

## RECENT DEVELOPMENTS

### *Gard v. United Kingdom: Does the State Know Best?*

I. OVERVIEW .....	405
II. BACKGROUND .....	406
III. COURT’S DECISION.....	411
IV. ANALYSIS .....	413
V. CONCLUSION .....	414

#### I. OVERVIEW

This case concerned the painful decision to withdraw life-sustaining treatment for an infant suffering from an extremely rare, and fatal, genetic disease.<sup>1</sup> By refusing to intervene, the European Court of Human Rights (ECtHR) upheld the decision of the U.K. Supreme Court to take the child off life support.<sup>2</sup> Charles Gard was an infant who suffered from a rare disease that caused his health to severely deteriorate and rendered him dependent on artificial ventilation.<sup>3</sup> Charles lost the ability to move his arms and legs and was unable to open his eyes.<sup>4</sup> He lacked signs of responsiveness and suffered from deafness and severe epilepsy.<sup>5</sup> While the possibility of trying an experimental treatment was being evaluated, Charles suffered numerous seizures, which caused severe and irreversible damage to his brain.<sup>6</sup>

His doctors agreed that any further therapy would be useless and only prolong his suffering.<sup>7</sup> The doctors applied to the U.K. High Court for an order to override the objections of Charles’ parents.<sup>8</sup> The doctors presented experts who testified that even with treatment, there could be no reversal of the structural damage to his brain.<sup>9</sup> The order was granted, and Charles’ parents appealed to the U.K. Court of Appeal, which

---

1. *Gard v. United Kingdom*, App. No. 39793/17 Eur. Ct. H.R. 2, 28 (2017), <http://hudoc.echr.coe.int/fre?i=001-175359>.

2. *Id.* at 9, 27-28.

3. *Id.* at 2.

4. *Id.*

5. *Id.*

6. *Id.*

7. *Id.*

8. *Id.* at 3.

9. *Id.* at 3-5.

dismissed their claim.<sup>10</sup> The parents then applied for appeal on point of law to the Supreme Court of England, and, after the court rejected their application, they applied to the ECtHR.<sup>11</sup> They contended that state authorities violated their positive obligations to protect life and that their parental rights had been disproportionately affected in violation of articles 2 and 8 of the European Convention on Human Rights (ECHR).<sup>12</sup> The ECtHR *held* that the United Kingdom should provide Charles with treatment to ensure that he suffers the least amount of pain, which translated into the withdrawal of life support because it was not in his best interest to receive experimental treatment in the United States. *Gard v. United Kingdom*, App. No. 39793/17, Eur. Ct. H.R. (2017), <http://hudoc.echr.coe.int/fre?i=001-175359>.

## II. BACKGROUND

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 lays out principles for the protection of human beings in the field of biology and medicine.<sup>13</sup> Article 2, entitled the Primacy of the Human Being, states "[t]he interests and welfare of the human being shall prevail over the sole interest of society or science."<sup>14</sup> Article 5 governs consent, while article 6 governs consent for those persons not able to consent.<sup>15</sup> Article 6 says that "[a]n intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit."<sup>16</sup> Article 6 specifies that "[t]he opinion of the minor shall be taken into consideration as an increasingly determining factor."<sup>17</sup> Finally, article 8 addresses consent in emergency situations, stating, "[w]hen because of an emergency situation the appropriate consent cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned."<sup>18</sup>

---

10. *Id.* at 6-7.

11. *Id.* at 8-9.

12. *Id.* at 14-15.

13. 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, Apr. 4, 1997, E.T.S. No. 164 [hereinafter Convention for the Protection of Human Rights].

14. *Id.* art. 2.

15. *Id.* arts. 5-6.

16. *Id.* art. 6.

17. *Id.*

18. *Id.* art. 8.

Article 24 of the European Union’s Charter of Fundamental Rights addresses the rights of children.<sup>19</sup> It asserts that children have the right to “such protection and care as is necessary for their well-being . . . [i]n all actions relating to children, whether taken by public authorities or private institutions, the child’s best interests must be a primary consideration.”<sup>20</sup> Article 24 also asserts that “[e]very 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.”<sup>21</sup>

The ECtHR examined general principles in its case law regarding access to experimental treatment for terminally ill patients.<sup>22</sup> Article 34 of the ECHR allows the ECtHR to receive applications from any person who claims to be the victim of a violation of the rights set forth in the Convention.<sup>23</sup> Article 2 of the Convention provides that “[e]veryone’s right to life shall be protected by law,” and article 8 protects against interference by public authorities “except such as in accordance with the law and is necessary in a democratic society.”<sup>24</sup>

The ECtHR in *Lambert v. France* addressed France’s compliance with positive obligations imposed by article 2 of the Convention and the withdrawal of life support of Vincent Lambert.<sup>25</sup> The Court noted that there was no consensus in the European Union authorizing the withdrawal of life-sustaining treatment.<sup>26</sup> Because of the lack of consensus, the Court held that Member States must be given a margin of appreciation to enact their own legal framework to regulate life-sustaining treatment.<sup>27</sup> Due to the extreme complexity of the medical, legal, and ethical matters raised by this case, the Court concluded that domestic authorities have the primary task of deciding whether to withdraw treatment.<sup>28</sup> Because Lambert’s case had been subjected to rigorous consideration by medical and ethical experts, the Court

---

19. Charter of Fundamental Rights of the European Union, art. 24, 2010 O.J. (C 83/02).

20. *Id.*

21. *Id.*

22. *Gard v. United Kingdom*, App. No. 39793/17 Eur. Ct. H.R. 2 (2017), <http://hudoc.echr.coe.int/fre?i=001-175359>.

23. Convention for the Protection of Human Rights and Fundamental Freedoms art. 34, Nov. 4, 1950, E.T.S. no. 5 [hereinafter ECHR].

24. *Id.* arts. 2, 8.

25. *Lambert v. France*, App. No. 46043/14, Eur. Ct. H.R. 1 (2014), <http://hudoc.echr.coe.int/eng?i=001-155352>.

26. *Id.* at 25.

27. *Id.* at 43.

28. *Id.* at 50.

concluded that France's actions were compatible with article 2 and dismissed the complaint.<sup>29</sup>

In *Nolkenbockhoff v. Germany*, the ECtHR addressed the transferability of standing rights in certain cases concerning various articles of the Convention.<sup>30</sup> The Court found that those close to the victim may have standing because they likely have a legitimate, material, and moral interest in the victim and, therefore, may act on their own behalf and that of the victim's family.<sup>31</sup> In *Sanles Sanles v. Spain*, the Court also looked for the presence of close family ties to transfer standing to those who are not direct victims.<sup>32</sup> In that case, the Court did not find that the applicants had standing because they were not close relatives to the victim.<sup>33</sup>

The ECtHR has addressed article 2 complaints, particularly access to experimental treatments for terminally ill patients, in *Hristozov v. Bulgaria*.<sup>34</sup> In that case, the Court addressed a complaint regarding Bulgaria's denial of access to an experimental treatment for terminally ill patients.<sup>35</sup> Bulgaria denied access because the product was not yet licensed, and this would be in violation of Bulgaria's regulations.<sup>36</sup> The applicants' complaint under article 2 was that there is no possibility for terminally ill patients to obtain authorized use of experimental methods once they have exhausted all conventional methods of treatment.<sup>37</sup> The applicants argued that this was in violation of article 2's language that "[e]veryone's right to life shall be protected by law."<sup>38</sup> The Court rejected this claim and ultimately dismissed the case on the grounds that Bulgaria had a regulatory system in place that was compatible with the requirements of the relevant European Directives.<sup>39</sup> Thus, the Court held that article 2 cannot be interpreted as requiring access to experimental or unauthorized treatment for terminally ill individuals or that such treatment must be regulated in a particular way.<sup>40</sup>

The ECtHR addressed what to do in the event of a disagreement between parents and hospitals regarding a severely disabled child's

---

29. *Id.*

30. *Nölkenbockhoff v. Germany*, App. No 10300/83, Eur. Ct. H.R. 13 (1987).

31. *Id.* at 14.

32. *Sanles Sanles v. Spain*, App. No. 48335/99, Eur. Ct. H.R. 502-03 (2000).

33. *Id.*

34. *Hristozov v. Bulgaria*, App. Nos. 47039/11 & 358/12, Eur. Ct. H.R. 2-4 (2012).

35. *Id.*

36. *Id.*

37. *Id.* at 28.

38. *Id.*

39. *Id.* at 31-32, 35, 38.

40. *Id.* at 31-32.

treatment in *Glass v. United Kingdom*.<sup>41</sup> Applicants in that case argued that the doctors' decisions to place a "do not resuscitate" (DNR) notice on their son's notes without their permission and to ignore their wishes against palliative treatment violated their article 8 rights.<sup>42</sup> They further argued that it was not the job of the doctors to balance their son's fundamental rights and contended that such balancing was a judicial function.<sup>43</sup>

Additionally, they contended that the United Kingdom lacked adequate legal framework because it did not "regulate what the medical authorities were required to do in circumstances where life-threatening treatment was proposed and a DNR notice included in the first applicant's medical notes without the second applicant's knowledge."<sup>44</sup> The Government contended, however, that the hospital staff's conduct was compatible with article 8.<sup>45</sup> They reasoned that in emergency situations, the hospital was not absolutely obligated to seek the consent of the parents before treating a child.<sup>46</sup> The Court concluded that the mother of the child acted as his legal proxy and, therefore, had authority to act on his behalf.<sup>47</sup> However, the Court dismissed the article 2 complaint as ill-founded because the doctors did not intend to unilaterally hasten the patient's death.<sup>48</sup> The Court also held that when there is a dispute between a parent and hospital concerning the treatment of a child, it is appropriate for the involved medical professionals to bring the issue before a court.<sup>49</sup>

In *X v. Latvia*, the ECtHR addressed disagreements among purported parents of a child about who had parental responsibility for the child.<sup>50</sup> The applicant argued that the Latvian Government's decision to order her daughter's return to Australia violated her right to respect her family life under article 8 of the ECHR.<sup>51</sup> The Court held that the interests of the child should predominate in cases involving family conflict.<sup>52</sup> The Court quoted article 3 of the Convention on the Rights of the Child: "In all actions concerning children, whether undertaken by

---

41. *Glass v. United Kingdom*, App. No. 61827/00, Eur. Ct. H.R. 2-3, 5, 7 (2004).

42. *Id.* at 15.

43. *Id.*

44. *Id.*

45. *Id.*

46. *Id.* at 19.

47. *Id.* at 17.

48. *Id.* at 19.

49. *Id.* at 20.

50. *X v. Latvia* [GC], App. No. 27853/09, Eur. Ct. H.R. 3, 17 (2013).

51. *Id.* at 16.

52. *Id.* at 27.

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.”<sup>53</sup> The Court emphasized that the inquiry should be centered around what is in the best interests of the individual child.<sup>54</sup>

The ECtHR has considered interference by domestic authorities and the absence of procedural safeguards.<sup>55</sup> In *H.L. v. United Kingdom*, the Court considered the detention of a five-year-old because the child was of unsound mind.<sup>56</sup> The Court held that article 5 of the Convention was violated because there were no procedural safeguards in place.<sup>57</sup> Additionally, the Court found a lack of guarantees by the state that the individual would maintain his liberty and have his detention subject to judicial review.<sup>58</sup>

The ECtHR, in *Parrillo v. Italy*, addressed the role of the state when there is no consensus among Member States of the Council of Europe, especially when considering moral and ethical issues.<sup>59</sup> The case involved a woman who wished to donate her harvested eggs to stem cell research.<sup>60</sup> Stem cell research, however, was banned during this time in the applicant’s home state of Italy.<sup>61</sup> The applicant argued that the ban violated her rights under article 8 of the ECHR, which provides that everyone has the right to respect for his or her private life.<sup>62</sup> The Court concluded that the applicant’s private life included having control over the fate of her embryos, and thus article 8 was applicable.<sup>63</sup> The Italian Government argued that the case also raised admissibility issues because the applicant had not exhausted all domestic remedies before petitioning the ECtHR.<sup>64</sup> The Court rejected the Government’s argument, however, and allowed the applicant’s petition to be heard.<sup>65</sup> The Court ultimately ruled against the applicant, finding that the importance of Italy’s ban on stem cell research outweighed the applicant’s right to privacy.<sup>66</sup> When

---

53. *Id.* at 12.

54. *Id.* at 13, 48.

55. *H.L. v. United Kingdom*, App. No. 45508/99, Eur. Ct. H.R. 40 (2004).

56. *Id.* at 32.

57. *Id.* at 45.

58. *Id.* at 32, 45.

59. *Parrillo v. Italy*, App. No. 46470/11, Eur. Ct. H.R. 39 (2015).

60. *Id.* at 3, 31.

61. *Id.*

62. *Id.* at 1.

63. *Id.* at 37-38.

64. *Id.* at 25.

65. *Id.* at 46.

66. *Id.* at 40, 43.

considering such issues, the Court held that the states will be given greater domestic freedom to make decisions.<sup>67</sup>

### III. COURT'S DECISION

In the noted case, the ECtHR relied on general principles in its case law regarding access to experimental treatment for terminally ill patients. The Court ruled that the Government of the United Kingdom is obligated to provide Charles Gard with treatment that ensures he suffers the least amount of pain.<sup>68</sup> In Charles' case, this translated into the withdrawal of his life support because it was not in his best interest to receive experimental treatment in the United States or to remain on life support.<sup>69</sup> The hospital was authorized to stop Charles' artificial respiration against the will of his parents, thus ending his life.<sup>70</sup>

The Court dismissed the article 2 complaint, holding that the United Kingdom's regulatory framework, which requires doctors to apply to the courts in uncertain cases, was compatible with article 2.<sup>71</sup> Additionally, the article 8 complaint was dismissed because the interference with the parents' rights was in accordance with the law because it pursued a legitimate end that protected the interests of the child.<sup>72</sup> The Court clarified the criteria that the best interest of the child must always predominate, basing its decision on broad consensus within the international community.<sup>73</sup>

The Court first evaluated whether Charles' parents had standing to bring suit because of actions pertaining to their son.<sup>74</sup> Relying on precedent, the Court articulated the criteria for allowing third parties to bring suit: "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."<sup>75</sup> The Court applied this criteria to consider whether Charles' parents had standing to bring a complaint on his behalf.<sup>76</sup> The Court determined that because Charles had a court-appointed guardian to act on his behalf and that guardian had been active

---

67. *Id.* at 39.

68. *Gard v. United Kingdom*, App. No. 39793/17, Eur. Ct. H.R. 26-27 (2017), <http://hudoc.echr.coe.int/fre?i=001-175359>.

69. *Id.*

70. *Id.*

71. *Id.* at 20.

72. *Id.* at 24.

73. *Id.* at 25.

74. *Id.* at 16.

75. *Id.*

76. *Id.* at 16-17.

in the legal process, the parents were not necessary actors to prevent risk of a failure to protect his rights.<sup>77</sup> Moreover, on the question of whether there was a conflict of interest between Charles and his parents, the Court gave weight to the “unambiguous and repeated findings of the domestic courts that what the parents sought for [Charles] was not in his best interests.”<sup>78</sup> Because of this, despite the fact that Charles had never been able to express his own views, the Court found there was an obvious conflict of interest between Charles and his parents, which decreased their ability to have standing under article 2.<sup>79</sup>

The Court examined the article 2 complaint that the hospital had blocked access to life-sustaining treatment through domestic legal proceedings.<sup>80</sup> The Court cited *Hristozov*, where it found that the state had not violated article 2 because it had put in place a regulatory framework governing access to experimental treatment.<sup>81</sup> In the noted case, a similar framework was in place in the United Kingdom.<sup>82</sup> The Court examined three elements to determine whether article 2 had been violated by withdrawing life-sustaining treatment: (1) regulatory framework, (2) views of patient, family, and medical experts, and (3) referral to courts.<sup>83</sup> The United Kingdom has a regulatory framework in place governing access to experimental treatment that is consistent with the European Directives.<sup>84</sup> The domestic courts took into account Charles’ wishes, expressed through his guardian, as well as the detailed opinions of all relevant medical personnel.<sup>85</sup> Doctors and specialists from the United Kingdom and the United States were invited by the domestic courts to submit their arguments.<sup>86</sup> Additionally, the wishes of Charles’ parents were given significant weight throughout the proceedings.<sup>87</sup> Finally, the Court found that the third element was satisfied because there was not only an opportunity but also a duty in the United Kingdom for hospitals to consult the courts in cases of uncertainty.<sup>88</sup> Because all three

---

77. *Id.* at 17.

78. *Id.*

79. *Id.*

80. *Id.* at 19-22.

81. *Id.* at 20-21.

82. *Id.*

83. *Id.* at 20-22.

84. *Id.*

85. *Id.* at 22.

86. *Id.*

87. *Id.*

88. *Id.*



elements were satisfied, the Court found that the article 2 complaint was manifestly ill-founded and therefore inadmissible.<sup>89</sup>

The Court then examined the article 8 complaint under the ECHR that the parents' rights to their son had been inappropriately interfered with by the United Kingdom.<sup>90</sup> The Court noted that "the essential object of article 8 is to protect the individual against arbitrary action by the public authorities."<sup>91</sup> It relied on precedent from *Glass* and *Lambert* in asserting that it was appropriate for the hospital treating Charles to turn to the courts if conflict occurred.<sup>92</sup> Additionally, the Court cited a broad consensus in international law that in all decisions concerning children, the children's best interests must be paramount.<sup>93</sup> The Court deferred to the domestic courts, who had been "meticulous and thorough" in ensuring that all who were concerned were represented throughout, including experts.<sup>94</sup> The Court, thus, found the article 8 complaint to be ill-founded, and therefore inadmissible, as it did with the article 5 complaint.<sup>95</sup>

#### IV. ANALYSIS

The Court's decision in the noted case creates a drastic precedent.<sup>96</sup> By the ECtHR upholding the United Kingdom's override of parental preferences, both the state and international court are taking on paternalistic roles.<sup>97</sup> Overriding parental rights is dangerous and contrasts with medical policy in the United States.<sup>98</sup> If this precedent is adopted, the results could be far-reaching for parents, minors, and the autonomy of the medical community in the European Union.<sup>99</sup> The noted case may be evidence of the European government taking on a bigger role in deciding who should live and who should die.<sup>100</sup> This is especially problematic when considering the center of the noted case was an

---

89. *Id.* at 23.

90. *Id.* at 24-25.

91. *Id.* at 27.

92. *Id.* at 24, 26.

93. *Id.* at 26.

94. *Id.* at 27.

95. *Id.* at 23.

96. Grégor Puppink, *Charlie Gard Case: The Limit of the Rights of Parents to Respect to the Life of Their Children*, EUR. CTR. FOR L. & JUST. (Oct. 10, 2017), <https://eclj.org/euthanasia/echr/affaire-charlie-gard--la-limite-du-droit-des-parents-au-respect-de-la-vie-de-leur-enfant>.

97. *Id.*

98. See Susan Scutti, *Could Charlie Gard's Case Happen in the United States?*, CNN (July 6, 2017), <http://www.cnn.com/2017/07/06/health/charlie-gard-us-laws/index.html>.

99. See *id.*

100. *Id.*

infant.<sup>101</sup> Thus, this opinion is worrisome because it reflects the paternalistic overreach of the United Kingdom and the European Union.<sup>102</sup>

The noted case is noteworthy because it is the first instance that the ECtHR has analyzed domestic law in the United Kingdom on passive euthanasia.<sup>103</sup> The Court attempted to resolve issues that had only been raised before domestic courts in accordance with the ECtHR.<sup>104</sup> Additionally, the noted case provides important clarification that the best interest of a child must always be the main criteria when analyzing cases involving minors and that the age of the minors is an important factor for consideration when analyzing parental authority.<sup>105</sup> The noted case represents an early development of case law on this topic for the ECtHR.

The noted case is further noteworthy because its holding is difficult to understand within the context of the American legal system.<sup>106</sup> When dealing with brain-dead children in the United States, courts give weight to medical opinions but, ultimately, allow the parents to pay for experimental treatment if they are so willing.<sup>107</sup> This is a drastically different result from the noted case, where the courts overruled the parents' desire to give their son experimental treatment, even when the parents were willing and able to pay for treatment.<sup>108</sup> It seems troubling that a court can step in and rule that because the child would be better off dead, the child's parents may not continue to seek care, even after finding the required money and a doctor in the United States who is willing to operate.<sup>109</sup>

## V. CONCLUSION

In conclusion, the noted case addressed the rights of a child when there is disagreement between the child's parents and the medical professionals treating the child.<sup>110</sup> In the noted case, the ECtHR analyzed

---

101. *Gard v. United Kingdom*, App. No. 39793/17 Eur. Ct. H.R. 2 (2017), <http://hudoc.echr.coe.int/fre?i=001-175359>.

102. Puppinc, *supra* note 96.

103. See *United Kingdom: Human Rights Judges Endorse Decisions by Courts in Charlie Gard Case*, HUM. RTS. EUR. (June 28, 2017), <http://www.humanrightseurope.org/2017/06/united-kingdom-human-rights-judges-endorse-decisions-by-courts-in-charlie-gard-case/>.

104. See *Gard*, App. No. 39793/17 at 2, 9, 16-17, 18, 24.

105. *Id.* at 10, 14.

106. Scutti, *supra* note 98.

107. *Id.*; see *McMath v. State of Cal.*, No. 15-CV-06042-HSG, 2016 WL 7188019, 7 (N.D.C.A. Dec. 12, 2016).

108. Scutti, *supra* note 98.

109. *Id.*

110. See *Gard*, App. No. 39793/17 at 2.

the facts under various articles of 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, and of the ECHR.<sup>111</sup> The articles lay out principles for the protection of human beings in the field of biology and medicine as well as provide the criteria for applicants to bring suit in the ECtHR.<sup>112</sup>

The noted case was part of the Court's early case law development in the area of end-of-life treatment and the rights of parents.<sup>113</sup> While it is noteworthy, it is also troublesome because of the paternalistic power that it vests in the European Union Member States.<sup>114</sup> The Court is allowing the states to override the wishes of parents based on the justification that the state knows what is in the best interest of the child, which is drastically different from the approach taken by American courts.<sup>115</sup> While deference to the state may be appropriate in some instances, it has the potential for government overreach and severe infringement on parental rights.

Rosalyn Broad\*

---

111. *Id.* at 15.

112. ECHR, *supra* note 23, arts. 2, 8, 34; *see* Convention for the Protection of Human Rights, *supra* note 13.

113. *See Gard*, App. No. 39793/17.

114. *See Puppink*, *supra* note 96.

115. Scutti, *supra* note 98.

\* © 2018 Rosalyn Broad. J.D. candidate 2019, Tulane University Law School; B.A. 2016, The University of Texas at Austin. The author is from Newport News, Virginia. She would like to thank her family for always encouraging her to pursue new international experiences.