

# Charlie Gard and Alfie Evans

## Their Medico-Legal Journeys

Kartina A. Choong

University of Central Lancashire, UK

### I. Introduction

Charlie Gard and Alfie Evans were two desperately ill children born to young first-time parents. They were treated at two renowned publicly-funded paediatric hospitals in England, namely the Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) in London and the Alder Hey Children's NHS Foundation Trust (Alder Hey Hospital) in Liverpool. The cases first captured public attention when both sets of parents vehemently opposed the court declarations sought by the hospitals that it would be in the infants' best interests to have their life-sustaining treatment (LST) withdrawn after the treating medical teams decided that the continuation of LST was futile and may even lead to the prolongation of pain and suffering. In each case, the declaration was granted by the High Court. In both, the parents appealed to the highest court in the land as well as to the European Court of Human Rights (ECtHR) in Strasbourg. However, none of the appeals managed to overturn the initial court declaration, and both infants died shortly after their LST was discontinued. This context-setting chapter chronicles their medico-legal journeys<sup>1</sup> and concludes by reflecting on their legacies for similar cases in the near future.

### II. Charlie Gard

Born on 4<sup>th</sup> August 2016, Charlie Gard<sup>2</sup> appeared healthy at birth. He gave cause for concern in the first two months when he seemed less able to lift his head and support himself compared to other babies his age. He was also not gaining weight. On 11<sup>th</sup> October 2016, he was placed under the care of GOSH after he became increasingly lethargic and his breathing became shallow. He was diagnosed as suffering from infantile onset encephalomyopathic mitochondrial DNA depletion syndrome (MDDS). This very rare and debilitating condition is caused by biallelic mutations in a gene called RRM2B, whose effect was to leave Charlie with severe depletion of the amount of mitochondrial DNA in his tissues. This had a profound impact upon his brain, muscles, and ability to breathe, and some effect on his heart, liver, and kidneys. As a consequence, he had progressive muscle weakness including of his breathing muscles. He was also not able to move his arms, fingers, legs, and toes; and not always able to open his eyes. As part of this underlying condition, he was also profoundly deaf. He further developed a severe epilepsy disorder and suffered persistent seizures. Although he was not brain dead, he did not display the usual signs of normal brain activities like responsiveness, interaction, or crying. Owing to the severity of his condition, regarded as "exceptionally rare,"<sup>3</sup> he had been, since his arrival at the hospital, cared for in the intensive care unit (ICU) where he breathed with the assistance of mechanical ventilation.

His parents, Connie Yates and Chris Gard, in the course of their researches came across a form of treatment known as nucleoside therapy which they had hoped would help decelerate or even halt Charlie's relentless deterioration. This therapy had evidently been beneficial when used on MDDS patients with TK2 mutation, a different and less severe mitochondrial condition that primarily causes muscle weakness but does not generally affect the brain. It operates by introducing an alternative source of energy which the cells can utilise to replace the energy depletion caused by MDDS. The energy is supplied through a chemical compound which is added to the patient's food. The parents made contact with a US-based Professor of Neurology with relevant experience of administering the therapy. He cautioned that there was no direct evidence that the therapy had any beneficial effect on the brains of TK2 patients, and that nucleoside therapy had up to then never been experimented on animals or human beings with RRM2B deficiency. It was therefore unknown whether the energy-giving supplement would replenish brain cells; whereas in order to be helpful to patients with RRM2B, it would have to cross the blood/brain barrier, something which he opined was a theoretical possibility.

When this option was posed by the parents to the doctors at GOSH, they briefly contemplated it in early January 2017 and began to prepare the documentations for Ethics Committee approval as the treatment was then still experimental. However, following an episode of brain seizures on 9<sup>th</sup> or 10<sup>th</sup> January 2017 which continued intermittently for 3 weeks, Charlie's doctors came to the conclusion that nucleoside therapy would be futile. The plan was therefore abandoned. However, as the parents were still hopeful that the nucleoside therapy would offer some amelioration of Charlie's conditions and that

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<sup>1</sup> The background information and medico-legal details referred to in this chapter are derived from the case reports cited herein. Where necessary, reference will be made to the relevant pages or paragraphs of those judgments.

<sup>2</sup> Hereinafter referred to as "Charlie."

<sup>3</sup> *Great Ormond Street Hospital v Yates, Gard & Gard* [2017] EWHC 972 (Fam), para. 15.

the administration of the supplement would cause little or no harm, they turned to crowdfunding to finance Charlie's journey to, and treatment in, the USA.<sup>4</sup>

Charlie's medical team, in the meantime, was of the opinion that the infant was still capable of experiencing pain. Hence not only would the administration of nucleoside therapy be potentially painful and could lead to the prolongation of his suffering, but that being ventilated, suctioned, and living as he did, were all possibly pain-inducing. They came to the decision that his condition has reached the stage where artificial ventilation should be withdrawn and only palliative care be given so as to allow him to die in peace and with dignity.

- High Court<sup>5</sup>

Thus on 24<sup>th</sup> February 2017, GOSH applied to the High Court for orders to be made (a) that Charlie lacked capacity to make decisions relating to his medical treatment; and (b) that it was lawful and in his best interests for his artificial ventilation to be withdrawn and (c) for him to be provided only with palliative care. The application, made pursuant to the inherent jurisdiction of the court, was opposed by Charlie's parents. They wanted GOSH to keep Charlie ventilated and alive until they could take him to the USA. As the question of possible nucleoside therapy was raised by the parents, GOSH added to their application for an order that (d) it would not be in Charlie's interest to undergo nucleoside therapy. Mr Justice Francis, who heard the case, joined Charlie to the proceedings and appointed a guardian to represent his interests.

Given his age, Charlie's lack of capacity was plainly not in issue. Outlining the relevant legal test for the other three matters, Mr Justice Francis acknowledged that whilst parents with parental responsibility have the power to make decisions regarding their child's medical treatment, overriding control is vested in the court. The latter exercises its independent and objective<sup>6</sup> judgment in the child's best interests. For this, the court is guided by the principle that the child's welfare shall be its paramount consideration, as enshrined in section 1 of the Children Act 1989.

In determining Charlie's best interests, Mr Justice Francis heard both the testimony of the treating team at GOSH and other eminent doctors from the UK including one who was instructed by the parents to give evidence. Evidence was also received over the telephone from the aforementioned American Professor of Neurology, whose identity we now know as Professor Michio Hirano<sup>7</sup> of Columbia University. All agreed that the nucleoside therapy would offer no effective benefit to Charlie and further treatment would be futile. The word "futile," Mr Justice Francis clarified, means "pointless or of no effective benefit."<sup>8</sup> Even Professor Hirano, having been presented with Charlie's medical records, said that "I agree that it is very unlikely that he will improve with that therapy. It is unlikely."<sup>9</sup> At most it would make a "modest difference in life expectancy,"<sup>10</sup> but could certainly not undo structural brain damage. He placed the benefit of the treatment to Charlie's brain "as low, but not zero"<sup>11</sup> and claimed that had Charlie been in the USA, he would have treated him.<sup>12</sup> In words that seemed to convey compassion rather than hope, he said "I would just like to offer what we can. It is unlikely to work, but the alternative is that he will pass away."<sup>13</sup>

However, given that Charlie's brain damage was already severe and irreversible, and nucleoside therapy was potentially painful and would not achieve anything positive,<sup>14</sup> Mr Justice Francis held, in a judgment dated 11<sup>th</sup> April 2017, that it was in Charlie's best interests "to let him slip away peacefully and not put him through more pain and suffering."<sup>15</sup> He therefore acceded to GOSH's application and made formal declarations that it was not in Charlie's best interests to continue to be artificially ventilated; and that it was not in his best interests to undergo nucleoside therapy in the USA. It was instead in Charlie's best interests to have the artificial ventilation withdrawn and for him to be provided only with palliative care; provided that the measures taken are compatible with maintaining Charlie's dignity. The judge ended his ruling with the recommendation that in future, some form of Issues Resolution Hearing or mediation could be attempted for similar cases in the hope that the confidential conversations between the parties could help them find common grounds, or a resolution, or at the very least, a better understanding between them.<sup>16</sup>

- Court of Appeal<sup>17</sup>

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<sup>4</sup> It was reported that they managed to gather approximately £1.3 million for this purpose – see C. Dyer, "Law, Ethics, and Emotion: The Charlie Gard Case," *British Medical Journal* 358 (2017): j3152, doi:10.1136/bmj.j3152.

<sup>5</sup> *Great Ormond Street Hospital* (n 3).

<sup>6</sup> Gillon nevertheless questioned whether it is ever possible to make an "objective" judgment in acute moral dilemmas such as this – see R. Gillon, "Why Charlie Gard's Parents Should Have Been the Decision-Makers About Their Son's Best Interests," *Journal of Medical Ethics* 44 (2018): 462-465, at 464.

<sup>7</sup> S. Mayor, "Charlie Gard Dies in Hospice After High Court Rules Against Prolonging Life Support," *British Medical Journal* 358 (2017): j3673, doi:10.1136/bmj.j3673.

<sup>8</sup> *Great Ormond Street Hospital* (n 3), para. 93.

<sup>9</sup> *Ibidem*, para. 98.

<sup>10</sup> *Ibidem*, para. 106.

<sup>11</sup> *Ibidem*, para. 104.

<sup>12</sup> *Ibidem*, para. 99.

<sup>13</sup> *Ibidem*, para. 127.

<sup>14</sup> *Ibidem*, para. 17.

<sup>15</sup> *Ibidem*, para. 128.

<sup>16</sup> *Ibidem*, para. 130.

<sup>17</sup> *Yates & Gard v Great Ormond Street Hospital & Gard* [2017] EWCA Civ 410.

On 2<sup>nd</sup> May 2017, the parents sought permission to appeal against the High Court's declarations, and to obtain declarations indicating that they had the right to transfer Charlie to a clinic where he could be provided with nucleoside therapy. GOSH agreed to maintain Charlie's treatment pending a full hearing. Of the five potential grounds of appeal lodged, only three were accepted. These relate to contentions that: a different approach should be employed as a matter of law to cases where a choice has to be made between viable treatment options; the High Court judge had no jurisdiction to grant an order on the application of one clinical team preventing another clinical team from carrying out a course of treatment that was offered in the reasonable exercise of professional judgment; and no or insufficient regard was given to Charlie's and his parents' rights under the European Convention on Human Rights (ECHR) (but permission to appeal was confined only to human rights arguments that supplement the previous two grounds).<sup>18</sup>

Concerning the first ground of appeal, the parents argued that the judge erred in making an order which prevented Charlie from being removed and transported to a reputable hospital abroad in circumstances where there was no risk that the treatment would cause "significant harm" to him. For this, they argued that it is important that a distinction is drawn between two categories of cases. Category 1 refers to cases where parental opposition to the course of action proposed by the medical team is not supported by a viable alternative therapeutic option. Category 2, by contrast, refers to cases where a viable alternative treatment option is presented by the parents. In such situations, it was contended that the parents' choice should only be overridden by the courts if it is established that the alternative route is likely to cause the child to suffer "significant harm." Whilst Category 1 cases should continue to be decided by reference to the "best interests" test, the legal decision-making process for Category 2 cases must be structurally different in order to safeguard the parents' autonomy and ability to pursue their choice of treatment insofar as it does not pose "significant harm" to the child. They cited *Re King*<sup>19</sup> in support, where the court, in ruling that the parents' wish to take their child abroad for a viable alternative treatment (namely proton beam therapy) was "entirely reasonable,"<sup>20</sup> stated that the:

responsibility for making decisions about a child rest with the parents. In most cases, the parents are the best people to make decisions about a child and the state – whether it be the court, or any other public authority – has no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give.<sup>21</sup>

In light of this, Connie Yates' and Chris Gard's legal team argued that the High Court had erroneously applied the best interests test (which is reserved for Category 1 cases) to their situation. The imposition of the withdrawal of LST upon the child of parents who hold a legitimate opposing viewpoint favouring a viable treatment option which does not cause "significant harm" constitutes, they further advanced, an intervention by the state on their right to private and family life as enshrined by Article 8 of the ECHR. Articles 2 and 5 were also mentioned in their submission, but these were not developed.

Next, their legal team acknowledged that GOSH was indeed entitled to apply for declarations concerning the lawfulness of its own plan to withdraw treatment, provide only palliative care and withhold nucleoside therapy on its site. However, the same cannot be said for its application to actively prevent external parties from arranging and delivering nucleoside therapy offsite. This, they claimed, was plainly beyond GOSH's powers as a public authority and/or the court's jurisdiction where proof of "significant harm" is not present. It is thereby wrong for the hospital to impose its view upon the parents by making the application; and the court, correspondingly, had no jurisdiction to uphold and support the hospital's stance on this matter. They were particularly concerned that the judge's declaration had *de facto* injunctive effect in that it prevented Charlie from being removed from GOSH to undergo treatment in the USA.

To these, the Court of Appeal responded as follows. As the first submission was premised upon the existence of a viable alternative treatment option, the fact that Mr Justice Francis had taken a very dim view of nucleoside therapy's potential to help Charlie, in and of itself signified that the question of whether, as a matter of law, there is a group of cases labelled "Category 2" did not arise for Charlie. On the second argument that GOSH was acting outside its legal powers in bringing the application regarding nucleoside therapy, the Court of Appeal reminded the parents that it was they, and not the hospital, who raised the issue. And since Professor Hirano had offered to treat Charlie in the USA by the time of the High Court hearing, GOSH raised it for determination within its overall application. Hence, rather than GOSH seeking to force its views on the parents and thereafter seeking the court's backing, it fell upon the judge to decide on the matter and this was reached on the basis of Charlie's best interests. It was thus incorrect on the part of the parents' legal team to frame this issue as being driven by GOSH. With this, the Court of Appeal concluded by a judgment dated 23<sup>rd</sup> May 2017 that both grounds of appeal, as supported by human rights arguments made under the third ground of appeal, must be dismissed; and that the High Court's ruling stands.

Subsequent to this, the Court of Appeal refused the parents' permission for appeal to the Supreme Court. This Court of Appeal Order was dated 25<sup>th</sup> May 2017.

- Supreme Court<sup>22</sup>

<sup>18</sup> *Ibidem*, para. 37.

<sup>19</sup> [2014] EWHC 2964 (Fam).

<sup>20</sup> *Ibidem*, para. 34.

<sup>21</sup> *Ibidem*, para. 31.

<sup>22</sup> *In the Matter of Charlie Gard* (Supreme Court, 8<sup>th</sup> June 2017).

The parents then lodged an appeal to the Supreme Court but their application for permission to appeal, presided over by Lady Hale, Lord Kerr and Lord Wilson, was declined on 8<sup>th</sup> June 2017. The Supreme Court affirmed that the High Court judge had applied the correct test, namely the “best interests test,” in deciding Charlie’s case and it also endorsed the factual findings of the High Court judge. It maintained that parents are not entitled to insist on treatment options which are not in their child’s best interests and that the significant harm requirement does not apply to hospitals seeking guidance on their patients’ best interests.

Not willing to give up, the parents took their case to the European Court of Human Rights (ECtHR) on 19<sup>th</sup> June 2017. The application was made by themselves and on behalf of Charlie. To facilitate this, the UK government requested that the Supreme Court consider making an order for a short stay of the declarations dated 11<sup>th</sup> April 2017. This was with a view to enabling the ECtHR to determine the parents’ request under Rule 39 of the Rules of the Court, and to indicate to the United Kingdom any interim measures that should be adopted or for the proper conduct of the proceedings. Recognising how a further stay would require GOSH to provide artificial ventilation when this had already been declared as not in Charlie’s best interests, the Supreme Court noted that

[w]e 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.<sup>23</sup>

The court nevertheless directed that Mr Justice Francis’ declaration be further stayed for three weeks until midnight on 10<sup>th</sup>/11<sup>th</sup> July 2017. This they did “with considerable hesitation,”<sup>24</sup> whilst urging the ECtHR to address the proposed application within that period, since they “would feel the gravest difficulty if asked to act yet further against Charlie’s best interests by directing an even longer extension of the stay.”<sup>25</sup>

- European Court of Human Rights<sup>26</sup>

Before the ECtHR, the parents complained both on their behalf and on Charlie’s behalf under Articles 2 and 5 of the ECHR. As regards Article 2, it was their argument that GOSH had blocked LST and that this constituted a violation of the positive obligation under the Article. This had resulted in Charlie being deprived of his liberty within the meaning of Article 5. They also put forward complaints on their own behalf under Articles 6 and 8. Their grievance as regards Article 6 related to how the Court of Appeal came to the conclusion that their intended parental decisions would cause Charlie “significant harm” without the benefit of witness evidence. As for the Article 8 violation, it was argued that the High Court’s declaration in April 2017 and other domestic courts’ decisions formed a disproportionate interference with their parental rights. By taking their decisions in Charlie’s best interests, rather than through an examination of whether there was a likelihood that Charlie was suffering or was likely to suffer significant harm, this constituted a disproportionate and unjustified interference with their parental rights under Article 8.

The parents did not provide reasons as to why the court should consider that they have standing to complain on Charlie’s behalf under Article 2. To make this finding on standing, the court had to therefore satisfy itself, using established criteria, that (a) there was a risk that Charlie, as the direct victim, would be deprived of effective protection of his rights; and (b) there was an absence of a conflict of interest between Charlie and his parents. As regards (a), the fact that Charlie had been and continued to be represented by a court-appointed guardian whose task it was to ensure that Charlie’s voice can be heard, led the court to the conclusion that the risk was minimised as far as possible. The court next considered (b) whether there was a conflict of interest between Charlie and the parents that would severely compromise the latter’s eligibility to make an application on Charlie’s behalf. Taking into consideration the “unambiguous and repeated findings”<sup>27</sup> of the domestic courts that the route they sought was not in Charlie’s best interests, the court concluded that this was a clear conflict of interest between the parents and Charlie. It was therefore held that the parents did not have standing to make an application under Article 2 in Charlie’s name and on his behalf.

The parents, on their own behalf, averred that GOSH had, through the domestic legal proceedings, blocked access to LST for Charlie. On this point concerning access to experimental treatment, Article 2 could not, according to the ECtHR, be interpreted as requiring access to unauthorised medicinal products for the terminally ill to be regulated in any particular way. This aspect of their complaint was therefore considered as manifestly ill-founded. Similarly for Article 5, whereupon the court pointed out that the availability of a domestic legal framework and the possibility to apply to the domestic courts, as creating the necessary safeguards regarding detention or deprivation of liberty. Hence, a claim under Article 5 was also considered as manifestly ill-founded.

As their Article 6 complaint related to how domestic courts arrived at their rulings, and this concerned an alleged interference in their private and family life, it was argued as a supplemental aspect of the parents’ Article 8 complaint. It was therefore examined under Article 8 alone. In the light of previous case law on similar matters, the court acknowledged that there was an interference in the parents’ Article 8 rights. Such an interference is a violation of the Article unless, pursuant to Article 8(2), it is in accordance with the law and is necessary in a democratic society. Considering the latter, the court opined

<sup>23</sup> *In the Matter of Charlie Gard* (19<sup>th</sup> June 2017), para. 17.

<sup>24</sup> *Ibidem*, para. 20.

<sup>25</sup> *Ibidem*.

<sup>26</sup> *Gard and Others v United Kingdom* (application number 39793/17).

<sup>27</sup> *Ibidem*, para. 67.

that the hospital should indeed approach the court when conflicts arise, and that the UK holds and engaged the appropriate legal framework. Rather than being arbitrary and disproportionate, domestic courts have been meticulous and thorough, heard and considered the opinions of numerous expert witnesses, had their decisions reviewed at 3 levels of jurisdiction and applied a test (namely the best interests test) which had been endorsed at domestic and international levels as the correct test in such cases. Their application on this ground was also thereby held to be manifestly ill-founded.

The ECtHR sat on 27<sup>th</sup> June 2017 and declared the application inadmissible the next day on 28<sup>th</sup> June 2017.

- High Court<sup>28</sup>

On 7<sup>th</sup> July 2017, the case returned to the High Court, upon the application of GOSH. The hospital asked the court to affirm the declarations it made on 11<sup>th</sup> April 2017 but to express them in the form of orders which would then be enforceable. This, the hospital felt, would provide the clarity which declarations do not hold.

Mr Justice Francis noted that the case had by then escalated to an international scale and had even involved prominent world leaders.<sup>29</sup> He observed that “[a] lot of things have been said, particularly in recent days, by those who know almost nothing about this case but who feel entitled to express opinions. Many opinions have been expressed based on feelings rather than facts.”<sup>30</sup> Although social media has, he opined, “very many benefits, one of its pitfalls is that when cases such as this go viral, the watching world feels entitled to express opinions, whether or not they are evidence-based.”<sup>31</sup>

This application was unopposed. According to Mr Justice Francis, [t]he parents have had to face the reality, almost impossible to contemplate; that Charlie is beyond any help even from experimental treatment and that it is in his best interests for him to be allowed to die. Given the consensus that now exists between parents, the treating doctors and even Dr Hirano, it is my very sad duty to confirm the declarations that I made in April this year, and I now formally do so. I do not make a mandatory order.<sup>32</sup>

He also renewed his recommendation that mediation be used in all such cases in the future even if the only thing to come out of it is a better understanding among the parties.<sup>33</sup>

Charlie died on 28<sup>th</sup> July 2017,<sup>34</sup> a few days before his first birthday.

### III. Alfie Evans

Alfie James Evans was born on 9<sup>th</sup> May 2016, i.e. three months before Charlie Gard. Like Charlie, he seemed healthy and well at birth. At two months old, however, he was referred to hospital for a “divergent squint.” Then, at four months old, during his first child development check with the General Practitioner, Alfie’s mother intimated that she had concerns about his general development. He was smiling less frequently; not interacting; and sleeping far longer than had seemed normal to the point where she would commonly had to wake him up. Furthermore, he showed little inclination to play with his toys. At six months, Alfie was clearly displaying significant developmental delay. He was assessed as functioning in a range appropriate to a six-week to a two-month old child. An MRI brain/spine scan performed on 30<sup>th</sup> November 2016 suggested either a degenerative or metabolic disorder. In December 2016, he was taken by his parents to the Accident and Emergency Department of the Aldey Hey Hospital after an episode of rhythmic jerking of all four limbs and his jaw, alongside a number of other problems. He was transferred to the Paediatric Intensive Care Unit (PICU), where he was observed as being profoundly encephalopathic/comatose and unresponsive to painful/uncomfortable stimulation. He was ventilator-dependent and it was clear that he had suffered abnormal loss of muscle control.

Further scans conducted in February 2017 and August 2017 showed that 70% of his brain had been destroyed. After this third scan, the hospital entered into discussion with Alfie’s parents and suggested that his treatment be limited including the insertion of “Do not resuscitate” in Alfie’s notes. Although the parents were initially receptive to these ideas, they subsequently changed their minds. Opinions from external experts were sought. These included doctors from Munich and the Bambino Gesù Hospital in Rome who travelled to the Alder Hey Hospital to examine Alfie. Whilst they agreed that Alfie had an untreatable and incurable neurodegenerative disease, they intimated that their hospitals were willing to treat Alfie at their premises.

Alder Hey Hospital issued an application to the High Court on 5<sup>th</sup> December 2017 for a declaration from the court that it was not in Alfie’s best interests to receive ongoing ventilatory support and that it was unlawful for this to continue. On 8<sup>th</sup> January 2018, a mediation meeting took place but it was reported that no agreement was achieved.

- High Court<sup>35</sup>

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<sup>28</sup> *Great Ormond Street Hospital v Yates, Gard & Gard* [2017] EWHC 1909 (Fam).

<sup>29</sup> *Ibidem*, para. 10.

<sup>30</sup> *Ibidem*, para. 1.

<sup>31</sup> *Ibidem*, para. 11.

<sup>32</sup> *Ibidem*, para. 14.

<sup>33</sup> *Ibidem*, para. 20.

<sup>34</sup> BBC News, “Charlie Gard Parents Announce Death of ‘Beautiful Boy’” (28<sup>th</sup> July 2017). <https://www.bbc.co.uk/news/uk-england-london-40752120> (accessed April 7, 2019).

<sup>35</sup> *Aldey Hey Children’s NHS Foundation Trust v Evans, James & Evans* [2018] EWHC 308 (Fam).

The case came before Mr Justice Hayden in the High Court in February 2018. The hospital's application was opposed by Alfie's parents, Tom Evans and Kate James, who insisted that ventilation should be continued for the purposes of transporting him by air ambulance to the Bambino Gesù hospital in Rome, and subsequently perhaps to a hospital in Munich. He was supposed to undergo a tracheostomy and a gastrostomy at one of these hospitals so as to enable ventilation to be given in a home environment (in one of these countries). If no improvement was to be registered after six months, they would accept the withdrawal of LST and Alfie would be allowed home to die.

As in the case of Charlie Gard, Alfie was represented by a guardian during the trial and the judge heard expert testimony from Alfie's treating clinicians, and external experts including those commissioned by his parents. The opinions offered were unanimous in that Alfie's brain condition was irreversible. However, unlike Charlie whose diagnosis had never been in any doubt, none of the doctors were able to offer a firm diagnosis for Alfie's condition.<sup>36</sup> There was nevertheless a consensus among all the doctors consulted that Alfie was suffering from a severe and progressive neurodegenerative disorder that was both catastrophic and untreatable.

Mr Justice Hayden visited him in hospital and ordered another scan during the hearing. This was conducted on 2<sup>nd</sup> February 2018. It revealed that nearly all of Alfie's brain had been destroyed. Fluid identical to water and cerebrospinal fluid (CSF) now replaced the damaged brain. The thalamus, which controls the stimuli to the most basic sensory functions, had completely disappeared leaving Alfie with no capacity to hear, see, smell, or respond to touch except only reflexively. His brain was only able to generate seizures. He was comatose and unaware of his surroundings. From a medical perspective, continuation of care was considered futile and although it was believed that he was unlikely to suffer pain, this possibility was not ruled out altogether.

In view of these, Mr Justice Hayden held on 20<sup>th</sup> February 2018 that it was no longer in Alfie's best interests to continue to be ventilated by it at the Alder Hey Hospital or elsewhere. He made a declaration that it was lawful and in Alfie's best interests for medical treatment and all forms of ventilation to be withdrawn so as to allow him to die in dignity. He was only to be given palliative care. The trip to Italy as suggested by the parents was found not to be compatible with Alfie's best interests. Apart from being burdensome, the journey risked rendering Alfie more vulnerable including to infection, and would compromise his anticonvulsant regime.

- Court of Appeal<sup>37</sup>

The parents immediately sought to overturn the High Court's decision. They put forward three grounds of appeal namely that the High Court had failed to:

- Properly weigh their views in the best interests decision, and that this constitutes a breach of Article 14 and Article 8 of the ECHR;
- Properly consider what would be an appropriate palliative care pathway and, more widely, how the consequences of the judgment were to be managed;
- Assess matters relevant to best interests or weigh up the available alternatives.

The Court of Appeal swiftly turned down Grounds 2 and 3. Re ground 2, this was because the court had received reassurance from the hospital that it would not act hastily in implementing any end of life plan for Alfie. Rather, it would provide the parents with the space and time to understand any proposed palliative care plan and allow them to contribute to its development. The court likewise turned down Ground 3 which alleged that Mr Justice Hayden should have given proper weight to the parents' alternative care plans when assessing Alfie's best interests. The fact that it was concluded, after hearing expert testimony and having assessed medical evidence, that it was not in Alfie's best interests to continue receiving ventilator support, meant that any alternative plans which involved the provision of a tracheostomy and gastrostomy, and being transported to another country (or other countries) could not possibly be in Alfie's best interests.

The Court nevertheless conceded that the parents' claim that the High Court's readiness to override parental choice in the absence of evidence of significant harm, breached Article 14 (read with Article 8) and deserved closer scrutiny. This Article states that:

the enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, associated with a national minority, property, birth or *other status*.

Relying on "other status," their legal team argued that it was wrong for parents to be treated differently depending on whether their application was pursued under care proceedings or the inherent jurisdiction – with the "significant harm" threshold applied to the former and "best interests" to the latter. These two proceedings were, it was claimed, appropriate

<sup>36</sup> It seemed that this was not known until after Alfie's death, where it was reported that he had been suffering from the extremely rare brain condition GABA-transaminase deficiency – see BBC News, "Alfie Evans Parents 'Feared' They Would Resent New Baby" (3<sup>rd</sup> September 2018). <https://www.bbc.co.uk/news/uk-england-merseyside-45402094> (accessed April 7, 2019).

<sup>37</sup> *Re E (A Child)* [2018] EWCA Civ 550.

comparators. Alfie's parents' situation should therefore be treated as analogous. This argument was nevertheless rejected by the Court of Appeal who opined that it was plainly wrong to put the two sets of proceedings on the same jurisdictional plane. The need to put the best interests of a sick child ahead of his parents' wishes serves as objective justification for differentiating between the two proceedings. For that reason, although permission to appeal was granted on ground 1, the appeal on that ground too was dismissed on 6<sup>th</sup> March 2018.

- Supreme Court<sup>38</sup>

The parents filed an application to appeal to the Supreme Court. It was their contention that it was wrong for the present issue to be determined solely by reference to the best interests test. Like the Gards, they were insistent that the matter should be considered by reference to whether their proposals for Alfie's future would cause him to suffer "significant harm." The courts have therefore, in their view, discriminated against their Article 8 right to respect for their family life, contrary to Article 14. The permission to appeal was refused by Lady Hale, Lord Kerr, and Lord Wilson.

The court confirmed that the child's "best interests" was indeed the "gold standard" for decision-making in this field and that this test was not only used in English Law but also used and supported internationally. To provide doctors with legal certainty, the court emphasised that the gold standard needed to apply to the present proceedings without qualification. It stressed that it is not lawful for doctors to provide medical treatment which is not in the child's best interests. On these bases, the Supreme Court reconfirmed on 20<sup>th</sup> March 2018 that it was not in Alfie's best interests for LST to be continued and for him to be transported by air ambulance to Italy.

- European Court of Human Rights<sup>39</sup>

Without delay, the parents brought the case before the ECtHR. However, both their applications for a recognition that their Articles 14 and 8 rights have been violated and for an interim measure under Rule 39 of the Rules of Court to stay the order of the domestic courts (allowing the withdrawal of LST) were rejected by the court on 23<sup>rd</sup> March 2018.

- High Court<sup>40</sup>

The case was brought back to the High Court soon after. This was upon the application of the Alder Hey Hospital who sought direction on how the order of the 20<sup>th</sup> February 2018 should be implemented. Following this application, Mr Justice Hayden endorsed the end of life care plan outlined by the hospital, which also met the approval of Alfie's guardian. This entailed the withdrawal of artificial ventilation and other treatment at a specified date and time, and for palliative care to take place at the Alder Hey Hospital itself.

This plan was rejected by Alfie's parents. They sought a writ of *habeas corpus* to release Alfie from hospital and made an application for further medical experts to be allowed access to Alfie's medical records. They argued that Alfie was being unlawfully detained at Alder Hey since the hospital refused to allow Alfie to be discharged and for his parents to remove him. As his parents, it was submitted that they have an unfettered right to make choices and exercise their right on their son's behalf. Their Article 5 right was violated by not being allowed to do so. Mr Justice Hayden nevertheless made clear that a writ of *habeas corpus* only applies to individuals who are unlawfully detained or whose civil liberties are compromised. It had no place in the present case since Alfie's liberty could not be said to have been compromised in light of his identified best interests. Mr Justice Hayden reiterated that none of the parents' alternative solutions, namely for Alfie to be taken to Italy and subsequently to Munich, cohere with Alfie's best interests. The application was therefore rejected on 11<sup>th</sup> April 2018 as being entirely misconceived.

- Court of Appeal<sup>41</sup>

The parents appealed to the Court of Appeal arguing that Mr Justice Hayden was wrong to apply the best interests test to an application for a writ of *habeas corpus*. It should instead have been determined by reference to whether there was any lawful basis for his alleged "detention" in hospital. To this, the Court of Appeal reemphasised how the parents' views and rights did not take precedence over Alfie's best interests. Where these were inconsistent with one another, Alfie's right came first. The

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<sup>38</sup> *In the Matter of Alfie Evans* (20<sup>th</sup> March 2018).

<sup>39</sup> *Evans v United Kingdom* (application no. 14238/18).

<sup>40</sup> *Alder Hey Children's NHS Foundation Trust v Evans, James & Evans* [2018] EWHC 818 (Fam).

<sup>41</sup> *Evans & James v Alder Hey Children's NHS Foundation Trust & Alfie Evans* [2018] EWCA Civ 805.

court expressly agreed with Mr Justice Hayden that the application for a writ of *habeas corpus* was misconceived. There was no basis, it held, for claiming that there was a deprivation of liberty. For it to be so, there had to be a detention, and that this must have been unlawful. Since legal precedents show that restrictions that result from the administration of medical treatment do not amount to a deprivation of liberty,<sup>42</sup> Alfie could not be said to have been deprived of his liberty, either with reference to Article 5 or the doctrine of *habeas corpus*. Even if there was a deprivation of liberty, it would clearly be lawful since the existing and proposed end of life plan at the Alder Hey Hospital was in Alfie's best interests whereas the same could not be said for the proposed transfer to Italy or elsewhere. Re-endorsing the best interests test as the gold standard, the appeal was dismissed on 16<sup>th</sup> April 2018.

- Supreme Court<sup>43</sup>

The parents at once sought permission to appeal the Court of Appeal's ruling. The Supreme Court nevertheless stressed that inasmuch as the parents did not have the right to determine Alfie's future medical treatment, they were also not able to remove Alfie from the Alder Hey Hospital for the purpose of taking him to another country when this was not without risks and could be detrimental to him. In this respect, the court stated that English Law is no different to the ECHR or to the law of the European Union.

Their complaint at this stage was that Alfie was deprived of his liberty in contravention of Article 5 of the ECHR. However, the court was of the opinion that someone who is not able to move by virtue of interventions that are taken in intensive care to keep him alive, is not being deprived of his liberty within the meaning of the Article. It seriously questioned whether an infant incapable of staying alive without mechanical ventilation and clinically assisted nutrition and hydration as provided to Alfie, could be said to have been deprived of his liberty. Further, it had hitherto been determined that it was not in Alfie's best interests to stay at the Alder Hey Hospital and continue to be kept alive, nor to travel abroad for the same purpose. It was thereby unlawful to continue to detain him for the purpose of being kept alive artificially whether in the UK or abroad. The freedom or release that Alfie was entitled to, was release from the imposition of medical procedures which were not in his best interests. By refusing the permission to appeal on the 20<sup>th</sup> April 2018, the Supreme Court also refused any further stay of the Court of Appeal's order, thereby freeing the hospital to act in Alfie's best interests.

- European Court of Human Rights<sup>44</sup>

On the very same day as the Supreme Court's ruling, the parents requested for an interim measure under Rule 39 for a stay on the withdrawal of Alfie's LST. They also argued that preventing Alfie to be transferred from the Alder Hey Hospital amounted to a deprivation of liberty contrary to their Article 5 rights. Both requests were rejected by the ECtHR who ruled the parents' application inadmissible on the 23<sup>rd</sup> April 2018.<sup>45</sup>

Alfie was thereby disconnected from artificial ventilation at 9.45pm on Monday 23<sup>rd</sup> April 2018.

- High Court<sup>46</sup>

As it happened, Alfie did not die immediately and continued to breathe unaided. After being in this condition for 20 hours, his parents brought the case back to the High Court on 24<sup>th</sup> April 2018. Alfie had, by then, seemed to have been conferred Italian citizenship.<sup>47</sup> Owing to this, and in view of his continued ability to breathe independently, the parents asked for the February declaration to be set aside and for the court to make ancillary orders that would allow Alfie to be taken immediately to Italy. The logistics for his transportation to Italy had been planned out. They argued that the availability of an alternative that would not lead to his immediate death should now be viewed as being in Alfie's best interests. This request was dismissed by Mr Justice Hayden on the same day, pointing out that in actual fact, there had been no significant change in Alfie's condition. While his brain stem was alive and sustained his respiration, the substantive part of his brain had disintegrated. He therefore rejected the parents' claim that Alfie's condition was better than originally contemplated by the medical team to justify a reconsideration of the order of 20<sup>th</sup> February 2018.

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<sup>42</sup> E.g. *Nielsen v Denmark* (application number 10929/84/84); *R(Ferreira) v HM Senior Coroner for Inner South London* [2017] EWCA Civ 31.

<sup>43</sup> *In the Matter of Alfie Evans No. 2* (20<sup>th</sup> April 2018).

<sup>44</sup> *Evans v the United Kingdom* (application no. 18770/18).

<sup>45</sup> *Ibidem*.

<sup>46</sup> *Alder Hey Children's NHS Foundation Trust v Evans, James & Evans* [2018] EWHC 953 (Fam).

<sup>47</sup> "Alfie Evans Granted Italian Citizenship," *Catholic Herald*, 23<sup>rd</sup> April 2018.

- Court of Appeal<sup>48</sup>

An application to appeal the decision was instantaneously lodged. The parents were still emphatic that their alternative plan, which would not result in Alfie's imminent death, should be deemed as being in his best interests. Represented by separate legal teams, they each presented their own grounds of appeal. The father's appeal was predicated on events that accompanied Alfie's removal from artificial ventilation, i.e. the fact that Alfie had by then continued to breathe unaided for around 42 hours represented a change in the circumstances that justified having the order of 20<sup>th</sup> February set aside. This was turned down by the Court of Appeal, according to whom expert testimony had confirmed that a period of life post-removal of ventilation was to be expected, the length of which could not be predicted with certainty. Further, not only would the alternative plan proposed not have any prospect of success, the journey abroad would expose Alfie to further epileptic seizures and deterioration of his neurological facility.

Alfie's mother, in the meantime, appealed on the grounds that their right of free movement within the European Union to access medical services from another member state (Italy) had been violated, and that the best interests test should be eroded or adapted in such cases. However, these arguments too were turned down by the court. It was pointed out that there can be no derogation from the application of the gold standard in these cases. Hence, if it was concluded in the home state by the home court that it was in Alfie's best interests to be allowed to die, another state did not have jurisdiction to come up with a conflicting decision on what was best for the patient. Her legal team also put forward the arguments that Mr Justice Hayden erred in holding that new medical evidence was not needed and that the original hearing did not consider the likelihood of Alfie surviving the extubation process. Both of these grounds were also held to be without merit as no application was made before the judge to direct any further medical evidence, and the argument that he survived the extubation was erroneous as considered previously when dealing with the father's arguments on this point. Her final ground of appeal was that, by imposing a course of action on an Italian citizen, this would amount to a criminal offence against Italian law, and could lead to extradition and prosecution of the clinical staff for the part they played in carrying out the judge's order. This ground of appeal too failed. The only relevant consideration, according to the Court of Appeal, was Alfie's best interests. The impact of that decision on healthcare professionals was not a matter which courts could take into consideration. Permission to appeal was therefore refused on 25<sup>th</sup> April 2018.

Alfie passed away 3 days later on 28<sup>th</sup> April 2018, two weeks before his second birthday.

#### IV. The Shape of Things to Come?

Charlie's and Alfie's stories were followed by many in the UK and around the world.<sup>49</sup> This was at a rate rarely seen for medical law cases. Public opinion was, and remains, divided over who should decide their fates.<sup>50</sup> When reflecting on the potential implications of their medico-legal journeys, the following trends can be identified.

In the parents' determination to leave no stone unturned,<sup>51</sup> the courts were turned to in rapid succession particularly in the case Alfie Evans. But is the courtroom the appropriate forum for such conflicts?<sup>52</sup> Was it instead over-used or even misused?<sup>53</sup> Should mediation be deployed as recommended by Mr Justice Francis in *Gard*? But how well would this alternative method of dispute resolution work for medical futility conflicts bearing in mind that it has reportedly been used in *Evans*,<sup>54</sup> yet the case still resulted in a long-running and acrimonious legal battle?

Further, several creative arguments were put forward during the protracted trials, the most recurrent of which was the preferability or alleged superiority of the "significant harm" test over the long-established "best interests" test. Although these were ultimately defeated in the two cases, the sustainability and fairness of the best interests test continue to be challenged today not least through the Gards' proposal for a *Charlie's Law* which aims to, among other things, protect parental rights by confining judicial powers only to cases where there is a risk of significant harm to the infant.<sup>55</sup> However, should parents have the last word on care?<sup>56</sup>

Their stories also illustrated a real potential for the antagonism from the courtroom battles to spill out into, and be played out in, the public arena. That this was also able to transcend geographical boundaries and gain a momentum of its own was attributable in no small measure to the power of social media.<sup>57</sup> Apart from engaging in a parallel process of "trial by

<sup>48</sup> *Evans & James v Alder Hey Children's NHS Foundation Trust & Evans* [2018] EWCA 984 (Civ).

<sup>49</sup> D. Wilkinson, J. Savulescu, "Alfie Evans and Charlie Gard – Should the Law Change?: Professionals and Families Need to Work Together" *British Medical Journal* 361 (2018): k1891, doi:10.1136/bmj.k1891.

<sup>50</sup> G. D. Coleman, "My Name was Charlie Gard" *Ethics and Medicine* 42:11 (2017): 1-4, at 1.

<sup>51</sup> *Alder Hey Children's NHS Foundation Trust* (n 40), para. 2.

<sup>52</sup> L. Austin, "UK Processes for Resolution of Disagreements About the Care of Critically Ill Children" (London: Nuffield Council on Bioethics, September 2018), 16-20.

<sup>53</sup> T. M. Pope, "Guest Editorial: Charlie Gard's Five Months in Court: Better Dispute Resolution Mechanisms for Medical Futility Disputes," *Journal of Medical Ethics* 44:7 (2018): 436-437. I. Freckleton, "Responding Better to Desperate Parents: Warnings from the Alfie Evans Saga," *Journal of Law and Medicine* 25:4 (2018): 899-918.

<sup>54</sup> *Re E (A Child)* (n 37), at para. 113.

<sup>55</sup> Charlie Gard Foundation, "Charlie's Law." <https://www.thecharliegardsfoundation.org/charlies-law/> (accessed March 31, 2019).

<sup>56</sup> A. Caplan, K. McBride Folkers, "Charlie Gard and the Limits of Parental Authority," *Hastings Center Report* (2017), 15-16, at 15.

<sup>57</sup> B. J. Richards, "Social Media: The Unnamed Plaintiff," *Journal of Bioethical Inquiry* 15:3 (2018): 309-312, at 309.

public opinion,”<sup>58</sup> parties external to the courtroom proceedings offered practical assistance including moral support, suggestions of external doctors to contact and of alternative treatments, and monetary contributions particularly through crowdfunding.<sup>59</sup> There were also more explicit interventions like the offers of free medical treatment abroad, flight and accommodation, and even, extraordinarily, the conferral of foreign citizenship. These resulted in the judiciary unusually commenting on events outside the courtroom in their judgments. Apart from the aforementioned comment by Mr Justice Francis in *Gard* regarding interferences from politicians and people who were not sufficiently acquainted with the medical evidence, there were at least four others articulated in the *Evans* case. In a postscript, the Court of Appeal recorded its condemnation of the clandestine manner in which Alfie was examined by a few foreign doctors, recommended by supporters, who were brought into the PICU by the parents without the permission of the court nor preceded by any consultation or approval by the treating team.<sup>60</sup> Apart from being in contravention of section 13 of the Children and Families Act 2014,<sup>61</sup> the judges observed that “a line has plainly been crossed, with such behaviour being wholly unacceptable.”<sup>62</sup> The third time the case came before the High Court, Mr Justice Hayden expressed dismay that many videos of Alfie had been posted online by his father. Whilst recognising the desperation that drove the act, the judge remarked that these videos severely compromised Alfie’s dignity and privacy.<sup>63</sup> The second time the case went before the Court of Appeal, the court recorded its disapproval and concern that supporters had blocked hospital staff from getting into the hospital which in turn compromised the sense of safety of staff, as well as other patients and their families. A group of supporters also marched into the PICU to the concern of staff.<sup>64</sup> Lord Justice McFarlane, the third time the case came before the Court of Appeal, censured the involvement of legally qualified but non-practising lawyers who provided legal advice to, and drafted some of the grounds of appeal for, the parents, as introducing “a darker side to what was otherwise valuable support.”<sup>65</sup>

Interestingly, but perhaps worryingly, these general trends may signal how medical futility conflicts involving infants would be contested in the future.

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<sup>58</sup> N. Hammond-Browning, “When Doctors and Parents Don’t Agree: The Story of Charlie Gard,” *Journal of Bioethical Inquiry* 14:4 (2017): 461-468, at 466.

<sup>59</sup> See GoFundMe at <https://www.gofundme.com/please-help-to-save-charlies-life>.

<sup>60</sup> *Re E (A Child)* (n 37), paragraphs 133-137.

<sup>61</sup> *Ibidem*, para. 143.

<sup>62</sup> *Ibidem*, para. 144.

<sup>63</sup> *Alder Hey Children’s NHS Foundation Trust* (n 46), para. 2.

<sup>64</sup> *Evans & James* (n 41), para. 66. Similar incidents took place in the *Gard* case whereby abusive messages, including death threats, were hurled online and on the street towards staff at the treating hospital - see A. Rimmer, “Charlie Gard’s Parents End Legal Fight to Keep Son Alive,” *British Medical Journal* 358 (2017): j3589, doi:10.1136/bmj.j3589.

<sup>65</sup> *Evans & James* (n 48), para. 39.