefore had no interests which suffered from his being kept alive:

> "I think that the fallacy in this argument is that it assumes that we have no interests except in those things of which we have conscious experience. But this does not accord with most people's intuitive feelings about their lives and deaths."

133. In *Airedale NHS Trust v Bland* [1993] AC 789, whilst the House of Lords upheld the decision of the Court of Appeal, in the course of their speeches both Lord Keith and Lord Mustill articulated the potential difficulties with the Hoffman LJ's proposition where it is the best interests of the *patient* who suffers no pain and is unaware and not those of others that are the focus of the court. Within this context, at 858 Lord Keith observed as follows:

> "It is argued for the respondents, supported by the amicus curiae, that his best interests favour discontinuance. I feel some doubt about this way of putting the matter. In *In re F. (Mental Patient: Sterilisation)* [1990] 2 A.C. 1 this House held that it would be lawful to sterilise a female mental patient who was incapable of giving consent to the procedure. The ground of the decision was that sterilisation would be in the patient's best interests because her life would be fuller and more agreeable if she were sterilised than if she were not. In *In re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam. 33 the Court of Appeal held it to be lawful to withhold life-saving treatment from a very young child in circumstances where the child's life, if saved, would be one irredeemably racked by pain and agony. In both cases it was possible to make a value judgment as to the consequences to a sensate being of in the one case withholding and in the other case administering the treatment in question. In the case of a permanently insensate being, who if continuing to live would never experience the slightest actual discomfort, it is difficult, if not impossible, to make any relevant comparison between continued existence and the absence of it. It is, however, perhaps permissible to say that to an individual with no cognitive capacity whatever, and no prospect of ever recovering any such capacity in this world, it must be a matter of complete indifference whether he lives or dies."

And Lord Mustill at 897 observed that:

> "Quite apart from this the case of Anthony Bland seems to me quite different. He feels no pain and suffers no mental anguish. Stress was laid in argument on the damage to his personal dignity by the continuation of the present medical regime, and on the progressive erosion of the family's happy recollections by month after month of distressing and hopeless care. Considerations of this kind will no doubt carry great weight when Parliament comes to consider the whole question in the round. But it seems to me to be stretching the concept of personal rights beyond breaking point to say that Anthony Bland has an interest in ending these sources of others' distress. Unlike the conscious patient he does not know what is happening to his body, and cannot be affronted by it; he does not know of his family's continuing sorrow. By ending his life the doctors will not relieve him of a burden become intolerable, for others carry the burden and he has none. What other considerations could make it better for him to die now rather than later? None that we can measure, for of death we know nothing. The distressing truth which must not be shirked is that is that the proposed conduct is not in the best interests of Anthony Bland, for he has no best interests of any kind."

134. In *Airedale NHS Trust v Bland* at 899 Lord Mustill further highlighted the potential for the difference between no awareness and some awareness to change the court's best interest evaluation:

> "In law, if my conclusion is right, the way is clear for the doctors to proceed as they and the family think best. If the principle of *Bolam* applies that is the end of the matter, since nobody could doubt that a body of reasonable medical opinion would regard the proposed conduct as right. But even if

> *Bolam* is left aside, I still believe that the proposed conduct is ethically justified, since the continued treatment of Anthony Bland can no longer serve to maintain that combination of manifold characteristics which we call a personality. Some who have written on this subject maintain that this is too narrow a perspective, so I must make it clear that I do not assert that the human condition necessarily consists of nothing except a personality, or deny that it may also comprise a spiritual essence distinct from both body and personality. But of this we can know nothing, and in particular we cannot know whether it perishes with death or transcends it. Absent such knowledge we must measure up what we do know. So doing, I have no doubt that the best interests of Anthony Bland no longer demand the continuance of his present care and treatment. This is not at all to say that I would reach the same conclusion in less extreme cases, where the glimmerings of awareness may give the patient an interest which cannot be regarded as null. The issues, both legal and ethical, will then be altogether more difficult."

135. During the course of the hearing, the court also heard a number of submissions concerning the role of the concept of dignity in the best interests analysis. Ms Gollop reminded the court that Art 1 of the CFR provides that human dignity is inviolable and must be respected and protected. She further reminds the court that Art 3 of the CFR enshrines the right to respect for a person's physical integrity. Within this context, I note the observations of Hoffman LJ, as he then was, in the Court of Appeal in *Airedale NHS Trust v Bland* [1993] QC 806 at 826:

> "And another principle, closely connected, is respect for the dignity of the individual human being: our belief that quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person. The fact that the dignity of an individual is an intrinsic value is shown by the fact that we feel embarrassed and think it wrong when someone behaves in a way which we think demeaning to himself, which does not show sufficient respect for himself as a person."

And of Handler J in the American decision *In re Conroy* (1985) 486 A.2d 1209, 124 at p 1249:

> "The medical and nursing treatment of individuals in extremis and suffering from these conditions entails the constant and extensive handling and manipulation of the body. At some point, such a course of treatment upon the insensate patient is bound to touch the sensibilities of even the most detached observer. Eventually, pervasive bodily intrusions, even for the best of motives, will arouse feelings akin to humiliation and mortification for the helpless patient. When cherished values of human dignity and personal privacy, which belong to every person living or dying, are sufficiently transgressed by what is being done to the individual, we should be ready to say: enough."

136. Against this, Mr Sachdeva submitted that dignity is a subjective concept that means different things to different people and, as such, is heavily value laden and extremely

difficult to define. In the circumstances, Mr Sachdeva cautioned against its use of such a mercurial concept as a reliable factor in the best interests analysis.

137. Not all human life is lived in dignity. Dignity also depends on the subjective frame of reference that is adopted (see *Christian Education South Africa v Minister of Education* (2000) 9 BHRC 53, Const Ct of South Africa). For example, whilst "the constant and extensive handling and manipulation of the body" by dedicated nursing staff in a medical establishment may in time reach a certain threshold of indignity, the location of that threshold and the extent to which it is reached might be very different if the "the constant and extensive handling and manipulation of the body" is undertaken at home by dedicated and loving parents. Within this context, in *M v N* [2015] EWCOP 76 at [72] Hayden J observed that, "There is an innate dignity in the life of a human being who is being cared for well, and who is free from pain".

138. Finally, and related to these difficult issues, the Royal College of Paediatrics and Child Health has issued guidance entitled '*Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice*', published in March 2015. The guidance was considered by the President in *Re Jake (A Child)* [2015] EWHC 2442 (Fam). With respect to the issues raised in this case, the Guidance states as follows with respect to the sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, as treatments cannot provide overall benefit:

> "**I When life is limited in quantity**
>
> If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:
>
> A. Brain stem death, as determined by agreed professional criteria appropriately applied;
>
> B. Imminent death, where physiological deterioration is occurring irrespective of treatment;
>
> C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.
>
> **II When life is limited in quality**
>
> This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:
>
> A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits;
>
> B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life;

> C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life."

139. In respect of circumstances where life may be of limited quality due to a lack of ability to benefit from continued life, the Guidance provides further illumination as follows:

> "**C. Lack of ability to derive benefit**
>
> In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation. Although it is possible to distinguish these different groups of decisions to limit LSTs that are based on quality-of-life considerations, in practice combinations may be present. For example, a child or infant in intensive care may have sustained such significant brain injury that future life may provide little benefit, while both intensive treatment and future life are likely to cause the child substantial pain and distress."

DISCUSSION

Judicial Review

140. I am satisfied in this case that, as is clear from the evidence filed and served by the Trust, that on or around 8 July 2019, in response to a request by the parents to transfer Tafida to the Gaslini Hospital in Italy, the Trust decided not to agree to that transfer pending an application to the High Court in light of the dispute concerning Tafida's best interests. I am further satisfied that the evidence demonstrates clearly that the Trust took this decision on the basis of its own assessment of Tafida's best interests. Contrary to the submissions made on behalf of the parents and Tafida, I am satisfied that there is no sufficiently cogent evidence to ground a conclusion that the Trust based its decision either on Tafida's nationality or on any philosophical or ethical differences as between the United Kingdom and Italy regarding the withdrawal of life sustaining treatment.

141. I am equally satisfied that, contrary to the submissions of Ms Gollop, the decision made by the Trust is amenable to judicial review. The Trust is a public body that exercises statutory functions under the National Health Service Act 2006. As

conceded by Ms Gollop, the treating doctors were acting in their capacity as employees of the Trust when they took the relevant decision. As I will come to, it is plain that the decision by the Trust acted to restrict the exercise of EU rights from which Tafida benefits and that have direct effect in domestic law. More widely, it is plain from the authorities that decisions of NHS bodies are amenable to judicial review (see for example *R(JB) v Haddock* [2006] EWCA Civ 961, [2006] HRLR 1237). Finally, I note that the NHS Constitution itself provides at page 10 that:

> "You have the right to make a claim for judicial review if you think you have been directly affected by an unlawful act or decision of an NHS body or local authority."

142. Within this context, I am not persuaded by the Trust's submission that the existence of a requirement on the Trust, both procedurally and pursuant to its statutory duties, to bring the dispute as to Tafida's best interests before the High Court, and the existence of a statutory regime to determine the dispute, renders the Trust's decision immune from judicial review. Whilst those matters will plainly be relevant to the question of whether the decision made constituted an interference with the EU rights engaged and, if so, the question of whether that interference was justified, I am entirely satisfied that they do not act to take the decision itself outside the proper ambit of judicial review.

143. I am not persuaded that the decision of the Trust deprived Tafida of her liberty for the purposes of Art 5 of the ECHR. The Court of Appeal has made clear that a person is not being deprived of their liberty where they are receiving treatment and are restricted physically by their infirmities and by the treatment they are receiving (see *Evans v Alder Hey Children's NHS Trust* [2018] 4 WLUK 624 at [12] and *Gard* [2017] 4 WLR 131). I am likewise not able to accept the submission that in taking the decision it did, the Trust discriminated against Tafida or her parents for the purposes of the Equality Act 2010. I am satisfied that, in deciding to refuse to agree to Tafida being transferred to the Gaslini Hospital pending a determination by the court as to her best interests in accordance with established procedure, the Trust cannot be said to have applied a provision, criterion or practice which is discriminatory in relation to a relevant protected characteristic of Tafida or her parents. I am also satisfied that it cannot be said that in taking its decision the Trust failed to have regard to, or contravened the NHS Constitution. However, I am satisfied that Tafida and her parents have made out their case under Art 56 of TFEU.

144. The Trust does not deny that, in making its decision not to agree to Tafida being transferred to the Gaslini Hospital, it did not give any consideration to whether that decision would interfere with Tafida's EU directly effective rights under Art 56 nor, if it did so interfere, to whether that inference was justified on the grounds of public policy. In the circumstances, and having regard to the decision of the Court of Appeal in *Blood*, it is beyond sensible dispute that the Trust did not comply with the usual administrative law standards which are enforced by judicial review, including failing to direct itself correctly as to the applicable EU law. In the circumstances, I am satisfied that the Trust's decision on 8 July 2019 was *prima facie* unlawful. I am however, also satisfied that *had* it considered Tafida's Art 56 rights when making its decision not to agree to Tafida being transferred to the Gaslini Hospital, the Trust would have reached the same decision for the following reasons.

145. As I have noted, the Trust does not dispute that Tafida benefits from EU rights under Art 56 having direct effect. Within this context, asking and answering the first question posed by the Court of Appeal in *Blood*, I am satisfied that, from a functional point of view, the ability for Tafida to benefit from her directly effective EU rights under Art 56 to receive medical treatment in another Member State was not only substantially impeded but made impossible by the decision of the Trust not to agree to her parents request that she be transferred to the Gaslini Hospital. Accordingly the decision of the Trust constituted a plain interference with Tafida's directly effective EU rights under Art 56 of TFEU.

146. However, interrogating the second question set out in *Blood*, I am also satisfied that it is clear that, having regard to the established national procedure in this jurisdiction for determining disputes between parents and doctors over whether a child should or should not continue to receive life-sustaining treatment and to the fact that the relevant EU jurisdictional provisions in the form of BIIa confer jurisdiction for the use of that national procedure in this case, had the Trust asked and answered the second question when making its decision, the Trust would have come to the conclusion that the interference in Tafida's EU rights constituted by its decision was justified on public policy grounds.

147. For the reasons set out above, I am satisfied that the position in this jurisdiction is that, in the event of a disagreement between a parent with parental responsibility and treating doctors as to the medical treatment of a child habitually resident in this jurisdiction that is not capable resolution by agreement, the resulting dispute as to best interests requires to be put before the court, either by the parents or the treating doctors, for determination by a judge. In this jurisdiction, that course is achieved by means of an application for a specific issue order under s.8 of the Children Act 1989 or by an application for declarations under the inherent jurisdiction of the High Court. It is this procedure that the Trust chose to invoke when it became apparent that the parents wished to transfer Tafida to the Gaslini Hospital and the Trust considered this transfer not to be in Tafida's best interests.

148. In considering whether this established national procedure for the determination of a dispute between parents and doctors concerning an aspect of a child's best interests amounts to a justification on public policy grounds for derogating from Tafida's directly effective EU rights under Art 56, the case law considered above makes clear that this is a question for the *national* court and that the following factors fall to be considered in answering it:

i) Is the measure equally applicable to all persons and undertakings operating in the Member State in question (and if not is it justified by one of the Treaty exceptions (see *Gouda v Commissariat voor de Media* C288/89 EU:C:1991:157))?

ii) Is the measure justified by some legitimate public interest objective that is consistent with, or not incompatible with, the aims laid down in the Treaty provisions?

iii) Is the measure suitable for securing the attainment of the objective that it pursues?

iv) Is the measure proportionate to the objective, i.e. does ensure the objective it pursues and not go beyond what is necessary to attain that objective?

149. Subject to the jurisdictional provisions of BIIa, which are applicable in all EU Member States save Denmark, the national procedure for the determination of a dispute between parents and doctors concerning a child's medical treatment is equally applicable to all children in this jurisdiction. In so far as the procedure cannot be invoked in relation to an EU citizen child who is not habitually resident in England and Wales for the purposes of Art 8 of BIIa, this distinction is solely a function of directly effective EU law. Moreover, the domestic procedure remains available with respect to such children in a case of urgency, pursuant to Art 20 of BIIa, and in relation to any EU citizen child whose habitual residence cannot be established, pursuant to Art 13 of BIIa. In circumstances where the jurisdictional foundation for the national procedure in question is provided by EU law, I am not able to accept the submission that that procedure conflicts in anyway with the primacy of EU law or is discriminatory on the grounds of nationality or otherwise.

150. Further, I am satisfied that the national procedure for the determination of a dispute between parents and doctors concerning a child's medical treatment is justified by a legitimate public interest objective that is consistent with, and not incompatible with, the aims laid down in the EU Treaty provisions.

151. The national requirement to bring a dispute between parents and doctors concerning a child's medical treatment before the court is promoted by a public policy objective in the United Kingdom founded on imperative requirements of public interest, namely:

i) The public interest in the protection of a child's best interests in the context of medical decision making, where the best interests of children are one of the fundamental interests of society and are the paramount consideration;

ii) The public interest in the courts and not treating doctors determining the outcome of a dispute between parents and treating doctors as to whether a child should continue to receive life-sustaining treatment;

iii) The public interest in treating doctors having a legally certain route available to them to determine what the law requires of them in cases where there is a dispute as to the child's medical treatment;

iv) The public interest in ensuring that a child has an independent voice in the determination of a dispute between parents and doctors as to the child's medical treatment;

v) The public interest in ensuring equal treatment of all children where a dispute arises as to their medical treatment.

In my judgment, the conclusion that the national procedure is justified on the grounds of public policy is further reinforced by the principle that on difficult moral or ethical questions there is a wider margin of appreciation accorded to Member States with respect to national measures. The question which the national procedure seeks to answer relates to a policy choice of a moral and philosophical nature which is a matter for Member States within the margin of appreciation and in respect of which they are entitled to invoke the ground of public policy referred to in Art 56.

152. The foregoing imperative requirements of public interest are consistent with the aims laid down by the EU Treaty provisions, which require the directly effective EU rights under Art 56 to be implemented in a manner that treats the child's best interests as a primary consideration. Within this context, EU law would not reproach a national authority for seeking to ensure that the Art 56 rights of a child are implemented in a manner consistent with the best interests of that child by determining, where there is a dispute, whether it is in the child's best interests to receive medical treatment in another Member State, particularly having regard to paragraphs 4, 7 and 12 of Directive 2011/24 EU. Again, that this must be the position is made clear by the fact that *EU law*, in the form of the jurisdictional provisions of BIIa, confers jurisdiction to determine such a dispute on the Member State of the child's habitual residence. Where there is a dispute in the Member State of the child's habitual residence between treating doctors and parents exercising their parental responsibility on an issue as fundamental as whether it is in a child's best interests to continue to receive life sustaining treatment in another Member State, the EU has *expressly* conferred upon the Member State of the child's habitual residence jurisdiction to determine that welfare dispute pursuant to Art 8 of BIIa in accordance with the child's best interests.

153. I am further satisfied that the national procedure is suitable for securing the attainment of the objective that it pursues, namely the fair and expeditious determination of a disagreement between doctors and parents as to what medical treatment in the child's best interests. The procedure adopted in this jurisdiction to attain that objective ensures that the dispute is put before an independent judge, who evaluates the dispute on the available evidence by reference to a legal framework that places the child's best interests as the paramount consideration (and which provides for consideration of the EU rights engaged) and in which process the child is provided with an independent voice on the issue central to his or her future. In order for a national rule to be justified under EU law it must be objectively necessary in order to help achieve the aim sought by the rule: that means that it must be useful (or relevant) and indispensable, in other words, it must not be capable of being replaced by an alternative rule which is equally useful but less restrictive of the freedom to supply services. In this respect, and once again, EU law *itself* confers jurisdiction on the domestic court in this case to determine the dispute between the parents and the treating doctors as to the medical treatment of the child using the procedure described. Further, the suitability of the national procedure for determining disputes of this nature is reinforced by the fact that it will generally be the jurisdiction in which the child is habitually resident who will have the information required to deal with the question that falls for decision. Within the foregoing context, I cannot accept the submission of advanced by Mr Sachdeva and Mr Lock that, where it is satisfied that the *transfer* itself is not antithetic to the child's best interests, the court could in the alternative proceed to determine the substantive best interests issue *after* the child has been transferred to receive treatment. Such a system plainly could not be said to be equally useful but less restrictive of the freedom to supply services. In addition, it would be manifestly contrary to a child's best interests to transfer a child between EU Member States in order to receive treatment where an extant dispute as to whether this is in the child's best interests remains to be determined.

154. Finally, I am satisfied that the national procedure is proportionate to the objective, i.e. it ensures the objective it pursues and does not go beyond what is necessary to attain that objective. The national procedure goes no further than the jurisdiction conferred by BIIa, namely the determination of a dispute concerning an aspect of parental responsibility. Where receipt of treatment is held to be in the child's best interests then the relevant EU right is implemented. Where it is not held to be in the child's best interests, then EU law would not require effect the implementation of an EU right in a manner that is antithetic to the child's best interests having regard to the provisions of the CFR. Within this context, whilst the national procedure does constitute a *prima facie* derogation from the EU rights under Art 56, such derogation is accordingly temporary and lasts only as long as necessary to determine the issue in dispute in accordance with the jurisdictional provisions of EU law. Within this context, I am satisfied that the national requirement to bring before the court a dispute between treating doctors and parents on an issue as fundamental as whether life sustaining treatment should continue of be withdrawn does not have an effect beyond that which is necessary and complies with the principle of proportionality.

155. Within the foregoing context, I am satisfied that in making its decision not to agree to Tafida being transferred to the Gaslini Hospital pending a decision of the court, the Trust did not give *any* consideration to Tafida's Art 56 rights and, in particular did not ask itself whether its decision constituted an interference in those directly effective rights and, if so, whether it was nonetheless justified. I am further satisfied therefore that, applying the principles in *Blood*, the decision of the trust is unlawful. I am also satisfied however, that had the Trust asked itself the first and second questions posed in *Blood* by reference to Art 56 of TFEU, it would inevitably have reached the same decision not to agree to Tafida's transfer pending a decision of the court on the basis that the national procedure it chose to follow constitutes a justified derogation from Tafida's rights under Art 56. In short, had the Trust adopted the correct approach, this matter would, I am satisfied, have arrived at precisely the point it has now reached.

156. As to any remedy in the judicial review proceedings in this context, the general approach should be that a claimant who succeeds in establishing the unlawfulness of administrative action in a claim for judicial review is entitled to be granted a remedial order. The court does however, have common law discretion to withhold a remedy (or grant a declaration) where a remedy would serve no practical purpose or where to do so would result in unacceptable delay. Whilst the common law discretion to refuse a remedy is a narrow one, and narrower still where the claimant has succeeded in demonstrating a directly effective right under European law, the existence of an EU law right does not act as a complete bar to the court's discretion.

157. Within this context, I am satisfied that it would now serve no practical purpose to quash the decision of the Trust not to agree to the transfer of Tafida to Italy pending court proceedings to determine her best interests where I am satisfied that this is the decision the Trust would have made had it properly taken its decision, where those proceedings are now before the court for determination and where the court is in a position to determine them. In addition, quashing the Trust's decision and remitting it to be retaken would engender unacceptable delay for Tafida (see *R v Legal Aid Board, ex p W (Minors)* [2001] 1 WLR 2502. Finally, and in any event, pursuant to the Criminal Justice and Courts Act 2015 s.84, the High Court must refuse relief on an application for judicial review if it appears to the court to be highly likely that the

outcome for the applicant would not have been substantially different if the conduct complained of had not occurred. That is the position here for the reasons I have given.

158. On this basis, whilst satisfied that decision of Trust is unlawful in circumstances where the Trust failed to consider Tafida's directly effective EU rights under Art 56 of TFEU at all when deciding whether to agree to the parents' request for Tafida to be transferred to the Gaslini Hospital, in the particular circumstances of this case I am also satisfied that it is not appropriate to grant relief on the application for judicial review, including a declaration in circumstances where this judgment speaks for itself.

Children Act 1989 and Inherent Jurisdiction Proceedings

159. In light of foregoing decision, I am satisfied that it is appropriate now to go on to determine the Trust's applications pursuant to s 8 of the Children Act 1989 and under the inherent jurisdiction of the High Court. Having anxiously balanced all of the conflicting considerations in this case, I have decided that I am *not* satisfied on the totality of the evidence that it is appropriate in this case to grant the declarations sought by the Trust and that, accordingly, the applications made by the Trust should be dismissed. My reasons for so deciding are as follows.

(a) Tafida's Medical Condition and Prognosis

160. In circumstances where the medical evidence in this case is unchallenged, and in the context of the assessment of Tafida's best interests, the medical issues that are central to that assessment are, in my judgment, the level of Tafida's awareness, the question of whether Tafida experiences pain, the question of the extent to which Tafida is able to benefit from treatment and the prognosis for Tafida in respect of each of these factors.

161. With respect to Tafida's level of awareness, it is clear on the medical evidence that she has a very severe generalised cerebral dysfunction. Tafida has a sleep wake cycle, with eye opening and closing, her eyes can sometimes be maintained fixed in axis with a direct and consensual pupillary light reflex and a 'dolls eye' response that is equivocal but not entirely absent. I have taken careful account of the evidence of the parents that Tafida demonstrates some level of awareness and small incidents of volitional response, some of which they contend are evidenced on the videos to which I have given detailed consideration. Whilst I am satisfied that this evidence must be viewed with caution for the reasons I have already articulated, I note that Dr Smith in his report makes reference to video (also shown to the court) where Tafida appeared to lift her arm and turn it outwards to place rolled up bandage into the hand of her nanny and to his observations of Tafida moving her eyes to the location of her mother in response to voice and touch, although after two incidences of this, that result was not replicated. Within this context, there is a consensus of medical opinion is that it is not possible to exclude in Tafida some level of conscious awareness. Dr Smith in particular is clear that he would be very wary of the risk of misinterpreting the absence of responses in Tafida as VS because of the inevitable limitations on the accuracy with which medical science is able to test for awareness in a child with Tafida's injuries. Within the context of this difficulty, and mindful of Dr Smith's evidence that, at least in a paediatric context, the distinction between VS and MCS is somewhat artificial, having regard to the totality of the evidence available to me I proceed on the basis that Tafida is likely to retain a minimal level of awareness.

162. With respect to the question of Tafida's ability to feel pain, I again bear in mind Dr Smith's caution that accurate and reliable assessment of ability to experience pain, like assessment of awareness, is fraught with difficulty in a patient as severely neurologically impaired as Tafida. As to the evidence that is available, Dr T noted in early July 2019 that Tafida "flexes to pain". The Italian team elicited similar flexion in the limbs with "intense pain stimulation" but also noted no EEG changes as the result of such painful stimulation. Within this context, the preponderance of medical evidence is to the effect that Tafida shows no facial grimace to deep pain, does not cough or gag to endotracheal tube suction and does not respond to pain by way of an increase in heart rate or withdrawal from painful stimuli. Accepting the difficulties, and doing the best I can on the available evidence, I am satisfied that, at least in her resting state or standard condition, it is likely that Tafida does not perceive pain.

163. With respect to Tafida's prognosis, on the unchallenged medical evidence before the court I am satisfied that Tafida's current medical condition is substantially irreversible. Whilst I am satisfied that the consensus of medical opinion is that some minimal neurological progress *may* be made by Tafida in the future, I am equally satisfied that Tafida will remain profoundly neurologically disabled for the rest of her life. I am further satisfied that, if she continues to receive life-sustaining treatment, Tafida will likely live for a further ten to twenty years. I am equally satisfied that it is more likely than not that over the course of this period she will develop a range of consequential conditions that will, in addition to the continuation of a severe movement disorder and immobility comprising combination of spasticity and dystonia and severe cognitive impairment, likely include drug resistant epilepsy, scoliosis with associated cardio-respiratory impairment, which may require surgery, partial or full hip dislocation, pneumonia with worsening respiratory failure, bone disease due to osteopaenia associated with pathological fractures, the development of renal stones, pressure sores, hypertension and malignancy.

164. Finally, the evidence is clear that Tafida is currently medically stable and has some ongoing breathing effort, albeit not sufficient to enable her to breath without the aid of a mechanical ventilator. In this context, I note that whether Tafida is capable of being weaned from that ventilator is a question that the Italian medical team consider requires further and detailed evaluation to definitively answer this question. The Italian medics likewise consider that a better prognostic definition might require serial standardised neurological and neurophysiological evaluations in addition to functional MRI studies.

(b) Best Interests

165. Within the foregoing medical context, it is plain that there are substantial factors in this case that tend to support the case made by the Trust that it is not in Tafida's best interests for life-sustaining treatment to continue. However, in this case, I am also satisfied that there are compelling factors on the opposite side of the balance that argue against the best interests declaration sought by the Trust in respect of Tafida's medical care. On balance, I am satisfied that the latter prevail over the former.

166. Taking as a starting point the assumed view of Tafida, there are obvious difficulties in a judge seeking to place him or herself in the shoes of a four year old child. However, the court must do the best it can on the evidence available. In this case, the parents and the maternal aunt in particular urge upon the court evidence of Tafida's

understanding of the religious tradition in which she was being raised as the basis for establishing Tafida's assumed view on the question of whether or not treatment should continue. Within this context, I accept the submission of Ms Gollop and Mr Gration that caution is needed when seeking to establish an assumed point of view for Tafida as a basis for taking account of her wishes and feelings. In relation to matters of thought, conscience and religion, children will move along a continuum from relying on the direction and guidance provided by their parents to ultimately having their own ideas and making their own choices about matters of religion and conscience. In the formative stages, their understanding will not be sophisticated. On the evidence available to the court, I am satisfied that that is the position in this case. It is plain on that evidence that Tafida had a growing understanding of the practices of Islam, had developed a concept of the importance of life and an accepting and non-judgmental approach to those with disability. However, and as fairly conceded by the mother, given Tafida's age and understanding, I am also satisfied that she would have had in February 2019 no concept or contemplation of her current situation, or of the complex and grave legal, moral and ethical issues it raises.

167. Within this context, in seeking an assumed point of view for Tafida as a starting point, it is important that the subject matter of that assumed view is properly formulated by reference to the issue before the court. In the context of this case, that subject matter is framed by the Trust as a bare situation of continued life likely, but not certainly, pain free but in a situation of minimal or no awareness, with no hope of recovery and the certain prospect of developing further debilitating conditions, which with any improvement in awareness will further burden Tafida. On the evidence, this is an accurate but as I will come to, incomplete formulation. Within this context, a formative appreciation that life is precious, a wish to follow a parent's religious practice and a non-judgmental attitude to disability is very different to the far more complex concept of living a life of minimal awareness with no prospect of substantive recovery. In such circumstances, and notwithstanding her developing conception of the value of life and of the religion in which she was being raised, I accept that it would be unsafe to infer from the available evidence an acceptance by Tafida of, or wish to live such an existence *per se*.

168. However, in this case I am satisfied that the subject matter of Tafida's assumed view must be framed somewhat more widely than the formulation contended for by the Trust having regard to the medical consensus between the doctors in this jurisdiction and in Italy of what can ultimately be achieved for Tafida, namely care by her family at home on ventilation in the same manner as children in a similar position to Tafida elsewhere in this jurisdiction. Further, I must also bear in mind that a person may wish to continue to receive treatment notwithstanding the presence of profound disability and that a child's attitude is often influenced by the views, beliefs and guidance of his or her parents. Within this context, whilst for the reasons I have set out above I am cautious about imputing to Tafida any sophisticated views generally given her age the levels of religious, I am satisfied that if Tafida was asked she would not reject out of hand a situation in which she continued to live, albeit in a moribund and at best minimally conscious state, without pain and in the loving care of her dedicated family, consistent with her formative appreciation that life is precious, a wish to follow a parent's religious practice and a non-judgmental attitude to disability.

169. Turning to the principle of the sanctity of life, the parents have, understandably, placed emphasis on the contents of the *fatwa* secured from the Muslim Council of Europe. Within the context of these proceedings however, the *fatwa* is simply a valuable restatement of the sanctity of life, a sanctity recognised by all the great religions and also by those who view life through a secular or scientific prism. The sanctity of life is a fundamental, indeed sacred, principle from which there flows a strong presumption in favour of a course of action that will prolong life. Within this context, Tafida's life has inherent value. It is also of value to Tafida herself, it is precious to her parents, sibling and family and even now it adds, in whatever small and incomplete way, to the body of collective human experience. Tafida is profoundly disabled but a life of disability is of equal value to all other lives.

170. Within this context, the *key* principle in these proceedings is that the sanctity of Tafida's life is, for the purposes of the law, not absolute but may give way to countervailing factors. At the urging of Ms Gollop, I have paid careful regard to fact that the authorities establish that the sanctity of life *may* be overborne in circumstances where a child feels no pain but where the child has, as Tafida has, minimal or no awareness of her family and social relationships, minimal or no ability to respond to external stimuli so as to take comfort or enjoyment from those who love her or the world around her and engage in the enlargement of knowledge and will derive no benefit from the medical treatment being administered such that she will continue to suffer from profound cognitive impairment that will not change. Within this context, the following extract from the RCPCH Guidelines *Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice* is of particular relevance in this case (emphasis added):

> "In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST *may* not be in their best interests because it cannot provide overall benefit to them."

171. With respect to the question of benefit, I accept that there is some force in the Trust's submission as to the minimal or absent *medical* benefit in continuing to maintain Tafida with life sustaining treatment. Within this context, a further important factor supportive of the Trust's application is that fact that the care proposed by the Gaslini Hospital in Italy is substantially the same as that currently being given to Tafida by the Trust and will not result in any substantial improvement in her condition, albeit that the Gaslini consider (and the clinicians in this jurisdiction agree) that Tafida can achieve a position whereby she is able to go home on ventilation. In these circumstances, I accept that further medical treatment may be considered futile (using that word in its technical sense) in that it will confer minimal neurological or physical restoration.

172. Against this, Tafida is more than simply a patient who is the subject of medical treatment. Within this context, the benefits of life-sustaining treatment may extend

beyond the merely medical. If the argument in *Bland* that Anthony Bland felt no pain or awareness and therefore had no interests which suffered from his being kept alive is demonstrated to be a fallacy because, in the words of Hoffman LJ (as he then was), "it assumes that we have no interests except in those things of which we have conscious experience", then the argument that a child who feels no pain and no or minimal awareness can derive no benefit from being kept alive is similarly fallacious in circumstances where, again to echo the words of Hoffman LJ, the foregoing assumption does not accord with many people's intuitive feelings about their lives, and particularly those people who have a strong religious faith.

173. Within this context, and again having regard to the medical consensus of what can ultimately be achieved for Tafida, namely care by her family at home on ventilation in the same manner as children in a similar position to Tafida elsewhere in this jurisdiction, the benefits for Tafida of continued life sustaining treatment include being at home, being in the care of her loving and dedicated family, and, insofar as she is minimally aware, gaining from such awareness as she has of those matters. Further, I accept the submission that within the religious and cultural tradition in which Tafida was being raised, and whilst not by itself sufficient to justify the continuation of life sustaining treatment on the basis of Art 9 or otherwise, a further benefit of continued life sustaining treatment is that it permits Tafida to remain alive in accordance with the tenets of the religion in which she was being raised and for which she had begun to demonstrate a basic affinity.

174. Finally, and in addition, I have born in mind the evidence from the Italian team that the question of whether Tafida could be weaned off a ventilator following a tracheostomy, and hence could return home without ventilation, requires further, detailed evaluation. I have also borne in mind the evidence of the Italian doctors that the natural history and prognosis of children with prolonged disorders of consciousness is not well-defined, with a greater uncertainty about definitive outcome compared to adults and that better prognostic definition might require serial standardised neurological and neurophysiological evaluations, in addition to MRI functional studies.

175. With respect to the question of burden, the medical consensus in this case is that there is in Tafida an absence of demonstrable pain or suffering. This is not a case where doctors have concluded that the subject child can probably feel pain but are unsure how he or she processes it, nor is it a case where the doctors have concluded that the subject child is suffering pain and suffering it at a significant level. It is not a case, to use the terms of the RCPCH Guidance where "intensive treatment and future life are likely to cause the child substantial pain and distress". I have given careful consideration to the submission of the Trust and the Children's Guardian that the *possibility* that Tafida feels pain cannot be completely excluded and that, accordingly, that Tafida will be increasingly burdened by pain consequent upon the other physical disabilities she will develop in the future, as she would be were she to develop a greater level of awareness, can likewise not be excluded as a possibility. However, some caution must be exercised in respect of this submission. The standard of proof applicable in these proceedings is the balance of probabilities. Whilst it is tempting to say simply that the possibility that Tafida's feels pain cannot be entirely ruled out and therefore the court must proceed on the basis that it is better to err on the side of caution, this does not maintain fidelity to the applicable standard of proof. Such

fidelity is important every case, but all the more so when the outcome being considered is so grave.

176. I have also paid careful regard to the Trust's submission that even if Tafida feels no pain, further invasive treatment over an extended period of time will impose an unacceptable burden on her human dignity, which burden will be increased as she develops further debilitating physical symptoms. Again, I accept that within the context of the frame of reference advanced by the Trust, namely continued invasive medical treatment over many years with little recuperative benefit may, for example in the manner articulated *Bland*, reach the point of indignity for Tafida. The concept of human dignity as an element of the best interests analysis is however, not without difficulty. The term 'human dignity' does not lend itself to precise definition and there is no universal agreement as to its meaning. The concept of human dignity must, accordingly, contain a significant element of subjectivity and thus be influenced by, for example, the religious or cultural context in which the question is being considered. In *M v N* [2015] EWCOP 76 at [72] Hayden J observed that:

> "There is an innate dignity in the life of a human being who is being cared for well, and who is free from pain. There will undoubtedly be people who for religious or cultural reasons or merely because it accords with the behavioural code by which they have lived their life prefer to, or think it morally right to, hold fast to life no matter how poor its quality or vestigial its nature. Their choice must be respected. But choice where rational, informed and un-coerced is the essence of autonomy. It follows that those who would not wish to live in this way must have their views respected too."

177. Within this context, the question of whether continued treatment would burden Tafida with indignity falls to be considered, once again, in the context of the agreed evidence that, ultimately, whilst moribund, with minimal awareness and entirely dependent on the care of others, it will be possible for Tafida to be cared for at home by a loving and dedicated family and consistent with the religious code and community values within which she had been raised. In the context of the concept of human dignity, although difficult to define, I am satisfied that this is a significantly different proposition to, for example, continued care over a period of years confined in a Tier 2 ICU unit.

178. Turning to the views of the doctors in this case, I have given weight to the fact that both the treating doctors from this jurisdiction, and those doctors from this jurisdiction who have provided expert reports in these proceedings are agreed in their view that it is no longer in Tafida's medical best interests to receive life sustaining treatment. Against this, two matters fall for consideration. First, it is clear from the report of Dr Smith that he considered the question of medical best interests to be a complex and finely balanced one in this case to which he had had to give anxious consideration. Second, in this case the court has a contrary view from a centre of paediatric excellence obtained with full co-operation of the applicant Trust rather than, as in some recent and unfortunate examples, the clandestine involvement of inappropriately qualified foreign medical practitioners (see *Kings College Hospital NHS Foundation Trust v Haastrup* [2018] 2 FLR 1028 at [15] and [81] and *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 308 (Fam) at [45], it appearing that those two incidents were in fact part of a single orchestrated effort per

Evans [2018] EWCA Civ 984 at [39] and [40]). Whilst I accept that the opinion of the Italian team that it would be appropriate to maintain Tafida on life-sustaining treatment is a view reached in the context of the particular legal and ethical framework applicable in Italy, this jurisdiction does not hold the monopoly on legal and ethical matters. Further, Italy is a Member State of the EU in which the rights and normative principles enshrined in EU and international law apply. Further, and in any event, in this case there is a compelling evidence that the course of action advocated by the Italian doctors is one that is often adopted in *this* jurisdiction with respect to children in a similar situation to Tafida, Dr Smith, Dr Playfor and Dr D being agreed on this. Within this context, whilst the positive obligation to provide life sustaining treatment under Art 2 does not extend to providing such treatment if that treatment would be futile in nature and where responsible medical opinion is of the view that the treatment would not be in the best interests of the patient concerned, in this case there is a body of responsible medical opinion who takes the contrary view.

179. Turning to the nature of the medical treatment, as I have stated, I have borne in mind the argument of the Trust that the care proposed by the Gaslini Hospital in Italy is substantially the same as that currently being given to Tafida by the Trust. However, as also noted above, that is not the end of the story. The care proposed by the Italian team comprises a detailed, fully thought out and funded care plan that will look to move Tafida to a position where she can, following a tracheostomy and a gastroscopy, be care for by her family at home on a ventilator (although the Italian team intends to further evaluate the potential for weaning Tafida from the ventilator). The Italian team are clear that a tracheostomy could be managed safely at home by well-trained family caregivers. Moreover, this evidence is not disputed by the Trust, Dr D expressing herself to be reasonably confident that, with a care package and training, Tafida will be able to go home. Professor Nobili agreed, as did Dr Playfor and Dr Smith. In the circumstances, this not a case where transport of child remains simply a theoretical option that carries with it the risk of inducing further damage to the brain through seizures, possibly fatal, rendering the whole process of transfer a risk. It is not a case in which what is proposed is transfer for the purposes of untried experimental treatment with no scientific basis for application to the child in question and it is also not a case where the only option for future care is a tier 2 ICU unit in hospital. Further, and once again, the care plan proposed by the Italian team is not only advanced by that competent body of professional opinion but is, on the Trust's own evidence, consistent with the domestic approach in other areas to children in a similar position to that of Tafida. I also bear in mind Tafida's directly effective Art 56 right to receive medical treatment in another EU Member State.

180. The views of Tafida's parents are important and fall to be considered within the foregoing context. The RCPCH Guidance recognises that:

> "Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation"

181. Further, whilst there is no requirement for the court to evaluate the reasonableness of the parents views before it embarks upon deciding what, objectively, is in the child's

best interests, as I have noted in *Re T (A Minor)(Wardship: Medical Treatment)* [1997] 1 All ER 906 at 916 to 917 Waite LJ observed as follows with respect to influence of the principle that, ordinarily, decisions affecting the length and quality of a child's life will be taken for that child by the parents in the exercise of their parental responsibility:

> "There is the scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare, widely accepted by the generality of mankind; and at the other end lie highly problematic cases where there is genuine scope for a difference of view between parent and judge. In both situations, it is the duty of the judge to allow the court's own opinion to prevail in the perceived paramount interests of the child concerned, but in cases of the latter end of the scale, there must be a likelihood (though never, of course, a certainty) that the greater the scope of general debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature."

182. Within the context I have set out above, in circumstances where Tafida is not in pain, where the burden of the treatment is low, where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to her being cared for at home on ventilation by her family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction, where there is a funded care plan to this end, where Tafida can be safely transported to Italy, where the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised and having regard to the sanctity of Tafida's life, this case *does* in my judgment lie towards the end of the scale where the court should give weight to the reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of the child's life will be taken for the child by a parent in the exercise of their parental responsibility. Further, whilst I did not hear detailed submissions on the import of Art 8 of the ECHR in the context of this case, and whilst the Art 8 rights of the parents are subordinate to the best interests of the child where the two conflict, in the circumstances I have just summarised there is in my judgment a cogent argument that the making of orders the effect of which would be to override the choice made by the parents in the exercise of their parental responsibility would not constitute a necessary and proportionate justification for the interference in their Art 8 rights that would thereby occur.

183. In addition to rights under Art 2 and Art 8, the Art 9 rights of the parents and of Tafida are engaged in this case. Within this context, Ms Gollop sought to persuade me to engage in a fine textured analysis of the *fatwa* with a view to establishing that, as a matter of logic, the declarations sought by the Trust would not imperil either the parents' or Tafida's religious beliefs in circumstances where it is the Trust who seek and the court who would endorse the cessation of life sustaining treatment, it is

neither desirable nor necessary for me to do so. As Hoffman LJ (as he then was) observed in *Bland*:

> "Why do we think it would be a tragedy to allow Anthony Bland to die? It could be said that the entire tragedy took place at Hillsborough and that the curtain was brought down when Anthony Bland passed into a persistent vegetative state. Until then, his life was precious to him and his family. But since then, he has had no consciousness of his life and it could be said to be a matter of indifference to him whether he lives or dies. But the fact is that Anthony Bland is still alive. The mere fact that he is still a living organism means that there remains an epilogue of the tragedy which is being played out. This is because we have a strong feeling that there is an intrinsic value in human life, irrespective of whether it is valuable to the person concerned or indeed to anyone else. Those who adhere to religious faiths which believe in the sanctity of all God's creation and in particular that human life was created in the image of God himself will have no difficulty with the concept of the intrinsic value of human life. But even those without any religious belief think in the same way. In a case like this we should not try to analyse the rationality of such feelings. What matters is that, in one form or another, they form part of almost everyone's intuitive values. No law which ignores them can possibly hope to be acceptable."

184. Within this context, whilst not determinative, the Art 9 rights of the parents and of Tafida to freedom of thought, conscience and religion fall for consideration in this case and in my judgment must be accorded weight in the balancing exercise in circumstances where the parents' beliefs, which beliefs would have influenced Tafida, included the belief that to withdraw life sustaining treatment from Tafida would be a sin in circumstances where they believe that where the breath of life subsists so too the soul.

185. Within the foregoing context, I consider this to be a very finely balanced case and one that I have wrestled with in reaching my decision. As Waite LJ made clear in *Re T (a minor)(wardship: medical treatment)* [1997] 1 All ER 906 at 916-917 "The starting point—and the finishing point too—must always be the judge's own independent assessment on the balance of advantage or disadvantage of the particular medical step under consideration". Balancing as I must the welfare factors I have summarised that inform the best interest evaluation, and having regard to Tafida's best interests as my paramount consideration, I am on balance *not* satisfied that I can conclude on the evidence before the court that life sustaining treatment is no longer in Tafida's best interests.

186. The court must face head on the question of whether it can be said that the continuation of life sustaining treatment is in Tafida's best interests. 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. In this context, I do not discount the grave matters prayed in aid by the Trust. However, the law that I must apply is clear and requires that the best interests decision be arrived at by a careful and balanced evaluation of *all* of the factors that I have discussed in the foregoing paragraphs. Having undertaken that balance, in circumstances where, whilst minimally aware, moribund and totally reliant on others, Tafida is not in pain

and medically stable; where the burden of the treatment required to keep her in a minimally conscious state is low; where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to placing her in a position where she can be cared for at home on ventilation by a loving and dedicated family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction; where there is a fully detailed and funded care plan to this end; where Tafida can be safely transported to Italy with little or no impact on her welfare; where in this context the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised; where, in the foregoing context, transfer for treatment to Italy is the choice of her parents in the exercise of their parental responsibility and having regard to the sanctity of Tafida's life being of the highest importance, I am satisfied, on a fine balance, that it is in Tafida's best interests for life sustaining treatment to continue. It follows from this conclusion that I am also satisfied, the court having determined the dispute regarding best interests in favour of the treatment being offered to Tafida in Italy, there can be no justification for further interference in Tafida's EU right to receive services pursuant to Art 56.

CONCLUSIONS

187. In the circumstances, on the evidence before the court and for the reasons set out in this lengthy judgment:

   i) In the proceedings for judicial review, I decline to grant relief to the claimant on her application for judicial review.

   ii) In the proceedings under the Children Act 1989 and the inherent jurisdiction of the High Court I dismiss the application of the applicant NHS Trust for an order under s 8 of the Children Act 1989 and I dismiss the application of the applicant NHS Trust for declarations under the inherent jurisdiction of the High Court.

188. The effect of these decisions is that either the NHS Trust or the Gaslini Hospital in Italy (or another hospital) will have to continue to provide Tafida with life-sustaining treatment (see *Evans* [2018] EWCA Civ 984 at [27]). With respect to treatment by the Gaslini Hospital, as I have noted, it also follows from my decision that there is now no apparent justification for interfering with Tafida's Art 56 right to receive treatment in another EU Member State and it is to be anticipated that this transfer will now take place.

189. During the course of the case, Ms Gollop on behalf of the NHS Trust urged the court to provide further guidance as to the proper course of action in cases where the child's EU rights are engaged. The first point to make is that each case will fall to be decided on its own facts and in such circumstances, detailed guidance is likely to be unhelpful. Second, the detailed position is made clear in the body of this judgment. However, for the avoidance of doubt, it follows from the matters set out above that, as matters currently stand, when faced with a request by parents of an EU citizen child for transfer for medical treatment in another Member State, in deciding whether or not to agree to that course of action an NHS Trust will need to consider the directly effective EU rights of the child. That said, and again for the reasons set out above, where an NHS Trust, having properly considered those directly effective EU rights, considers

that a transfer would not be in the best interests of the child and that an application to the Family Division of the High Court is required to determine the resulting dispute as to the child's best interests, it is highly likely that that decision will constitute a justified derogation from the EU rights engaged on public policy grounds.

190. Finally, as Hoffman LJ (as he then was) noted in *Airedale NHS Trust v Bland* at 825 "Modern medicine therefore faces us with fundamental and painful decisions about life and death which cannot be answered on the basis of normal everyday assumption". As Dr Smith notes in his report, "We have the technology to maintain the lives of children with severe neurodisability, the question for each individual child is whether it is right to make use of it." These difficult issues that arise from question are also now far more likely to require answering in a public rather than a private context. In the decision of the US Supreme Court in *Cruzan v Director, Missouri Department of Health B* (1990) 110 S.Ct. 284 Brennan J observed:

> "Medical advances have altered the physiological conditions of death in ways that may be alarming: highly invasive treatment may perpetuate human existence through a merger of body and machine that some might reasonably regard as an insult to life rather than as its continuation. But those same advances, and the reorganisation of medical care accompanying the new science and technology, have also transformed the political and social conditions of death: people are less likely to die at home, and more likely to die in relatively public places such as hospitals or nursing homes. Ultimate questions that might once have been dealt with in intimacy by a family and its physician have now become the concern of institutions."

191. Within this context, and particularly where a child is not in pain and is not aware of his or her parlous situation, these cases can place the objective best interests test under some stress. Absent the fact of pain or the awareness of suffering, the answer to the objective best interests tests must be looked for in subjective or highly value laden ethical, moral or religious factors extrinsic to the child, such as futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, which factors mean different things to different people in a diverse, multicultural, multifaith society. Nevertheless, the gold standard against which cases of this nature are measured and determined remains that of the child's best interests and as the march of medical innovation continues to bring cases of this nature before the courts the courts will be required to apply this standard to the best of their ability. That is what I have endeavoured to do in this very sad case.

192. That is my judgment.