

EUROPEAN COURT OF HUMAN RIGHTS
COUR EUROPÉENNE DES DROITS DE L'HOMME

FIRST SECTION

DECISION

Application no. 39793/17
Charles GARD and Others
against the United Kingdom

The European Court of Human Rights (First Section), sitting on 27 June 2017 as a Chamber composed of:

Linos-Alexandre Sicilianos, *President*,

Kristina Pardalos,

Aleš Pejchal,

Krzysztof Wojtyczek,

Armen Harutyunyan,

Tim Eicke,

Jovan Ilievski, *judges*,

and Abel Campos, *Section Registrar*.

Having regard to the above application lodged on 6 June 2017,

Having regard to the interim measure indicated to the respondent Government under Rule 39 of the Rules of Court of 9 and 13 June 2017,

Having regard to the decision to grant priority to the above application under Rule 41 of the Rules of Court.

Having deliberated, decides as follows:

THE FACTS

1. A list of the applicants is set out in the Appendix.

A. The circumstances of the case

1. *The background facts*
2. The facts of the case may be summarised as follows.

3. The first applicant ("CG") was born on 4 August 2016. His parents are the second and third applicants. CG initially appeared to have been born healthy. Medical professionals subsequently observed that CG was failing to gain weight, and his breathing was becoming increasingly lethargic and shallow. He was admitted to Great Ormond Street Hospital ("GOSH") on 11 October 2016, where he has remained since.

4. There is no dispute that CG is suffering from a very rare and severe mitochondrial disease called infantile onset encephalomyopathic mitochondrial DNA depletion syndrome ("MDDS"). The disease is caused by mutations in a gene called RRM2B. The mutations cause the deterioration and death of fuel-giving mitochondrial cells in every part of the patient's body, depriving him of the essential energy for living. In CG's case, his brain, muscles and ability to breathe are all seriously affected. He has progressive respiratory failure and is dependent on a ventilator. He can no longer move his arms or legs and is not consistently able to open his eyes. He is persistently encephalopathic, meaning that there are no usual signs of normal brain activities such as responsiveness, interaction or crying. In addition he has congenital deafness and a severe epilepsy disorder. His heart, liver and kidneys are also affected but not severely.

5. The parents became aware of a form of therapy ("nucleoside treatment") which has been used on patients with a less severe mitochondrial condition known as TK2 mutation. This type of mutation primarily causes myopathy (muscle weakness) but does not affect the brain in the majority of cases. There is some evidence that patients with TK2 mutation have benefited from nucleoside treatment. The parents contacted Dr I, Professor of Neurology at a medical centre in America. Dr I confirmed that nucleoside treatment had not been used on either mice or humans with RRM2B mutation, but that there was a "theoretical possibility" that the treatment might be of benefit to CG.

6. At the start of January 2017, a plan was devised by CG's treating clinicians in the United Kingdom for nucleoside treatment to be administered in the United Kingdom. As the treatment is experimental, an application to the Ethics Committee was prepared to authorise its use and a meeting planned for 13 January. However before a treatment plan could be agreed, CG experienced an episode of brain seizures as a result of his epilepsy, which started on around 9 or 10 January and continued intermittently until 27 January. On 13 January, CG's treating clinicians informed the parents that CG was suffering severe epileptic encephalopathy. They concluded that nucleoside treatment would be futile and would only prolong CG's suffering. His case was also considered by an expert team in Barcelona, which reached the same conclusion. The meaning of "futile" was the subject of argument at the domestic level. The Court of Appeal concluded:

"44. In relation to the judge's use of the word "futile" it is argued that there is a distinction between the medical definition of futility and the concept of futility in law Medicine looks for "a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering", whereas, for the law, this sets the goal too high in cases where treatment "may bring some benefit to the patient even though it has no effect on the underlying disease or disability" In the present case, tragically, this is a difference without a distinction in the light of the judge's finding that the potential benefit of nucleoside therapy would be "zero". It would therefore be, as the judge held at paragraph 90. "pointless and of no effective benefit".

2. Judgment of the High Court of 11 April 2017, Great Ormond Street Hospital v. (1) Constance Yates, (2) Chris Gard, (3) Charles Gard (A child by his Guardian Ad Litem) [2017] EWHC 972 (Fam)

7. In February 2017, GOSH made an application to the High Court for an order stating that it would be lawful, and in CG's best interests, for artificial ventilation to be withdrawn and palliative care provided. The application was opposed by the parents. The question of possible nucleoside therapy was raised by the parents as the proceedings progressed and they put information before the High Court that Dr I was willing to treat CG. Accordingly, the order ultimately included a third element, that it would not be in CG's interest to undergo nucleoside treatment (see paragraph 31).

8. Over the course of three days in April 2017, the High Court heard evidence from the parents, CG's guardian (see paragraph 17) and a number of expert witnesses including Professor A, Dr B and CG's two nurses at GOSH, and Dr I by telephone. It received a report from the medical expert instructed by the parents, Dr L. The Court also received 4 second opinions from world leading medical experts in paediatrics and rare mitochondrial disorders. They were Dr C, Consultant in Paediatric Intensive Care at St. Mary's Hospital; Dr D, Consultant Respiratory Paediatrician at Southampton Hospital; Dr E, Consultant and Senior Lecturer in Paediatric Neurology at the Newcastle Upon Tyne NHS Foundation Trust, and Dr F, Consultant Paediatric Neurologist at St. Mary's Hospital. The judge also visited CG in hospital.

(a) The Medical Evidence as Presented by Great Ormond Street Hospital and Dr L

9. Dr B, Consultant Paediatric Intensivist at GOSH, gave evidence that CG was so damaged that there was no longer any movement (noting that there was no evidence of a sleep/wake cycle). He said that there were no further treatments available to CG which could improve him from his current situation and that this was the opinion of the entire treatment team, including those from whom a second opinion had been obtained. He stated that CG can probably experience pain, but was unable to react to it in a meaningful way.

10. Professor A, a leading expert with a special interest in mitochondrial diseases, gave evidence on the prospect of successful nucleoside treatment. She noted that the treatment had never been tried on humans or even on animals with the RRM2B mutation. She stated that even if there was an ability to cross the blood/brain barrier, the treatment could not reverse the structural damage already done to the CG's brain. She said that seizures in mitochondrial disease are a sign that death is, at most, six to nine months away.

11. Professor A added that:

"90 ... she and Dr I did not really differ on the science and that both agree that, very sadly, it is extremely unlikely to help Charlie. She said that, in her view, there was a cultural difference in philosophy between treatment in the United States and in the United Kingdom. She said that she tried to have the child at the centre of her actions and thoughts whereas in the United States, provided there is funding, they will try anything."

12. Dr L, Consultant Paediatric Neurologist, was instructed on behalf of the parents. His report was produced on the second day of the hearing. Dr L concluded that:

"The nature of [CG's] condition means that he is likely to continue to deteriorate, that he is likely to remain immobile, that he will exhibit severe cognitive impairment, that he will remain dependent on ventilatory support to maintain respiration, will continue to need to be tube fed and that he will always be dependent on mechanical ventilation to maintain life."

(b) The Medical Evidence as presented by Dr I

13. Although he had never examined CG himself, Dr I had full access to his medical history. After reviewing recent EEG results, Dr I stated:

"98.[...] I can understand the opinion that he is so severely affected by encephalopathy that any attempt at therapy would be futile. I agree that it is very unlikely that he will improve with that therapy [nucleoside treatment]. It is unlikely."

14. The judge summarised Dr I's evidence stating:

"127. Dr I who has not had the opportunity of examining Charlie, and who operates in what has been referred to as a slightly different culture in the United States where anything would be tried, offers the tiniest chance of some remotely possible improvement based on a treatment which has been administered to patients with a different condition. I repeat that nucleoside therapy has not even been tried on a mouse model with RRM2B. As Dr I candidly said,

"It is very difficult for me never having seen him, being across the Atlantic and seeing bits of information. I appreciate how unwell he is. His EEG is very severe. I think he is in the terminal stage of his illness. I can appreciate your position. I would just like to offer what we can. It is unlikely to work, but the alternative is that he will pass away."

15. Asked what level of functioning could reasonably be expected after treatment with nucleoside, he said that the main benefit would be improvement of weakness, increased upper strength, and reduced time spent

on ventilators. He however accepted that the treatment, if administered, was unlikely to be of any benefit to CG's brain. He described the probability as low, but not zero. He agreed that there could be no reversal of the structural damage to Charlie's brain.

(c) Position of the parents

16. The parents denied that CG's brain function was as bad as the expert evidence made out. They denied that CG did not have a sleep/wake cycle. They acknowledged and accepted that the quality of life that CG had was not worth sustaining without hope of improvement.

(d) Position of CG represented by his guardian (appointed by the High Court)

17. At the outset of the proceedings the High Court joined CG to the proceedings and appointed a guardian to represent CG's interests throughout the proceedings, who in turn appointed legal representatives. The relevant procedural rule permits joining a child where the court considers this is in the best interests of the child. The Court must then appoint a guardian unless it is satisfied that it is not necessary to do so to safeguard the interests of the child. According to the relevant practice direction (see section 3 below):

"It is the duty of a children's guardian fairly and competently to conduct proceedings on behalf of the child. The children's guardian must have no interest in the proceedings adverse to that of the child and all steps and decisions the children's guardian takes in the proceedings must be taken for the benefit of the child."

18. Throughout the domestic proceedings, the guardian argued that it was not in CG's best interests to travel to America to receive purely experimental treatment with no real prospect of improving his condition or quality of life.

(e) Decision

19. On 11 April 2017, the High Court acceded to GOSH's applications.

20. The High Court judge firstly outlined the relevant legal test as applied to decisions relating to medical treatment of children (see section 2 below). He acknowledged that though parents with parental responsibility have the power to give consent for their child to undergo treatment, as a matter of law, overriding control is vested in the court exercising its independent and objective judgement in the child's best interests. In making that decision, the welfare of the child is paramount. The starting point is the strong presumption of the sanctity of life, and a course of action which will prolong life. The judge must look at the question from the assumed point of view of the child. The term 'best interests' encompasses medical, emotional, and all other welfare issues.

21. The judge observed that there was a consensus from all of the doctors that had examined CG, including the medical expert instructed by the parents that nucleoside treatment would be futile, that is to say pointless and of no effective benefit.

22. The judge concluded that subjecting CG to nucleoside treatment would be to enter unknown territory and could possibly subject him to pain, accepting the evidence that:

“22...the GOSH team believe that Charlie can probably experience pain but is unable to react to it in a meaningful way. Their evidence was that being ventilated, being suctioned, living as Charlie does, are all capable of causing pain. Transporting Charlie to the USA would be problematic, but possible.”

23. The judge concluded:

“128. As the Judge whose sad duty it is to have to make this decision, I know that this is the darkest day for Charlie’s parents who have done everything that they possibly can for him and my heart goes out to them as I know does the heart of every person who has listened to this tragic case during the course of the past week or so. I can only hope that in time they will come to accept that the only course now in Charlie’s best interests is to let him slip away peacefully and not put him through more pain and suffering”.

3. *The Court of Appeal Decision of 23 May 2017, (1) Constance Yates, (2) Christopher Gard – and – (1) Great Ormond Street Hospital for Children NHS Foundation Trust - and – (2) Charles Gard (a child, by his guardian) [2017] EWCA Civ 410*

24. Before the Court of Appeal, the applicants sought to argue that the High Court judge had erred by relying on the ‘best interests’ test alone. They sought to make a distinction between two types of cases relating to medical treatment of children. The first type of case involves parents who oppose the course of treatment for which the treating clinicians apply, and who do not have a viable alternative treatment to put before the court. In the second type of case there is a viable alternative treatment option put forward by the parents. The applicants submitted that their case fell into the latter category. In these circumstances, the applicants (relying on a recent High Court case (*Re King* [2014] EWHC 2964 (Fam.)) argued that a parent’s preferred treatment option should only be overridden if it is established that the option would likely cause the child “significant harm”. The applicants also argued that it was the hospital who had applied to prevent the delivery of a therapy which it did not, itself, intend to provide. This was outside its powers as a public authority, and the court had no jurisdiction to uphold the hospital’s position.

25. The applicants relied on Article 8 of the Convention to say that applying a “best interests” test, rather than a “significant harm” test permitted unjustified interference in their parental rights under that Article. They also referred to Articles 2 and 5 of the Convention, but did not

develop any arguments under those Articles. CG's guardian and GOSH maintained their position that the course of action proposed by the parents was not in CG's best interests.

26. Permission to appeal was granted in respect of the human rights grounds, but only in so far as they supplemented the core grounds for appeal.

27. On 23 May 2017, the Court of Appeal dismissed the appeal. It stated:

"96. If one option is favoured by a parent, that may give it weight, or as Lord Justice Waite put it, incline 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" Notwithstanding that that is the case, in the end it is the judge who has to choose the best course for a child. Whereas, in the case of *Re King* before Mr Justice Baker, there really was nothing to choose as between the benefits and detriments of two forms of radiotherapy, the court readily stood back and allowed the parents to make their choice".

...

"112. It goes without saying that in many cases, all other things being equal, the views of the parents will be determinative. Very many cases involving children with these tragic conditions never come to court because a way forward is agreed as a result of mutual respect between the family members and the hospital, but it is well recognised that parents in the appalling position that these and other parents can find themselves may lose their objectivity and be willing to "try anything" even if, when viewed objectively, their preferred option is not in a child's best interest. 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 alternate view."

28. It found that the High Court was entitled to conclude that the nucleoside treatment option would be futile, and would have no benefit. As a consequence, nucleoside treatment was not a viable option before the court. The court therefore concluded that the factual basis for the applicants' submissions was undermined, and that the question of whether a distinction existed between types of cases involving medical treatment for children advocated by parents did not arise.

29. Nevertheless, the Court of Appeal considered the "significant harm" test proposed by the applicants and stated that:

"114...It must follow from that unanimous professional and expert evidence that to move Charlie to America and expose him to treatment over there would be likely to expose him to continued pain, suffering and distress".

30. The court said:

"114... it is plain that the [High Court] judge was not invited to consider the law in the way that is now put before this court let alone to consider the existence of "category 2" cases with the need to establish a threshold for significant harm. I have made extensive reference to the evidence as recorded by the judge regarding Charlie's current state. It is clear, in my view, that if the judge had been invited to form a

conclusion on whether Charlie was or was not suffering significant harm currently, that finding would have been made. At paragraph 49 the judge records the evidence of the doctors, the medical staff who have knowledge of the current state of Charlie's life in the hospital and each of the other experts as follows:

"In some parts of the media this has been referred to as "pioneering treatment". In fact, this type of treatment has not even reached the experimental stage on mice let alone been tried on humans with this particular strain of MDDS. It is the view of all those who have treated and been consulted in relation to Charlie in this country and also in Barcelona that such treatment would be futile, by which I mean would be of no effect *but may well cause pain, suffering and distress to Charlie*. This is the principal issue with which I have to grapple in this case [emphasis added]".

...

115. The administration of nucleoside therapy, which involves no more than the introduction of some powder into the nutritional feed to Charlie's body and may, at most, trigger some adverse bowel reaction, may be relatively benign and may not itself cause significant harm. The prospect of significant harm arises, however, in the context of such treatment from the judge's finding that it would be of no benefit for Charlie and that he would need to continue with the regime of life-sustaining treatment, which the judge concluded was not otherwise in his best interests, so that the nucleoside therapy could be administered".

31. The court also concluded that the hospital had not acted outside its powers. The issue of nucleoside treatment had been raised by the parents, not by the hospital. The appeal court found that the High Court judge's decision resulted from a "child-focused, court-led evaluation of the baby's best interests". The fact that the merits of the alternative treatment represented a large part of the evaluation demonstrated that the judge had regarded the parents' views as an important part of the process.

32. On the basis that the human rights grounds supported the applicant's primary grounds, the Court of Appeal found that they too should be dismissed.

4. The Supreme Court decision of 8 June 2017, in the Matter of Charlie Gard

33. The applicants requested permission to appeal from the Supreme Court, who heard their application on Thursday 8 June 2017. Before the Supreme Court the applicants repeated the arguments made before the lower courts with a particular focus on the respect for their parental rights under Article 8, repeating the argument rejected by the Court of Appeal that the only reason which could justify interference in their Article 8 rights would be if there were a risk of "significant harm" to the child.

34. GOSH and CG's guardian underlined that in accordance with domestic and international law, the best interests of the child were of paramount importance. They repeated their arguments that taking Charlie to America for experimental treatment was not in his best interests. CG's guardian underlined that even if the proposed "significant harm" test were

applied, the applicant's claim would still fail because as stated by the Court of Appeal, continuing to maintain his life and taking him to America would be likely to expose him to continued pain, suffering and distress.

35. The Supreme Court rejected the applicants' request for permission on the basis that no point of law of general, public importance had been identified. With reference to the domestic statute; the Convention; this Court's case law; and the UN Convention on the rights of the child, the Supreme Court underlined that the welfare of the child shall be the paramount consideration. In its determination of the application on permission to appeal it concluded:

"Finally, the European Court of Human Rights has firmly stated that in any judicial decision where the rights under Article 8 of the parents and the child are at stake, the child's rights must be the paramount consideration. If there is any conflict between them the child's interests must prevail".

36. The Supreme Court also reiterated the finding of the Court of Appeal that even if the "best interests" test were replaced with a test of "significant harm", it is likely that Charlie would suffer significant harm if his present suffering is prolonged without any realistic prospect of improvement.

5. The Supreme Court decision of 19 June 2017. in the Matter of Charlie Gard

37. In light of the indication of this Court of 13 June 2017 under Rule 39, the government requested a hearing before the Supreme Court for directions on whether the Supreme Court could direct a further stay of the declaration of the High Court of 11 April 2017 (see paragraph 19 above). In their judgment the Supreme Court stated:

"15. Every day since 11 April 2017 the stays have obliged the hospital to take a course which, as is now clear beyond doubt or challenge, is not in the best interests of Charlie. The hospital finds itself in an acutely difficult ethical dilemma: although the stays have made it lawful to continue to provide him with AVNH, it considers it professionally wrong for it to have continued for over two months to act otherwise than in his best interests.

...

"17. We three members of this court find ourselves in a situation which, so far as we can recall, we have never previously experienced. By granting a stay, even of short duration, we would in some sense be complicit in directing a course of action which is contrary to Charlie's best interests".

38. The court also recalled the importance of protecting the applicants' right to petition this Court and accordingly, granted a further stay until midnight on 10/11 July 2017.

39. In closing the Supreme Court noted:

"22. By way of postscript, the court was today informed that the proposed application to the ECtHR will be made not only by the parents but also by or on behalf of Charlie. It is not, of course, for this court to comment on how the ECtHR

should address the status of an application made by parents on behalf of a child for a declaration that his rights have been violated by decisions found to have been made in his best interests. But, as the ECtHR well knows, our procedures have required that Charlie's participation in the domestic proceedings should at all times have been in the hands of an independent, professional guardian".

B. Relevant domestic law and practice

1. The Children Act 1989

40. Subsection 1 is titled "Welfare of the child". It provides:

(1) When a court determines any question with respect to—

(a) the upbringing of a child; ...

the child's welfare shall be the court's paramount consideration.

(2) In any proceedings in which any question with respect to the upbringing of a child arises, the court shall have regard to the general principle that any delay in determining the question is likely to prejudice the welfare of the child.

41. The Act also addresses "parental responsibility". It provides that where a child's father and mother were married to each other at the time of his birth, they shall each have parental responsibility for the child. Each of the parents, or the mother if she is unmarried, has parental responsibility over the child. Section 3 states. In the Act "parental responsibility" means:

"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."

42. Section 8 (1) grants the courts the powers to make orders with respect to children in certain circumstances, known as "specific issue" orders.

2. Domestic case law

(a) *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR at p.480.

43. The court stated that a child's parents having parental responsibility have the power to give consent for their child to undergo treatment, but overriding control is vested in the court exercising its independent and objective judgment in the child's best interests.

(b) *An NHS Trust v. MB (A Child represented by CAFCASS as Guardian ad Litem)* [2006] 2 FLR 319.

44. The court said as follows:

"(i) As a dispute has arisen between the treating doctors and the parents, and one, and now both, parties have asked the court to make a decision, it is the role and duty of the court to do so and to exercise its own independent and objective judgment.

(ii) The right and power of the court to do so only arises because the patient, in this case because he is a child, lacks the capacity to make a decision for himself.

(iii) I am not deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.

(iv) The matter must be decided by the application of an objective approach or test.

(v) That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.

(vi) It is impossible to weigh such considerations mathematically, but the court must do the best it can to balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies.

(vii) Considerable weight (Lord Donaldson of Lynton MR referred to 'a very strong presumption') must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive; and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.

(viii) These considerations remain well expressed in the words as relatively long ago now as 1991 of Lord Donaldson of Lynton in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33 at page 46 where he said:

'There is without doubt a very strong presumption in favour of a course of action which will prolong life, but ... it is not irrebuttable ... Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment... We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.'

(ix) All these cases are very fact specific, i.e. they depend entirely on the facts of the individual case.

(x) The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

(c) *An NHS Trust v. MB (A Child represented by CAFCASS as Guardian ad Litem)* [2006] 2 FLR 319.

45. In this case, the Supreme Court stated as follows:

"[22] Hence the focus is on whether it is in the patient's best interests to give the treatment, rather than on 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.

[39] ...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 to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

3. *Family Procedure Rules 2010*

46. Rule 16.2 sets out when a child can be joined as a party in family proceedings, stating:

"(1) The court may make a child a party to proceedings if it considers it is in the best interests of the child to do so".

47. If the court decides to join a child as a party in family proceedings then a guardian must be appointed to represent them, unless the court is satisfied that it is not necessary to do so to safeguard the interests of the child.

48. The Family Court Practice Direction – Representation of Children, Part 4, Section 2, sets out the duty of the guardian as follows:

"It is the duty of a children's guardian fairly and competently to conduct proceedings on behalf of the child. The children's guardian must have no interest in the proceedings adverse to that of the child and all steps and decisions the children's guardian takes in the proceedings must be taken for the benefit of the child".

49. The Court of Appeal considered the role of the guardian in *R & Ors v. Cafcass* [2012] EWCA Civ 853, commenting:

"23. No detailed analysis of this statutory regime is necessary. The provisions speak for themselves. All we need say is that the children's guardian is on any view pivotal to the whole scheme. The guardian is both the voice of the child and the eyes and ears of the court. As any judge who has ever sat in care cases will be all too aware, the court is at every stage of the process critically dependent upon the guardian. In a jurisdiction where the State is seeking to intervene – often very drastically – in family life, the legislature has appropriately recognised that determination of the child's best interests cannot be guaranteed if the proceedings involve no more than an adversarial dispute between the local authority and the parents. Parliament has recognised that in this very delicate and difficult area the proper protection and furthering of the child's best interests require the child to be

represented both by his own solicitor and by a guardian, each bringing to bear their necessary and distinctive professional expertise.”

4. Access to experimental medication

50. All clinical trials to establish whether experimental medical treatment is appropriate and safe for human use need to be approved by the National Health Service Research Ethics Committee. The statutory framework is contained in the Medicines for Human Use (Clinical Trials Regulations) 2004, which transposes the European Clinical Trials Directive (EC/2001/20) into domestic law. The General Medical Council, which is the standard setting body for doctors in the United Kingdom, has also published guidelines on “Good practice in research covering clinical trials”.

C. International Law and Practice

1. United Nations

51. Article 3 (1) of the United Nations Convention on the Rights of the Child states:

“In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration”.

2. Council of Europe

52. The Council of Europe’s Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (opened to signature at Oviedo on 4 April 1997), contains the following principles regarding consent:

“Chapter II – Consent

Article 6 – Protection of persons not able to consent

1. Subject to Articles 17 and 20 below, an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit.

2. 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.

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.

3. Where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, 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.

The individual concerned shall as far as possible take part in the authorisation procedure.

4. The representative, the authority, the person or the body mentioned in paragraphs 2 and 3 above shall be given, under the same conditions, the information referred to in Article 5.

5. The authorisation referred to in paragraphs 2 and 3 above may be withdrawn at any time in the best interests of the person concerned.

53. According to the Explanatory report to the Convention, Article 6 is intended to be in conformity with the provisions in the United Nations Convention on the Rights of the Child (see paragraph 51). The Guide on the decision-making process regarding medical treatment in end-of-life situations was drawn up by the Committee on Bioethics of the Council of Europe in the course of its work on patients' rights and with the intention of facilitating the implementation of the principles enshrined in the Oviedo Convention.

3. European Union

54. The European Union's Charter of Fundamental Rights, which became legally binding with the entry into force of the Lisbon Treaty on 1 December 2009, contains the following Article:

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."

COMPLAINTS

55. The second and third applicants complained on their own behalf and on behalf of the first applicant under Articles 2 and 5 of the Convention. They argued that the hospital has blocked life-sustaining treatment to CG in violation of the positive obligation under Article 2. In respect of Article 5, they argued that CG is deprived of his liberty within the meaning of that article by the order of 11 April 2017.

56. The second and third applicants complained on their own behalf under Articles 6 and 8 of the Convention. Under Article 6 they complained that the Court of Appeal concluded that their intended parental decisions would cause the first applicant "significant harm" without hearing witness evidence on this point. Under Article 8 they argued that the declaration by

the High Court of 11 April 2017 and subsequent domestic court decisions amount to a disproportionate interference in their parental rights because the domestic courts had taken their decisions in the “best interests” of the child. Whereas they should have asked whether there is a likelihood that the child “is suffering, or likely to suffer, significant harm”. As a result, the interference in their parental rights under Article 8 is disproportionate and cannot be justified.

THE LAW

I. STANDING TO ACT IN THE NAME AND ON BEHALF OF CG

57. Article 34 of the Convention provides as follows:

“The Court may receive applications from any person, non-governmental organisation or group of individuals claiming to be the victim of a violation by one of the High Contracting Parties of the rights set forth in the Convention or the Protocols thereto. The High Contracting Parties undertake not to hinder in any way the effective exercise of this right.”

A. Articles 2 and 5 of the Convention

58. In respect of Articles 2 and 5, the second and third Applicants have argued on their own behalf and that of CG that the hospital has blocked life-sustaining treatment to CG and the result is that he is unlawfully deprived of his liberty. The second and third applicants did not give any reasons why the Court should consider that they have standing to make those complaints on CG’s behalf.

B. The Court’s assessment

1. *The relevant principles*

59. In respect of Article 2, the relevant principles are set out in *Lambert and Others v. France* [GC], no. 46043/14, §§ 89-95, ECHR 2015 (extracts). In order to rely on Article 34 of the Convention, an applicant must be able to claim to be a victim of a violation of the Convention. An exception is made to this principle where the alleged violation or violations of the Convention are closely linked to a death or disappearance in circumstances allegedly engaging the responsibility of the State. In such cases the Court has recognised the standing of the victim’s next-of-kin to submit an application (see *Lambert and Others*, cited above, §§ 89-90).

60. Amongst the authorities cited in that case, the Court notes that under Article 8 of the Convention, it has also accepted on several occasions that

parents who did not have parental rights could apply to it on behalf of their minor children (see *Lambert and Others*, cited above, § 94, with further references). The key criterion for the Court in these cases was the risk that some of the children's interests might not be brought to its attention and that they would be denied effective protection of their Convention rights.

61. In respect of Article 5, the Court has regarded this right as one which is non-transferable (see *Tomaszewscy v. Poland*, no. 8933/05, § 77, 15 April 2014). However, in certain cases concerning Articles 5, 6 and 8 of the Convention, the Court has recognised that those close to the victim can be regarded as having standing due to a legitimate material interest and a moral interest, on behalf of themselves and of the family (see *Nolkenbockhoff v. Germany*, no 10300/83, § 33, 25 August 1987 § 33). Where there was an absence of close family ties, the Court has considered this one reason why standing should not be afforded to those who are not direct victims (see *Sanles Sanles v. Spain* (dec.), no. 48335/99, ECHR 2000-XI).

62. Overall, a review of the cases in which the Convention institutions have accepted that a third party may, in exceptional circumstances, act in the name and on behalf of a vulnerable person reveals the following two main criteria: the risk that the direct victim will be deprived of effective protection of his or her rights, and the absence of a conflict of interests between the victim and the applicant (see *Lambert and Others*, § 102).

2. Application to the present case

63. Applying those two criteria set out above to the present case, the Court must consider whether concluding the second and third applicants do not have standing to complain on CG's behalf would deprive CG of effective protection of his rights. In the present case, the Court finds the application of the criterion is more complex than that in *Lambert and Others*, (cited above) because the applicant is a minor, who has never been able to express his views.

64. The first criterion is whether there is a risk that CG as the direct victim, would be deprived of effective protection his rights if the present application could not go ahead on his behalf.

65. In this case that risk has been minimised where CG is represented by an independent, professional, court appointed guardian precisely to ensure that his own voice can be heard. That guardian has been active in the legal proceedings throughout the domestic procedures and it would be possible for the guardian to represent CG in an application to the Court.

66. The Court therefore concludes that based on the procedural possibility for CG to be represented, and the fact that this procedural possibility has functioned effectively in practice, the risk of a failure to protect CG's rights has been reduced as far as possible, in the circumstances.

67. On the second criterion, the question is whether there was a conflict of interest between CG and the second and third applicants. The existence of such a conflict would obviously raise doubts over whether the second and third applicants could make an application on CG's behalf. In this respect, the Court takes into account the unambiguous and repeated findings of the domestic courts that what the parents sought for CG was not in his best interests (see paragraph 37 above). Therefore, even though CG has never been able to express his views, the Court considers that there is a evident conflict of interest between the applicants.

68. Therefore, it could be argued that the second and third applicants do not have standing to raise a complaint under Article 2 of the Convention in the name and on behalf of CG. Indeed, this point was underlined by the Supreme Court in its judgment of 19 June 2017 (see paragraph 39 above).

69. The Court also recalls that applying those criteria in *Lambert and Others* (cited above § 106) it found that the parent applicants did not have standing to raise the complaints on the part of Vincent Lambert and concluded their complaint was incompatible *ratione personae* with the provisions of the Convention. However, looking at the situation as a whole, the Court considers that it is somewhat different to that in *Lambert and Others* (cited above), in light of the fact that CG is a minor, who has never been able to express his views or live an independent life. The second and third applicants' status as parents is therefore arguably to be accorded greater weight in the present case, than in that of *Lambert and Others*, where Vincent Lambert had lived an adult life, separately from his parents and clearly expressed his views. Such an approach would accord with that set out in Article 6.2 of the Oviedo convention (see paragraph 52).

70. However, the Court does not see a need to come to a final conclusion on this point because as in *Lambert and Others* (see § 112) the Court will examine all the substantive issues arising in the present case under Articles 2 and 5 of the Convention, given that they were raised by the applicants on their own behalf.

II. EXHAUSTION OF DOMESTIC REMEDIES

A. The relevant principles

71. The rule of exhaustion of domestic remedies in Article 35 § 1 which provides that the Court may only deal with the matter after all domestic remedies have been exhausted, reflects the fundamentally subsidiary role of the Convention mechanism. It normally requires that the complaints intended to be made at international level should have been aired before the appropriate domestic courts, at least in substance, in compliance with the formal requirements and time-limits laid down in domestic law.

72. The object of the rule is to allow the national authorities to address the allegation of a violation of a Convention right and, where appropriate, to afford redress before that allegation is submitted to the Court. If the complaint presented before the Court has not been put, either explicitly or in substance, to the national courts when it could have been raised, the national legal order has been denied the opportunity which the rule on exhaustion of domestic remedies is intended to give it to address the Convention issue. It is not sufficient that the applicant may have exercised another remedy which could have overturned the impugned measure on other grounds not connected with the complaint of a violation of a Convention right. It is the Convention complaint which must have been aired at national level for there to have been exhaustion of “effective remedies”. It would be contrary to the subsidiary character of the Convention machinery if an applicant, ignoring a possible Convention argument, could rely on some other ground before the national authorities for challenging an impugned measure, but then lodge an application before the Court on the basis of the Convention argument (see, among many other authorities, *Vučković and Others v. Serbia* (preliminary objection) [GC], nos. 17153/11 and 29 others, §§ 69-77, 25 March 2014 *Peacock v the United Kingdom* no. 52335/12 (dec.) 5 January 2016 § 32).

B. Application to the present case

Articles 2, 5 and 6

73. The Court notes that in their application the applicants have highlighted that the domestic courts have not given consideration to the arguments raised under Articles 2 and 5 of the Convention. Given the meticulous and careful nature of the judgments of the domestic courts and their flexible approach to procedure in this case, the Court considers that the fact they did not address the Convention arguments does not indicate any arbitrariness in those judgments but rather results from the fact that those arguments were not made in any detail until the final stages in the proceedings. This conclusion is supported by a review of the content of the applicants’ pleadings before the domestic courts. Concerning the arguments made under Article 6 about the fairness of the proceedings before the Court of Appeal, the Court notes that these were raised in brief by the applicants before the Supreme Court and expressly coupled with their complaints under Articles 5 and 8.

74. Therefore, the Court considers that a question is raised over whether the applicants have clearly shown that they provided the authorities with the opportunity which is in principle intended to be afforded to a Contracting State by Article 35 § 1 of the Convention, namely that of addressing, and thereby preventing or putting right, the particular Convention violation alleged against it, in line with the rule of exhaustion of domestic remedies.

75. However, it does not need to come to a final conclusion on the point because the arguments are manifestly ill-founded, for the reasons set out below.

III. ALLEGED VIOLATION OF ARTICLE 2 OF THE CONVENTION

76. Article 2 of the Convention provides as follows:

“1. Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally”

The relevant principles

1. Access to experimental treatment for terminally ill patients

77. Concerning access to experimental treatment, or treatment which is not usually authorised, the Court has previously considered that the positive obligations under Article 2 may include the duty to put in place an appropriate legal framework, for instance regulations compelling hospitals to adopt appropriate measures for the protection of their patients’ lives (see *Hristozov and Others v. Bulgaria*, § 108). This caused the Court to note in relation to its finding of no violation of Article 2 in that case, where the applicants sought experimental cancer treatment at a private clinic in Germany, that Bulgaria had in place a regulatory system adopted in line with the requirements the relevant European Directives governing access to unauthorised medicinal products in cases where conventional forms of medical treatment appeared insufficient.

78. Overall the Court concluded that Article 2 of the Convention cannot be interpreted as requiring access to unauthorised medicinal products for the terminally ill to be regulated in a particular way (see *Hristozov and Others*, cited above, § 108).

2. Withdrawal of life-sustaining treatment

79. As to the question of the withdrawal of life-sustaining treatment, the Court has examined this question in detail in its landmark Grand Chamber case *Lambert and Others* (cited above) from the standpoint of the State’s positive obligations (see § 124).

80. In addressing the question of the administering or withdrawal of medical treatment in that and previous cases, the Court has taken into account the following elements:

- the existence in domestic law and practice of a regulatory framework compatible with the requirements of Article 2;
- whether account had been taken of the applicant’s previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel;

- the possibility to approach the courts in the event of doubts as to the best decision to take in the patient's interests (*Lambert and Others*, cited above, § 143).

81. As to the first of those three elements, the Court recalls its conclusion in its admissibility decision in *Glass v. the United Kingdom*, no. 61827/00, (dec.), 18 March 2003 that:

"Having regard to the detailed rules and standards laid down in the domestic law and practice of the respondent State in the area under consideration, it cannot be maintained that the relevant regulatory framework discloses any shortcomings which can lay the basis of an arguable claim of a breach of the domestic authorities' obligation to protect the first applicant's right to life."

82. Accordingly, it dismissed the Article 2 complaint in that case as manifestly ill-founded.

83. The Court notes that no consensus exists among the Council of Europe member States in favour of permitting the withdrawal of artificial life-sustaining treatment, although the majority of States appear to allow it. While the detailed arrangements governing the withdrawal of treatment vary from one country to another, there is nevertheless consensus as to the paramount importance of the patient's wishes in the decision-making process, however those wishes are expressed (see *Lambert and Others*, cited above § 147).

84. 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, B and C v. Ireland* [GC], no. 25579/05, § 237, ECHR 2010). However, this margin of appreciation is not unlimited (*ibid.*, § 238) and the Court reserves the power to review whether or not the State has complied with its obligations under Article 2 (*Lambert and Others*, cited above, § 148).

3. Application to the present case

85. The applicants complain that through the domestic legal proceedings, the hospital has blocked access to life-sustaining treatment for CG. This is a different argument to that advanced before the domestic courts, which concerned the withdrawal of life-sustaining treatment. The Court will therefore examine this argument in light of the general principles in its case law concerning access to experimental medication for terminally ill patients. In this respect it notes that it is not the subject of dispute between the parties that the treatment the second and third applicants seek for the first applicant is experimental, having never been tested on humans

or animals (see paragraph 5), and any prospect of it having an effect is purely theoretical.

86. In relation to this argument, the Court recalls that in *Hristozov and Others* (cited above) it found no violation of Article 2 because the state had put in place a regulatory framework governing access to experimental medication. The applicants have not sought to argue in this case that such a framework is missing. However, the Court notes from the domestic proceedings, for example the need for permission from an Ethics Committee in order to access the nucleoside treatment (see paragraphs 6 and 50 above) that such a framework is in place in the United Kingdom. In addition it notes that like in *Hristozov and Others* (cited above), that regulatory framework is derived from the relevant European Directives.

87. As a regulatory framework is in place, this condition is fulfilled and the Court therefore recalls its conclusion in *Hristozov and Others* (cited above), that Article 2 of the Convention cannot be interpreted as requiring access to unauthorised medicinal products for the terminally ill to be regulated in any particular way. Accordingly, it considers that this aspect of the complaint is manifestly ill-founded.

88. As said, the applicants have not made an argument under Article 2 concerning the withdrawal of life-sustaining treatment. Nonetheless, the Court considers that in the circumstances of the case, and in light of the domestic judgments which turned on these arguments, that it is also appropriate to analyse the applicants' complaint from this perspective.

89. In this context, the first of the three elements identified in the general principles set out above (see paragraph 81) is the existence in domestic law and practice of a regulatory framework compatible with the requirements of Article 2. In *Glass* ((dec.), cited above), the Court found the Article 2 complaint inadmissible because the framework in place was appropriate (see paragraph 81 above). Moreover, in its later judgment in that case it concluded that it did not consider that the regulatory framework in place in the United Kingdom is in any way inconsistent with the standards laid down in the Council of Europe's Convention on Human Rights and Biomedicine in the area of consent (see *Glass*, cited above, § 75). Given that the applicants have not raised arguments on this point in their present application, or before the domestic courts, the Court sees no reason to change its previous conclusion. It therefore considers the first element to be satisfied.

90. The second element is whether account had been taken of CG's previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel. The applicants have not complained under this head, that their wishes were not taken account of in this context, although the Court considers that there is some overlap with the complaint made by the second and third applicants under Article 8 that their wishes as parents were not respected.

91. Examining the question from the perspective of Article 2, the Court recalls that neither Article 2 nor its case-law can be interpreted as imposing any requirements as to the procedure to be followed with a view to securing a possible agreement (see *Lambert and Others*, cited above, § 162).

92. It notes that whilst CG could not express his own wishes, the domestic courts ensured that his wishes were expressed through his guardian, an independent professional appointed expressly by the domestic courts for that purpose (see paragraph 48).

93. Moreover, the opinions of all medical personnel involved were examined in detail. These included the views of CG's treating specialist who enjoyed an international reputation in the field, and her supporting clinical team including paediatric doctors and nurses. Opinions were also sought from a clinical team at a specialised hospital in another European country. For the purposes of the domestic proceedings the applicants were invited to privately instruct their own medical expert, which they did (see paragraph 12) and the domestic courts engaged in detail with the views of that expert.

94. The High Court judge who made the first instance decision met with all the parties and medical professionals involved and visited CG in hospital. The Court of Appeal also heard from the doctor in America who was willing to treat the child who was also invited to discuss his professional views with CG's doctors in the United Kingdom, with a view to seeing whether they could narrow any of the issues between them. Finally, the parents were fully involved and represented through all the decisions made concerning CG and significant weight was given to their views.

95. This second element is therefore satisfied.

96. 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 paragraphs 39 to 45 above). The Court also recalls that in its judgment in *Glass* (cited above), 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.

97. Accordingly, the third element is satisfied.

98. Therefore, in light of the above, and in view of the margin of appreciation left to the authorities in the present case, the Court concludes that this complaint is manifestly ill-founded.

IV. ALLEGED VIOLATION OF ARTICLE 5 OF THE CONVENTION

99. The applicants have not specified under which of the categories under Article 5 they wish to raise their arguments concerning deprivation of liberty, making reference only to the general principles. Moreover, the applicants did not detail their arguments on this point at the domestic level with reference to the Convention case law (see paragraph 73 above). Nor, do there appear to be previous examples within the Court's case law which might bear comparison with the arguments as set out in the present case. Although, the Court notes that in the case of *Nielsen v. Denmark* (no. 10929/84, Court (Plenary), 28 November 1988 (§ 72), it considered that hospital treatment of a minor was not in violation of Article 5, stating that the conditions in which the applicant stayed thus did not, in principle, differ from those obtaining in many hospital wards where children with physical disorders are treated.

100. In light of this lack of clarity, the Court does not consider that it would be appropriate to come to any definitive conclusion on the application of Article 5 in this context and in any event, there is no need for it to do so, as the point is manifestly ill-founded for the reasons set out below.

101. Insofar as they have specified their argument, the applicants have contended that the case of *H.L. v. the United Kingdom*, no. 45508/99, ECHR 2004-IX applies to the circumstances of the case. That case concerned the detention of the applicant under 5 § 1 (e) as a person of unsound mind. The Court found violations of Articles 5 § 1 and 5 § 4 of the Convention due to the absence of procedural safeguards (see § 124); and the lack of guarantees of the right of an individual deprived of his liberty to have the lawfulness of that detention reviewed by a court (§ 142), respectively.

102. As to the absence of procedural safeguards concerning detention, the Court considers that on the facts of the case, this element is linked to availability of a domestic legal framework and the possibility to apply to the domestic courts, which it has already considered in the context of Article 2 (see paragraphs 89 to 97 above). Accordingly, it cannot see that the applicants' complaint under this article adds anything further to their claim from a Convention perspective.

103. Accordingly, the Court considers that this aspect of the complaint is manifestly ill-founded.

V. ALLEGED VIOLATION OF ARTICLES 6 AND 8 OF THE CONVENTION

104. The Court recalls that it is the master of the characterisation to be given in law to the facts of a case (see *Söderman v. Sweden* [GC],

no. 5786/08, § 57, ECHR 2013). In the present case, it considers that the applicants' complaint under Article 6 about the manner in which the domestic courts made their decisions, concerns exclusively the alleged arbitrary interference in their private and family life. Indeed, it notes that it was argued as a supplemental aspect of the applicants' Article 8 complaint (see paragraph 73). The complaint is therefore to be examined under Article 8 of the Convention alone, which provides as follows:

"1. Everyone has the right to respect for his private and family life, ...

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

A. The relevant principles

105. As to the scope of Article 8 in this context, the Court has previously considered that a decision to impose treatment on a child contrary to the objections of the parent gave rise to an interference with the child's right to respect for his private life, and in particular his right to physical integrity (see *M.A.K. and R.K. v. the United Kingdom*, nos. 45901/05 and 40146/06, § 75, 23 March 2010; and *Glass*, cited above, §§ 70-72).

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*, cited above, § 83).

107. However, as acknowledged by the domestic courts, the facts of the present case are exceptional and the Court does not have examples in its case law which address the approach to be taken in resolving such conflicts. Nonetheless, it has on many occasions considered the manner in which domestic authorities intervene when families are in conflict, often in situations relating to care and custody arrangements. In such cases the Court has frequently recalled that the decisive issue is whether the fair balance that must exist between the competing interests at stake – those of the child, of the two parents, and of public order – has been struck, within the margin of appreciation afforded to States in such matters, taking into account, however, that the best interests of the child must be of primary consideration (see *X v. Latvia* [GC], no. 27853/09, § 95, ECHR 2013; *Paradiso and Campanelli v. Italy* [GC], no. 25358/12, § 208, ECHR 2017; *Dubská and Krejzová v. the Czech Republic* [GC], nos. 28859/11 and 28473/12, § 74, ECHR 2016; *Mandet v. France*, no. 30955/12, §§ 53-55, 14 January 2016; *Korneykova and Korneykov v. Ukraine*, no. 56660/12,

§ 129-130, 24 March 2016; *N.T.s. and Others v. Georgia*, no. 71776/12, §§ 81-83, 2 February 2016).

108. The Court has also reiterated that there is a broad consensus – including in international law – in support of the idea that in all decisions concerning children, their best interests must be paramount (see *X v. Latvia*, cited above, § 96 with further references).

B. Application to the present case

109. The Court notes at the outset that when it previously considered similar issues in the case of *Glass*, it considered that it was only asked to examine the issues raised from the standpoint of the first applicant's (the child's) right to respect for his physical integrity, having regard, of course, to the second applicant's role as his mother and legal proxy (§ 72). In the present case, the second and third applicants complain only on their own behalf in respect of the interference with their rights under Article 8. Accordingly, it will conduct its analysis in light of the alleged interference with the second and third applicants and in light of its case law cited above relating to their "family ties" with the first applicant.

110. In light of the case law set out above (see paragraph 105), it considers there has been an interference in the Article 8 rights of the applicants. Any such interference constitutes a violation of this Article unless it is "in accordance with the law", pursues an aim or aims that are legitimate under Article 8 § 2 and can be regarded as "necessary in a democratic society".

1. "In accordance with the law"

111. The applicants have not complained as such about a failure to apply the legal framework in place. In respect of that legal framework, the Court recalls the conclusion in its judgment in *Glass*, cited above, § 75:

"Firstly, the regulatory framework in the respondent State is firmly predicated on the duty to preserve the life of a patient, save in exceptional circumstances. Secondly, that same framework prioritises the requirement of parental consent and, save in emergency situations, requires doctors to seek the intervention of the courts in the event of parental objection. It would add that it does not consider that the regulatory framework in place in the United Kingdom is in any way inconsistent with the standards laid down in the Council of Europe's Convention on Human Rights and Biomedicine in the area of consent; nor does it accept the view that the many sources from which the rules, regulations and standards are derived only contribute to unpredictability and an excess of discretion in this area at the level of application".

112. No reasons have been advanced to challenge the Court's conclusions. Therefore, the Court considers that the interference was in accordance with the law.

2. "*Legitimate aim*"

113. The Court also finds that the interference was aimed at protecting the "health or morals" and the "rights and freedoms" of a minor – the first applicant – and thus pursued aims that are legitimate under Article 8 § 2.

3. "*Necessary in a democratic society*"

114. The second and third applicants argued that the interference with their parental rights based on the "best interests" test of the child was unnecessary. According to them, such an interference could only be justified where there was a risk of "significant harm" to the child. They have also argued that it was not appropriate for the question of CG's treatment to be taken by the courts and that this amounted to an unjustifiable interference.

115. Dealing with the latter point first, the Court recalls that it found a violation of Article 8 in the case of *Glass* (cited above), because the hospital concerned did not go before the domestic courts to obtain authorisation to treat the applicant's child, stating that (§ 83):

"...the decision of the authorities to override the second applicant's objection to the proposed treatment in the absence of authorisation by a court resulted in a breach of Article 8 of the Convention"

116. It also notes that in this context the possibility to access court supervision is the third element identified in *Lambert and Others* (cited above) and already examined in the context of this case (see paragraph 96).

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

118. In respect of the applicants' argument that the appropriate test was not one of the child's "best interests", but one of a risk of "significant harm" to the child, the Court recalls that there is a broad consensus – including in international law – in support of the idea that in all decisions concerning children, their best interests must be paramount. But, the facts of the present case are exceptional (see paragraph 107) and there is therefore a lack of guidance in the Court's case law on this point.

119. In any event, the Court does not consider this question to be decisive in the circumstances of the case. That is because even if the test suggested by the applicants is the appropriate one, the Court of Appeal and Supreme Court concluded that there was a risk of "significant harm" to CG (see paragraphs 30 and 36). They arrived at this conclusion on reviewing the decision of the High Court which considered extensive, expert evidence and heard from all concerned with CG's daily care, who concluded, unanimously that it was likely he was being exposed to continued pain, suffering and distress.

120. The domestic courts also found, based on that extensive, expert evidence that for CG to undergo experimental treatment, with no prospects of success would offer no benefit, and prolong his suffering.

121. The Court reiterates that the question of whether an interference is “necessary in a democratic society” requires consideration of whether, in the light of the case as a whole, the reasons adduced to justify the measures are “relevant and sufficient”. In considering the reasons adduced to justify the measures, the Court will give due account to the fact that the national authorities had the benefit of direct contact with all of the persons concerned (see *M.A.K. and R.K.*, cited above, § 68). In the present case, the Court accords the benefit of that direct contact even greater weight given the contact that the domestic courts have had with all those concerned and the extensive amount of technical expertise they have examined.

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 and Krejzová*, cited above, § 178, ECHR 2016, and also *Parrillo v. Italy* [GC], no. 46470/11, § 169, ECHR 2015 with further references). The Court has previously considered in the context of Article 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 and Others*, cited above, § 124). Moreover, it is clear that the case before it raises sensitive moral and ethical issues.

123. The Court is also mindful that the essential object of Article 8 is to protect the individual against arbitrary action by the public authorities. The Court has already found that the legal framework in place was appropriate and that the authorities have a margin of appreciation in this sphere. The Court therefore considers that the legal framework as a whole has not been shown to be disproportionate. It has also found that the benefit of the direct contact with all persons concerned should be accorded significant weight. In such circumstances, it reiterates that it is not for the Court to substitute itself for the competent domestic authorities but rather to review under the Convention the decisions that those authorities have taken in the exercise of their power of appreciation (see *Jovanovic v. Sweden*, no. 10592/12, § 76, 22 October 2015, with further references).

124. Therefore, examining the decisions taken by the domestic courts in light of those considerations, the Court recalls that they were meticulous and thorough; ensured that all those concerned were represented throughout; heard extensive and high-quality expert evidence; accorded weight to all the arguments raised; and were reviewed at three levels of jurisdiction with clear and extensive reasoning giving relevant and sufficient support for their conclusions at all three levels. Accordingly, the Court does not see any element suggesting that those decisions could amount to an arbitrary or disproportionate interference.

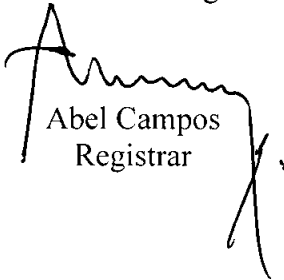
125. Therefore, this part of the complaint is manifestly ill-founded.

In view of the above, it is appropriate to discontinue the application of Rule 39 of the Rules of Court.


For these reasons, the Court, by a majority,

Declares the application inadmissible.

Done in English and notified in writing on 28 June 2017.



Abel Campos
Registrar



Linos-Alexandre Sicilianos
President

APPENDIX

N°.	Name	Date of birth	Nationality
1.	Charles GARD	04/08/2016	British
2.	Christopher GARD	24/06/1984	British
3.	Constance YATES	02/12/1985	British