

Neutral Citation Number: [2015] EWHC 1706 (Admin)

Case No: CO/3077/2014

IN THE HIGH COURT OF JUSTICE QUEEN'S BENCH DIVISION ADMINISTRATIVE COURT

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 15/06/2015

Before :

MR JUSTICE OUSELEY

Between :

THE QUEEN (on the application of IM and MM)Claimants- and --Human Fertilisation and Embryology AuthorityDefendant

Jenni Richards QC (instructed by Natalie Gamble Associates) for the Claimant Catherine Callaghan (instructed by Blake Morgan) for the Defendant

Hearing dates: 8th May 2015

Approved Judgment

MR JUSTICE OUSELEY:

- 1. On 12 June 2011, AM died aged 28 from the bowel cancer with which she had been diagnosed in November 2005. She was the only and much loved child of the Claimants. It is her parents' desire to carry out her deepest wishes, as they believe them to be, which underlies this very sad case.
- 2. AM had wanted to preserve the possibility of having a child, notwithstanding the cancer and its treatment. During a period of remission in 2008, she underwent treatment, at the IVF Centre, Hammersmith, for the removal of her eggs, which were then frozen and stored, unfertilised. She signed a form produced by the Human Fertilisation and Embryology Authority, HFE Authority, which permitted the posthumous storage of those eggs. They are not embryos; they are gametes. She was not married and had no partner during any of this time. The Claimants believed that, before she died, AM expressed the strong wish to her mother, Mrs M, notably in January 2010, that one or more of her eggs, after being fertilised, should be implanted in her mother who would give birth to the baby and, with Mr M, would bring it up.
- 3. The Claimants want Mrs M to be implanted with one or more of the eggs, fertilised by an anonymous sperm donor, yet to be chosen by them. But this is not permissible in the UK under the Human Fertilisation and Embryology Act 1990, the HFE Act, as the necessary written consents were not obtained during AM's lifetime, nor could the eggs be exported for that purpose under General Directions made by the HFE Authority under the HFE Act, since certain requirements could not be met, notably in relation to informed written consent. So the Claimants applied for a Special Direction from the HFE Authority which would permit their export to a treatment centre in New York, for use in the way proposed. The HFEA refused this three times: in November 2013, on reconsideration in March 2014, and on 28 August 2014. The last decision is the one in substance now challenged. The decisions were made by the Authority's Statutory Approvals Committee, the Committee, under its delegated powers.
- 4. The Claimants challenge that decision on the basis first, that the Committee's appraisal of the evidence about the wishes and understanding of AM especially as expressed to her mother was irrational; second, on the basis that the Committee had failed to observe the necessary distinction between General and Special powers of Direction and had decided the case effectively on the basis of the General Directions rather than on the full discretionary powers in relation to Special Directions; and third, that the decision was an interference with the Article 8 ECHR rights of the Claimants and of Mrs M in particular, for which there was no proportionate justification.
- 5. I should also say at the outset what this case is not about. The Defendant did not reach its decision on the basis of any adverse view about the mother carrying her daughter's fertilised egg through pregnancy to birth, nor, save in relation to AM's understanding of the risks to her mother, about the mother's age, now 58. Nor did it reach its decision forming any adverse view about the welfare or upbringing of any future child. Those are issues upon which the Defendant could have decided that a Direction be refused, but it did not do so here. No such issues are before the Court for decision either. I am concerned only with the lawfulness of the decision on the grounds on which it was made: the scope of the discretionary powers, the appraisal of the

evidence about AM's wishes, and the effect on the Article 8 rights, if any, of the Claimants.

The Legal Framework

- 6. The HFE Authority was set up under section 5 HFE Act 1990. Section 4 prohibits the storage or use of any gamete, that is unfertilised egg or live sperm, except in pursuance of a licence. Licences are granted under s11 by the HFE Authority. Section 12(1)(c) makes it a condition of every licence that Schedule 3 to the Act is complied with by the licence holder. Schedule 3 is concerned with consent, which is a very important aspect of the HFE Authority's approach to the regulation of licensed activities under the Act.
- 7. Schedule 3 para 1(1) provides that consent under the schedule "must be signed by the person giving it". "Effective consent" means consent which has not been withdrawn, i.e. written and continuing consent. Para. 2 provides:

"2(1) A consent to the use of any embryo must specify one or more of the following purposes—

(a) use in providing treatment services to the person giving consent, or that person and another specified person together,

(b) use in providing treatment services to persons not including the person giving consent, [...]

(2) A consent to the storage of any gametes, or any embryo or any human admixed embryo must—

a) specify the maximum period of storage (if less than the statutory storage period),

b) except in a case falling within paragraph (c), state what is to be done with the gametes, embryo or human admixed embryo if the person who gave the consent dies or is unable, because the person lacks capacity to do so, to vary the terms of the consent or to withdraw it, ...

and may (in any case) specify conditions subject to which the gametes, embryo or human admixed embryo may remain in storage."

8. Para 3 imposes two separate requirements in relation to effective consent:

"(1) Before a person gives consent under this Schedule—

(a) he must be given a suitable opportunity to receive proper counselling about the implications of taking the proposed steps, and (b) he must be provided with such relevant information as is proper."

Thus effective consent must be fully informed as well.

9. Paras 5 and 6 and 8 apply here and are important:

"5(1) A person's gametes must not be used for the purposes of treatment services or non-medical fertility services unless there is an effective consent by that person to their being so used and they are used in accordance with the terms of the consent.

(2) A person's gametes must not be received for use for those purposes unless there is an effective consent by that person to their being so used.

(3) This paragraph does not apply to the use of a person's gametes for the purpose of that person, or that person and another together, receiving treatment services.

6 (1) A person's gametes or human cells must not be used to bring about the creation of any embryo in vitro unless there is an effective consent by that person to any embryo, the creation of which may be brought about with the use of those gametes or human cells being used for one or more of the purposes mentioned in paragraph 2(1)(a), (b) and (c) above.

8 (1) A person's gametes must not be kept in storage unless there is an effective consent by that person to their storage and they are stored in accordance with the consent."

- 10. I should also refer to the definition of "mother" in s28: "the woman who is carrying or has carried a child as a result of the placing in her of an embryo or of sperm and eggs, and no other woman, is to be treated as the mother of the child". This applies wherever, in the UK or elsewhere, the mother was when the embryos, sperm or eggs were placed in her.
- 11. In the UK, the child at 18 is entitled to know the identity of the sperm donor, and to establish contact; sperm is donated on that basis. I was told by Counsel that, in New York, the sperm donor has the option of deciding whether that should occur.
- 12. As Ms Callaghan for the HFE Authority submitted, the HFE Act prohibits the storage or use of gametes in the UK without effective, fully informed consent. The Act itself permits no exceptions. Posthumous use of gametes requires the effective consent of the gamete provider. The donor's next of kin, here AM's parents, the Claimants, have no right under the Act to decide on the use or disposal of her gametes.

13. The Act does contain some flexibility, however, over the import and export of gametes and embryos. Section 24(4) contains a general power to give directions and in relation to export provides:

"Directions may authorise any person to whom a licence applies to... send gametes... outside the United Kingdom in such circumstances and subject to such conditions as may be specified in the directions, and directions made by virtue of this subsection may provide for sections 12 to 14 to have effect with such modifications as may be specified in the directions."

- 14. The reference to ss12-14 means that schedule 3 conditions can be modified, including effective consent provisions.
- 15. This power has been exercised by way of General Directions 0006 "The import and export of gametes and embryos". Its requirements in schedule 4 include, in paragraph 1(d), that the person who provided the gametes "has...given and not withdrawn consent in writing to the gametes...being exported to the country in which the receiving centre is situated", 1(e) before giving that consent, that the gamete provider "has been given a written notice stating that the law governing the use of gametes...and the parentage of any resulting child may not be the same as in the UK, and they have been given any further information which they may require", and 1(h) that the gametes are not exported "if they could not lawfully be used in licensed treatment services in the United Kingdom in the manner or circumstances in which it is proposed that the gametes... are used by the receivering centre." These were the requirements of the General Directions which the Statutory Approvals Committee accepted, and it is agreed, were not met.
- 16. The s24(4) power can also be exercised to give Special Directions in relation to a case where the General Directions are not satisfied.
- 17. Section 25 requires the Defendant to maintain a code of practice, giving guidance about the "proper conduct of activities carried on in pursuance of a licence under this Act".
- 18. The HFE Authority's Code gives guidance as to the information which is relevant and proper for the purposes of paragraph 3(1) of schedule 3 to the Act. The 7th edition of the Code's guidance, in force in 2008, but the 8th edition is not significantly different, states that information should be given about the possible outcomes and limitations of the treatment, possible side effects and risks, and where a donor is used, relevant information about genetic inheritance, in particular about inheriting physical characteristics from the donor, and about legal parentage.
- 19. It is the Code which explains that where the General Direction requirements are not fulfilled, or cannot be assured, a person can apply for a Special Direction.
- 20. This is the power which the Claimants applied to the Defendant for it to exercise, recognising that the General Directions could not be satisfied by reference to the requirements of paragraphs 1(d), (e) and (h) of Schedule 4 to the General Directions

cited above. The Defendant has delegated power to make a Special Direction permitting the export of gametes to the Committee.

21. I accept what Ms Callaghan submitted, and which was not really at issue between the parties, about the central role which consent and effective or informed consent plays in the Act, in the way in which Parliament has resolved or balanced the various sensitive and complex medical, social, ethical and legal issues arising over the taking, storage and use of gametes and embryos. In *U v Centre for Reproductive Medicine* [2002] EWCA Civ 565, Lady Justice Hale said at [24]:

"The whole scheme of the 1990 Act lays great emphasis upon consent. The new scientific techniques which have developed since the birth of the first IVF baby in 1978 open up the possibility of creating human life in ways and circumstances quite different from anything experienced before then. These possibilities bring with them huge practical and ethical difficulties. These have to be balanced against the strength and depth of the feelings of people who desperately long for the children which only these techniques can give them, as well as the natural desire of clinicians and scientists to use their skills to fulfil those wishes. Parliament has devised a legislative scheme and a statutory authority for regulating assisted reproduction in a way which tries to strike a fair balance between the various interests and concerns. Centres, the HFEA and the courts have to respect that scheme, however great their sympathy for the plight of particular individuals caught up in it."

22. The witness statement of Mr Thompson, Chief Executive of the HFE Authority, sets out the history of the legislation, from the Warnock Report to the Green and White Papers, and, following a review of its operation, the amendments to the HFE Act 1990 made by the 2008 Human Fertilisation and Embryology Act. This evidence supported Ms Callaghan's submission.

The application

- 23. The Claimants applied for a Special Direction to enable 3 eggs, cryopreserved oocytes, to be exported to a treatment centre in New York, for donation to the mother; the treatment centre had agreed to treat the mother by implanting an egg into her, after fertilisation by an anonymous sperm donor. The application confirmed that the receiving or treatment centre was licensed under the laws of New York, and had quality management and traceability systems in place. The form acknowledged that written consent to this export had not been given by AM, the gamete provider, nor had she been given a written notice saying that the law in New York governing the use of gametes, and embryos, and the parentage of any resulting child, may not be the same abroad as in the UK.
- 24. As the form explained, export was necessary "because only an overseas centre has agreed to provide treatment". IVF Hammersmith had refused to treat the mother in the way proposed; the unit felt "that this is beyond what the patient might have consented to and we can not assume that these would have been her specific wishes,

as there is no documented confirmation for them." Before reaching that conclusion, the unit had consulted the Imperial College Ethics Committee which had been unable to reach a consensus or definitive conclusion, which was one of the reasons for that refusal.

The evidence

- The Minutes of the decision noted the forms signed by AM in 2008 when the three 25. eggs were removed from her for storage: one was a treatment consent form devised by IVF Hammersmith, and one was a specific consent to storage form, WS, devised by the Defendant. The first IVF Hammersmith form provided consent to treatment by the retrieval of the eggs, as its title stated. No mixing with sperm was consented to, but that was not then the purpose of the treatment and so did not need to be covered. The signed form for consent to treatment involving egg retrieval included the following provision: "2. We do not consent to the transfer of my eggs or embryos so produced into any female other than the above named unless specific surrogacy or donation consent has been agreed." Clause 5 said that if the eggs were donated, the donor would not be the legal parent of any resulting child. Just below the signature the form said: "I understand that I will become the legal mother of any resulting children." Clearly that form as signed did not contemplate donation of the eggs by AM, as Ms Richards for the Claimants accepted. AM was at this time concerned with being able to preserve eggs which the cancer treatment might harm. There was also an IVF Hammersmith form consenting to oocyte freezing.
- 26. The Claimants put great weight on the Defendant's WS form also signed on 18 February 2008, which was entitled "Consent to the storage of eggs". AM consented to the storage of her eggs for 10 years. There followed a section entitled "Posthumous storage of your eggs". AM was required by law to decide in advance what should happen to the stored eggs if she were to become mentally incapacitated or die. In each event, she refused consent for her eggs to perish and ticked the "Yes" box, giving consent for "my eggs to continue in storage for later use". Immediately below that, and above the signature, was this: "There is a separate form on which you can say how you want your eggs to be used. Your eggs can only be used if you have also completed the storage form." The WD form dealt with donation. As I have said, AM had been single then, and remained so at the time of her death.
- 27. No other form was ever signed; I was told and accept that she was not offered another form, then nor later, nor did she ask for one, though I was told that she was given a copy of the WS form.
- 28. The consultant gynaecologist at IVF Hammersmith provided email statements about what AM had and had not said to him in relation to treatment. This was provided in response to a specific request from the Committee for the purposes of its third decision. The consultant gynaecologist had first seen AM in January 2006 at her request for an initial discussion about embryo freezing with donor sperm as a result of concern that radiotherapy might damage her womb. Collection, freezing of egg and sperm were discussed, along with egg donation. She had two possible surrogates in mind. Eight days later, he had advised her to have counselling with the IVF team, but in a short while, the cancer had spread so that fertility treatment was not proceeded with. There was a conversation about AM's mother carrying a child as surrogate if radiotherapy did damage the womb, but not in the context of her death or egg export.

Surrogacy had been discussed in a "very hypothetical" way, and not in the detailed way normal where it is the advised medical option. He had had no conversations with AM's mother about surrogacy, its implications or risks, nor with AM about the implications for her mother in that role. It was not till 2008 that she returned for egg freezing.

- 29. The evidence in support of the application came from Mrs M's statement. She explained how happy a family they had been, and what a lively and popular girl their daughter had been. AM had always wanted to have a family; this was "incredibly important to her". She had been so concerned that the cancer had attached itself to her womb that if that happened she said "she would not want to be woken up" after surgery. Although the cancer had not affected AM's womb, she feared the chemotherapy might make her infertile. Her mother offered AM her own womb. The IVF consultant refused IVF treatment in January 2006, after which AM wondered about an ovary transplant into her mother, for the purpose of the IVF treatment. This too was thought unwise, but the suggestion that AM could conceive with donated eggs was not a solution to AM: "she wanted her own genes to be carried on".
- 30. When in her second remission in 2008, AM was told that she could now have IVF treatment to remove her eggs, and this would be done at IVF Hammersmith. Mrs M said this:

"12. On the way to the clinic, [AM] and I discussed that I could carry a pregnancy for her if this became necessary. She was concerned that Mr Lavery might not agree to collect her eggs if she was not able to carry a pregnancy due to her stoma bag. I suggested that I could carry a pregnancy for her if necessary and [AM] said "thank you mum." I held her hand and we didn't speak again until we got out of the taxi when I asked her "are you ready for this?" She took a deep breath, closed her eyes and nodded yes. [AM] was very clear that she wanted to make sure that her eggs would be collected for future use, whether or not she was able to carry the pregnancy herself."

31. The consultant was asked whether if AM could not carry the child because of the stoma bag, the mother could carry the pregnancy for her but he told her that was not a very good idea, without explaining why, and this answer distressed AM. AM signed the forms, to which I have referred, without discussion about what she wanted done with the eggs after death, and no additional form was given to her. She did not complete the form she was given about the use of the eggs after her death for research. Mrs M said:

"16. I am absolutely clear that [AM] wished her eggs to be collected, stored and used to conceive a child, and that (although her hope at the time was that she would be able to do this herself) she had also considered what should happen if she were to die, and that she wanted her eggs to be used to conceive a child after her death. On the day she signed the consent forms, we discussed me being the person who would carry a pregnancy for her if she could not do so herself, and I am certain that this was her expectation of how her eggs could be used after her death. I am absolutely clear that [AM] believed she had signed all the necessary forms to authorise this, and that she would be devastated to think that her eggs cannot now be used because of a paperwork issue."

- 32. After the painful IVF treatment, there appears to have been little discussion over what was to happen in the event of her death. In 2009, during the visit to hospital of a pregnant cousin, who feared that this had upset AM, AM had comforted her by saying "I have already got my babies, they are just on ice", looking at her mother for confirmation. The implication was that this confirmed an understanding between the two of them as to what could happen if AM could not herself carry the pregnancy.
- 33. There was a significant change in AM's prospects in January 2010. Further UK surgery had been refused; surgery abroad had been ruled out, and she realised that she would never leave hospital in the UK, and would never be able to carry a child. She told her mother that she wanted her mother to carry "my babies. I didn't go through the IVF to save my eggs for nothing, I want you and dad to bring them up, they will be safe with you. I couldn't have wanted for better parents, I couldn't have done this without you." As these proceedings were underway, a close friend of AM's told Mrs M, confirmed by email, that AM had told her that she wanted Mrs M to be her surrogate, if she could not carry a child. In June 2011, when she was very ill, AM also kept saying that she wanted her babies.
- 34. Mrs M was absolutely certain that to AM, her eggs "held a life force and were living entities in limbo waiting to be born. She was clear that she wanted her genes to be carried forward after her death." Seeing this through would be to honour AM's wishes, and would be the last thing they could do for her.
- 35. The parents were aware of the very small chance that Mrs M would become pregnant and of the many stages at which things could go wrong. They spoke of the family support, and how at the right moment they would tell any child about her and how the child came to be born. Arrangements had been made for other eventualities.

The decision

- 36. The Committee consisted of three lay members, and one professional; it had an external legal adviser. The decision of 28 August 2014 is the only decision to which effective challenge is pursued, though one failing in the second decision was said to have continued, implicitly, into the third.
- 37. The Committee noted the purpose of the application, being the export of the gametes as AM's parents wished to use AM's eggs for the creation of one or more embryos using donor sperm for Mrs M to carry, medically, that is in Mrs M's own treatment. In paragraph [5] it said: "Although it is stated that the chances of IM becoming pregnant are "very small" and that "any complications could be life threatening", [the parents] say that they are determined to "honour [AM's] wishes". This reference to complications was based on the advice of a consultant obstetrician who examined Mrs M: "the risks are greater than normal; it was likely that she would give birth safely

albeit with a significant risk of complications...she would appreciate that pregnancy related complication can be life threatening on occasion".

- 38. The parents had details of two sperm banks in the USA with donor profiles from which "they would select a donor who is as close to A's origins as possible".
- The reasons why a Special Direction was required were set out: the requirements of 39. schedule 4 paragraphs 1(d), (e) and (h) of the General Directions were not satisfied. The advice of the Legal Adviser was recorded. This identified the great emphasis placed by the Act on consent, in writing and informed. Effective and fully informed consent was said to be missing by the Authority's Executive in its submissions in respect of the export of the eggs, their mixing with donor sperm, surrogacy and the use of gametes in the treatment of another. The Legal Adviser noted the parents' contention that the evidence established plainly that AM did consent to the use of her eggs posthumously in the way now sought. She pointed out that the absence of effective, ie written informed, consent was not decisive, since were it decisive there would be no role for a Special Direction, which permits modifications of the relevant statutory requirements. But the power to modify those statutory requirements should only be pursued in ways "that serve and promote the objects of the HFEA's legislation which clearly attaches great importance to consent, the quality of it and the certainty of it. "Sufficient" evidence of AM's wishes was required. The Committee in its second decision had erred here, overstating the evidential requirement as "ample, overwhelming or substantial". Article 8 ECHR was discussed on the basis that it was unclear whose rights, the parents' or the deceased's, were said to be at issue.
- 40. The next section is headed "Discussion". The two main issues were: whether the evidence pointed cumulatively to the posthumous use of A's eggs in the way sought being exactly what she wished for; and Article 8. On the first, the Committee said at [30]:

"30. ... It noted that the strongest and only statement of A's wishes apparently applying to the posthumous use now being sought, was her statement to her mother about her mother carrying her babies and her parents bringing them up, in the context of her not expecting to leave hospital alive. Details of this conversation with IM were set out in IM's witness statement."

- 41. This conversation took place in January 2010. Ms Richards accepted that up till then, the conversations between AM and her mother had been in the context of how AM and then the eggs should be treated so that, whether carrying them herself or not, AM, if she lived, could have a child to bring up as its mother.
- 42. The Decision section reads:

"33. As previously the Committee was clear that its consideration of this case did not require it to have regard to the mother's age or family connection with the prospective child.

34. The Committee considered all the evidence before them and in particular the forms that were completed (and the consent to research form which was not completed) at the time of the egg collection and storage, and all the reported discussions and conversations with IA, a friend and cousin. The Committee concluded that it did not have evidence to support the view that:

- A had tried to seek out more information about this treatment for herself before her death;
- A had explicitly expressed a wish for her mother to carry her child as a surrogate in the event of her death, with the possible exception of the comments made in about January 2010;
- A had or would have consented to the use of an anonymous sperm donor;
- A consented to the use of her eggs after her death.

35. In relation to the comments made in January 2010 (set out at paragraph 22 of IA's statement) the Committee was of the view that this expression of wishes was made without sufficient information for A to fully understand the implications of such a statement and the issues involved, particularly the risks for IA in relation to surrogacy and the legal implications of such arrangements. [IA is also referred to as IM, the mother.]

36. The Committee noted that the suggested "cumulative evidence" referred to in this case, emerged over a number of years and the Committee was concerned that A had had ample time, for example between the conversation in about January 2010 and June 2011 to put in place clearer instructions, or discuss with others, any wishes for her mother to carry her embryos (fertilised by donor sperm). None of the conversations contemplated or considered the use of donor sperm outside the UK and the particular implications of such arrangements.

37. The Committee noted that these steps could have included:

- Signing the necessary consent forms;
- Undergoing counselling in relation to any of these treatments;
- Seeking more information from others about what might be involved in such arrangements;
- Speaking to others about her wishes and intentions

- Having others witness her wishes and intentions
- Leaving something as a token to the anticipated "baby"
- A having formal discussions with the doctors involved in her treatment;
- A requesting information about what might be involved in donor insemination, surrogacy, the implications for parental status;
- A formally noting her wishes.

38. The Committee concluded that, contrary to the submissions, it did not accept the proposed posthumous use of her eggs, was exactly what A had wished for. It considered that a number of the statements contemplated IA potentially acting as a surrogate in the event A was unable to carry a child, but that the context was whilst A was still alive. In the Committee's assessment nearly all of the evidence supported an understanding of A's wishes during her life but it did not make clear her intentions in the event of her death.

41. The Committee was extremely sympathetic to the views of A's parents and understood that in seeking this export the parents believed that they were trying to fulfil the wishes of A, but in the light of everything considered the Committee still did not find they had evidence to support the issuing of the Special Direction for the export of gametes in this case. The Committee was not satisfied that there were exceptional circumstances that could justify the issue of Special Directions in this case and refused the application."

43. It did not consider that the Article 8 rights of either AM or her parents were engaged or if so that any refusal to allow the gametes to be exported would be a disproportionate interference with those rights.

Ground 1: was the decision based on a rational and lawful appraisal of the evidence?

44. Ms Richards submitted that it was not a rational and lawful appraisal: the evidence unequivocally established that AM had explicitly expressed the wish for her mother to carry her child as a surrogate in the event of her death, and did consent to that use of her eggs after her death. She pointed to the language of the WS form, which gave consent for the storage of her eggs in the event of her death "for later use", and refused consent for them to be allowed to perish, which would be the inevitable consequence of the Committee's decision. The only ways those eggs could be used was either for research, which no one suggested was ever in her mind, or for use by fertilisation to create embryos. That inevitably meant that someone other than AM would have to carry any babies; she had only ever wanted her mother as surrogate,

and her parents to bring them up. It also inevitably meant that someone would have to donate sperm. She had no partner, and so she must have known that, if not of her choosing, the donor would be someone her parents would choose. It was irrational for the Committee not to reach the contrary conclusion to the one it did reach.

- 45. It had also ignored the fact or failed to appreciate the significance of the fact that AM and Mrs M did not know that there was another form which had to be signed for effective consent to what A was proposing. This would have had to happen when AM was trying to stay alive, but battling cancer. Ms Richards contended that AM believed that everything was in place. She trusted her mother, and had no reason to seek out any further form or information about the implications of her mother being her surrogate. So the absence of a further signed form should not have led to any adverse inference, or been given weight in reaching the decision. AM's clear wishes should not fail for want of paperwork. There was no requirement either for counselling. Ms Richards contended, but it was not in evidence before the Committee, that AM had developed a distrust of counselling, not on this aspect however, over her years in hospital. The Committee should not have taken account of the fact that AM left no mementoes for any child, since she would obviously have known that her parents would keep whatever she had to pass on, for any babies.
- 46. I cannot accept these submissions, although there is an undoubted logical force to her reasoning by inference from the conversation in January 2010. I accept largely the submissions of Ms Callaghan. The Committee, as I read the decision, concluded that, although AM had wanted her mother to be her surrogate in her lifetime, there was no sufficiently clear evidence that she had intended her mother to be her surrogate after her death in the particular circumstances which the application entailed. This is closely allied to and largely overlaps with its conclusion that AM's wishes were not a sufficiently clear and informed expression of her wishes about what was proposed to happen. Those were conclusions which it was entitled to reach. The Committee did not reject the factual evidence which Mrs M gave, although the implications of it and the conclusions which she drew from it were clearly not accepted.
- 47. The conversations AM had had up to January 2010 all contemplated that the mother would be the surrogate for AM while AM was alive but unable to bear a child herself. That was not in issue before me. The Committee was entitled to conclude, as it did in the first and third bullet points to paragraph 34, that there was no evidence that AM herself had tried to find out more about the treatment before her death, or that she had or would have consented to the use of an anonymous sperm donor. While I accept that AM, if explicitly asked, would not have imagined that her eggs would become babies without fertilisation with sperm, the reality is that there is no evidence that she ever addressed the practical issues involved with a sperm donor or an anonymous one: she never said anything about this other person who would be equally involved in the genetic make-up and creation of "her babies", his preferred characteristics physical or otherwise, how he should be chosen, whether before or after death, and whether or not this child should know who her father was and be able to contact him, and never said therefore whether or not the donor should be from the UK.
- 48. I do not think that the conclusion in the second bullet point is entirely correct, if the mother's factual evidence was accepted, as in the absence of any specific rejection of it, it must have been. To describe the conversation with the mother in about January 2010 as a "possible exception" to the absence of an explicitly expressed wish that

AM's mother carry her child as a surrogate after death, is too narrow an appraisal of the evidence. On the face of the evidence that is exactly what it was. (It may also be the case that what AM told her close friend, who reported this to Mrs M during the proceedings, but it was before the Committee, related to the period about January 2010). However, and this illustrates the close relationship between consent and informed consent in the Committee's appraisal of the evidence, paragraph 35 of the decision points to the absence of informed consent, or informed expression of wishes, in those conversations. The Committee was clearly concluding that the expression of wishes in January 2010 was not an informed expression of wishes.

- 49. The fourth bullet point seems to me also to require qualification, but that is what followed in paragraph 38: the proposed posthumous use of her eggs was not shown to be "exactly what A had wished for". There was a general expression of wishes to her mother, and to a friend about what should happen after her death, but between the wishes and their fulfilment lay many unconsidered and unresolved practical and legal issues of importance. Again, this illustrates the Committee's concern that the general expression of wishes in January 2010, 18 months before death was not sufficient. It was not, as the Committee said in paragraph 38, a clear statement of her intentions in the event of her death. I read that paragraph as being concerned with the clarity of intentions in the circumstances which actually had to be faced.
- 50. As I have said, the issue of the expression of her wishes was closely allied to, and very largely overlapping, with the issue of their informed expression or the clarity with which the expression of wishes resolved the relevant issues. The Committee's conclusions in paragraphs 35-38 are entirely supported by the evidence. I accept that the Committee was entitled to look for evidence of consent which went beyond some general consent in the abstract for posthumous use, to a consent which went more clearly to the reality of the particular use proposed. A close and loving relationship with her parents did not mean that AM had consented to them making all those decisions.
- 51. There was no evidence that AM had ever contemplated or consented to the export of her eggs, or to a sperm donor or overseas sperm donor or one selected by her parents, or had thought through and consented to the implications of foreign law governing the ability of the child to establish the identity of the father and to make contact. There was no evidence that AM had ever discussed the question of donor sperm with anyone. There was no evidence that she understood the implications for her mother's health or the legal implications of her mother acting as surrogate, namely that her mother would be the legal mother of her daughter's child.
- 52. AM had time after January 2010 but before her death in June 2011 to discuss these issues with her mother at least. She had had sufficient time to obtain further information, to give clearer instructions and to have had detailed conversations about the process with her mother. Instead, between the treatment and death, AM in January 2010 had only the one conversation with her mother about all the aspects of her mother being her surrogate after her death. Posthumous use of the eggs had not been the context of the other conversations of which her mother had given evidence, and even in January 2010, the conversation had been emotionally fraught, general, and AM's tone reflected her severe disappointment at the treatment of her cancer. It could not amount to a settled intention. The discussion with her friend did not, or at least not explicitly, relate to surrogacy after death.

- 53. Ms Callaghan accepted that it was neither the fault of AM nor of her parents that further forms were not given to AM, but I accept her submission that nobody knew if AM would have consented to this particular use of her eggs if she had known of the steps which her parents would have to take to fulfil her wishes. Moreover, the WS form which she did sign, and which she kept, made it clear that there was another form to sign for the use she is said to have intended. She never appears to have checked, nor did her mother, that there was nothing more which was required over any part of the period of 18 months she was alive after January 2010. The IVF Hammersmith form, signed at the same time as the WS form, clearly conveys no consent to the creation of embryos.
- 54. Of course, she was battling cancer, but the Committee was entitled to find, indeed it is hard to see that it could reach any other conclusion, that her wishes lacked a definitive and settled expression, she had not focussed on the practical and legal issues, and that she had had time to discuss them with her mother and doctors but did not do so.
- 55. It is this which causes the logic of the Claimants' argument to fail. Inference is not enough. The Committee was entitled to conclude that what Ms Richards submitted should have been inferred from AM's single conversation with her mother, as to which I accept there is some logic, could have been made explicit over the 18 months after January 2010, orally or in writing. Those aspects, however, had not been discussed with her mother or anyone else, and the effect of express consideration of those aspects on how AM would view them was not known with the necessary clarity.
- 56. I cannot accept Ms Richards' contention, expressing the mother's perception, that the Committee was simply allowing a want of paperwork to stand in the way of AM's clear wishes. The completion of the forms would have resolved the issues, but their absence was not fatal at all to a positive decision. It was instead the fact that so many issues of importance were never discussed, and resolved, when there had been time for them all to be discussed with the mother and others, and resolved. The Committee was entitled to conclude that AM's expression of her wishes was not clear at all in many respects where it needed to be clear. The Committee instanced in paragraph 37 many ways in which the expression of wishes could have been made clearer and more settled, and in which issues could have been resolved. It is clear that this was not simply or solely a matter of paperwork, or even a matter of paperwork at all.
- 57. The absence of a memento was not a crucial ingredient in the decision; it was merely one ingredient in a variety of ways in which AM's informed and settled intention could have been evidenced. Some of the Committee's individual suggestions would obviously be rather more powerful than others.
- 58. The Committee did not decide either that absence of counselling meant that the application had to be refused. The purpose of the reference to the absence of counselling in paragraph 37 was not to say that it had been required but to point out that it would have been one of the ways in which evidence supporting the existence of a settled and fully considered consent to the crucial elements of what was now proposed could have been provided.
- 59. Ground 1 must fail.

Ground 2: was the decision based on an unlawful approach to the scope of the powers to issue a Special Direction?

- 60. Ms Richards' main submission was that the Committee, in each decision, had failed to appreciate that the reason for the Special Direction procedure was to deal with situations in which the General Directions were not satisfied. To refuse a Special Direction because of the absence of proven informed consent equivalent to a signed consent form was unlawfully to deny s24 its full scope. A full oral equivalent to statutory effective consent was not required. It was not necessary either for AM to have gone through all the various issues which a counsellor would have taken her through, in order for a Special Direction to be granted; that would be to impose too high a test. She also submitted that the Committee had refused the Special Direction because there was no written consent. The Committee's unlawful rigidity was illustrated by its insistence that there was no consent to the export of the gametes, when the only issue to which that could give rise was the position of the sperm donor.
- 61. Ms Callaghan submitted, as the Legal Adviser had advised the Committee, that the s24 powers to make a Special Direction had to be exercised so as to serve and promote the objects of the HFE Act, and not to make a Special Direction inconsistent with the statutory objectives or purposes of the Act, albeit that the General Direction procedures can be disapplied. Therefore, it was quite right for the Committee to refuse a Special Direction where there was no oral consent equivalent to effective consent, i.e. informed written consent or where there was significant non-compliance with the requirements for informed consent, or a significant gap between what was sought in the Special Direction and what had been consented to in writing. Section 24 did not give the Committee a free hand.
- 62. I accept Ms Callaghan's submissions. The starting point, as she submitted, is that effective, written and informed, consent is at the heart of the way in which the HFE Act resolves and balances the many and complex issues of storage and use of gametes. As the Executive said in its summary to the Committee, the Act is concerned not just with the fact of consent but with clear written evidence of it, coupled with a mechanism for ensuring that, before giving consent, the person has the opportunity for counselling and receives relevant information, so that the consent is fully informed. In R v HFEA ex p Blood [1999] Fam 151, which also concerned a Special Direction since the General Directions could not be complied with, Lord Woolf MR, said, p185B, "In giving a particular direction, the authority is using delegated powers, which should be used to serve and promote the objects of the legislation, which clearly attach great importance to consent, the quality of that consent, and the certainty of it." (That is a judicial comment and not the HFE Authority's).
- 63. It cannot be disputed but that the Committee had to exercise its powers to advance the purposes of the Act and not to undermine them. The discretion could not be exercised to dispense with crucial policies underlying the Act. Treating the question of the nature and quality of the consent as a whole as crucial was in line with the policy of the Act, and indeed the only way it could lawfully approach its task. The Special Direction is not a means to reach a different approach. The Committee's approach was clearly lawful in focussing on that issue. The Committee's findings, that the evidence showed that many aspects of informed consent were missing and that there was no adequate evidence of a settled intention that what was proposed in the

application should happen, were rational. It was entitled to treat that whole as decisive in this case. That involved no failure to realise or consider the full extent of its discretionary powers.

64. In *Blood*, above, Lord Woolf held that the reasons why the 1990 Act had not been complied with was "a permissible and proper starting point" for the Committee in considering how to exercise its undoubted discretion to permit export. Lord Woolf continued, p185D:

"(3) The third reason given by the authority, is based on the desirability of the consent being in clear and formal terms. This is unexceptional. However it does not acknowledge that the evidence that Mrs. Blood puts forward that her husband would have given his consent in writing if he had had the opportunity to do so is compelling. (4) The fourth reason given by the authority that Mr. Blood had not considered or given his consent to the export of his sperm is a consideration to which the authority was entitled to have regard."

- 65. The question of why the General Directions cannot avail, and why a Special Direction is sought, is therefore obviously relevant to the issues which the Committee must consider. It cannot be ignored that the issue of what was consented to and on what information only arises because written consent could have been but was not given. The absence of written consent, when forms exist, and the issue of what AM wished to happen to her eggs after death had been known to AM and her parents over a number of years, but with especial force since about January 2010, is an important factor.
- 66. When deciding whether to make a Special Direction, the Defendant was entitled, even obliged, to consider whether the oral consent or expression of wishes was clear, covered the same issues as would have been covered by written consent, and was as informed as it would have been had the written consent procedure been gone through, at least on the issues which mattered in this particular case. The Committee concluded, as it was entitled, and probably bound to conclude, that such oral consent as there was did not cover the many aspects which the written consent form would have covered, and which mattered.
- 67. The WD form was not given to AM, or her parents, but it is not, as Ms Richards suggested, a question of the Committee drawing an adverse inference from the absence of a signed form. The fact that no such form was offered is only part of the picture, since the form which she did sign and keep a copy of, makes its limitations clear, and refers expressly to the further, relevant form. It simply cannot be ignored that no such form was signed; that would have made consent clear. But it is plain that the Committee did not decide the application against the Claimants on the basis that there was simply no written consent. Its focus was on the nature and quality of AM's oral expression of her wishes in relation to what was actually proposed.
- 68. I see no error of approach in the third decision. The Committee obviously did not decide that the Special Direction had to be refused for want of written consent. Nor did it decide that there was a requirement for oral consent to be the precise equivalent of effective, written and informed, consent. It concluded, as it was entitled to, that the

expression of wishes was not settled and did not cover a variety of matters which were involved in the application, and it was entitled to regard the missing requirements of effective informed consent as a whole, as decisive. It did not decide that the absence of any one particular aspect, which the oral expression of wishes did not cover but which written consent would have done, necessarily required of itself the refusal of the Special Direction. That might have been an indication that an over rigid approach had been adopted, if there had been no assessment of the weight to be given to that factor. It did not decide the application adversely to Mrs M on the basis of what to it was some unimportant aspect of consent which was not covered by the oral expression of wishes. The Committee reached its decision on the combination of deficiencies in the expression of AM's wishes as settled and informed consent. It did not adopt an unlawfully limited approach to the exercise of its discretionary powers.

- 69. Although I am by no means sure that the few passages in the second decision which deal with the significance of the absence of written consent betray any failure to understand the scope of s24 in relation to Special Directions, I am satisfied that the question of whether too narrow an approach in law has been adopted can only be measured in relation to the words of the third decision. They are different. As I have said the Committee was advised to approach the decision afresh, and that is how the decision reads on this aspect. Some of the evidential references are bound to be repetitious.
- 70. Ms Richards also submitted that the third decision actually made, suffered from the same admitted vice as the second decision, namely that the Committee had required that the evidence of AM's wishes be "ample, overwhelming or substantial".
- 71. I cannot accept that reading of the third decision. I accept that the second decision applied a probably inconsistent, and certainly unsatisfactory and confusing melange of adjectives to the standard of proof required. But the Committee was specifically advised to approach the third decision as a fresh decision, that the previous adjectives had suggested too high a bar, and that "sufficient" should be given its ordinary meaning of "adequate" or "enough". There is no basis for supposing that the advice was not accepted; certainly the third decision carries no trace of the earlier erroneous thinking.
- 72. This second ground must also fail.

Ground 3: breach of Article 8 ECHR

73. Ms Richards made it clear that the claim only concerned the Article 8 rights of the Claimants and not those of the daughter. She contended that their rights were engaged, in view of the broad concept of private life underlying Article 8. The right interfered with was the Claimants' right, and the mother's in particular, to become the parents of their daughter's child; informed consent was not the issue. The refusal of the Special Direction, which would lead to the destruction of the eggs and the frustration of the Claimants' wish to have a child using the eggs and donor sperm, honouring their dead daughter's dying wishes, interfered with their private and family life. It did so without pursuing a legitimate aim and was a disproportionate interference, not justified by reliance on the HFE Act, since that contemplated that a Special Direction could be granted where the effective consent provisions were not met.

- 74. Ms Richards referred to a number of authorities. Some dealt with very broad propositions about the right to family and private life, which set the scene for but did not go to the heart of the issues here; Pretty v UK (2002) 35 EHRR 1 was an example. Others closer to the issue here but not at its heart included Evans v United Kingdom (2008) 43 EHRR 21 at [71], a case concerning embryos where the male partner withdrew his consent to them being implanted in the female partner, after their partnership had ended, and also ending, because of her cancer, her chance to have a child to whom she would be genetically related. It was not at issue but that her Article 8 right to respect for her private life applied. But it was not breached. The HFE Act struck a legitimate balance within the margin of appreciation afforded to Parliament. Another was Dickson v United Kingdom (2008) 46 EHRR 14, in which a convicted murderer serving his sentence was refused facilities to inseminate the second applicant artificially. Article 8 was applicable: the refusal of such facilities concerned their private and family lives, which incorporated the right to respect for their decision to become genetic parents. Article 8 was breached by the refusal because the "exceptional circumstances" test applied in deciding whether or not to grant permission did not permit the required individual assessment of the proportionality of the interference. A third was SH v Austria (2011) 52 EHRR 6 in which a couple who could only conceive by *in vitro* fertilisation using donor sperm, but were unable to do so because it was forbidden by domestic law, were held to have had their Article 8 rights breached; at [60] the ECtHR said that the right of a couple to conceive a child, and to make use of medically-assisted procreation for that end, came within the ambit of Article 8; such a choice was clearly an expression of private and family life.
- 75. However, none of these cases grapple with the issue here of donor consent. This case is not equivalent to the position in *Evans*, where the would-be mother was seeking to use an embryo: her egg fertilised with the sperm of her partner who subsequently withdrew his former consent to its being implanted in her. Article 8 rights were engaged in that case. Ms Richards, although relying on *Evans*, did not assert that Article 8 encompassed the right to use the gamete of someone who had not consented to its use. She was right not to do so.
- 76. Her case was that AM had indeed consented to its use, for fertilisation by an unknown sperm donor and to its implantation in her mother for the purposes of her having and bringing up the daughter's genetically related child. Even if the HFE Authority were right that she had not given the full oral equivalent of the informed effective consent, she had given sufficient consent for the purposes of Article 8. It was on that basis that the refusal of the Special Direction was an interference with Article 8 rights, not justified and was disproportionate.
- 77. Ms Callaghan submitted that Article 8 conferred no right to use the gamete of another person who had not consented to that use, and that a refusal to allow a person's gamete to be used by another could not interfere with any Article 8 right of that other person. The lawfulness of the HFE Act had not been challenged, and its careful balance should not be undermined by the use of Article 8 in cases where there was no informed consent. The Act provided a strong justification for the Committee's decision, which was proportionate and in accordance with the law, even were its decision to engage or interfere with any Article 8 rights of the Claimants.

- 78. Both counsel cited *R*(*Lord Carlile*) *v SSHD* [2015] UKSC 60; [2014] 3 WLR 1401, Lord Sumption, at [29-32] and Lord Neuberger [57, 67-68]. The standard of review of proportionality is not only formal and procedural but to some extent substantive. But, however intensive the standard of judicial review in human rights case, it stopped short of transferring the decision-making power to the courts. Even where the only issue is one of proportionality, and the decision is rational and without errors of primary fact or principle, the decision cannot simply be "franked" by the court; but the decision must nonetheless be given appropriate weight by the court, which weight may be decisive, depending on the nature of the decision and the reasons for it.
- 79. I take first the position on the evidence before the Committee, before turning to the new evidence. I do not accept that the Claimants have any Article 8 right to use the gametes. It was not suggested that this Court should make primary findings of fact. The evidence and findings by the HFE Authority show that there was no settled consent, informed about the particular circumstances, or their implications, in which the Claimants propose to use them. I do not think that the required consent can be other than a sufficiently informed consent. That is simply not present on the HFE Authority's findings. It might be, I express no view, that such consent by the gametes donor to their use by another, as is required to show that the refusal of permission by the HFE Authority for that use engaged that other person's Article 8 rights, does not need precisely to match all its requirements for effective consent. But here the deficiencies in the consent mean that it does not amount to a sufficiently informed consent for the HFE Authority's refusal of the Special Direction to engage the Claimants' Article 8 rights.
- 80. Even were that the wrong analysis, it is clear that the refusal does not breach their Article 8 rights, since it is in accordance with law, and if an interference, it is one which is justified by the public interests underlying the structure and procedures in the Act. There is no challenge to the lawfulness of the Act. Effective consent is required. That is missing. The Act envisages that gametes can nonetheless be exported, as a result of an individual decision. The HFE Authority is an expert and experienced body, to which Parliament has given the task of reaching an individual decision. It has done so on the basis of its reasoned consideration of the individual circumstances. Its approach was in line with that of IVF Hammersmith as well. There was no breach of Article 8.
- 81. There was further evidence after the decision which Ms Richards sought to rely on, as relevant to the Article 8 issues of whether there had been an interference with the Claimants' rights, and whether such interference had been proportionate.
- 82. This further evidence was a witness statement from AM's aunt. She said that she had often visited AM in hospital, spending time with her alone. When they were alone, AM had often confided to her aunt that she wanted to have children. She wanted her mother involved in the upbringing of her children, and any partner of hers would have to accept that or go. After AM had realised that she could never be pregnant, she had told her aunt, when they were alone on one occasion, that she had asked her mother if she would be her surrogate, to which her mother had agreed; AM had added that she did not want anyone else as surrogate. AM asserted her indifference to what people might think about her mother "bearing" her children, whether she were alive or dead. She told her aunt that she had rejected the counselling offered by the hospital as she had lost trust in the hospital and its staff. AM saw this as a way to thank her mother

for her support and devotion. After AM realised that she was going to die, she had spoken to her aunt on the telephone, and was quite adamant that she wanted her mother to carry her babies after her death, and asked her aunt to build a bond with the children, and to look after her parents. She asked her aunt not to mention this conversation to her mother as it would upset her mother. The aunt had therefore not done so. Indeed she had had no idea that this could be relevant to the case, until at some point the two sisters were talking about it.

- 83. Ms Callaghan submitted that it was not admissible, as it had not been before the Committee whose decision were being challenged. She also submitted that the explanation for the aunt not telling the mother was difficult to understand, since a discussion between AM and her mother was inevitable if her mother was to act as a surrogate to fulfil her wishes. Even if admitted and taken at face value, it did not deal with any of the issues of informed consent with which the Committee had rightly been concerned. It could, on that basis, make no difference to the Article 8 decision.
- 84. I do not think that this case requires an examination of the circumstances in which on a human rights claim, the Court should receive the further information to decide the issue itself or remit the issue for a further decision by the public body. But it illustrates the problem since the evidence goes to the nature and quality of the consent, about which the Committee made findings, and that is the issue which lies at the heart of the Article 8 issue. It is difficult to draw a line between its admissibility for the Article 8 claim and its inadmissibility for the first and possibly second grounds of challenge, because it was not before the Committee. Indeed, it would be quite difficult to maintain that distinction in any coherent way were the evidence to have real potential to make a difference to the Article 8 case, given the importance to the claim of the Committee's decision. That might mean that the Article 8 issue had to be remitted, and that would have the unintended effect of re-opening the first or second issues.
- 85. However, I have come to the conclusion that in neither respect does it advance the Claimants' case to any significant degree. The conversation with the aunt does advance the issue of AM's intentions to the limited extent that she had a conversation with someone other than her mother after the January 2010 discussion with her mother, the precise date of which is not known. But it also confirms that she had not given any further thought to any of the circumstances to which the application for the Special Direction gave rise, and which were of greatest concern to the HFE Authority. That means that its decision would have remained the same and with no change in the reasons, but with a small change to the history of AM's expression of her wishes.
- 86. As Ms Callaghan said, the reason given by AM for asking her aunt not to discuss the conversation with her mother, since it might upset her, is strange in view of what were said to be AM's wishes about her mother's role as surrogate after AM's death. I cannot help but feel that this evidence would be seen as supporting the Committee's view that AM had not given informed consent to the particular process covered by the application. There were important issues which she simply did not want to address as she thought that it would upset her mother, despite the settled intention attributed to her.

Conclusion

87. I must dismiss this claim, though I do so conscious of the additional distress which this will bring to the Claimants, whose aim has been to honour their dying daughter's wish for something of her to live on after her untimely death.