

Charlie Gard, the sick baby hospital doctors want to disconnect. Our medical and ethical assesement



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BIOETHICS / COMA PATIENTS / ETHICS OF SCIENTIFIC RESEARCH / HUMAN DISABILITY / MEDICAL DEONTOLOGY/ PALLIATIVE CARE / SPECIAL REPORTS

He and his parents await the Judge's decision regarding the possibility of withdrawing or not the life support who keep him alive and the possibility of receiving an experimental treatment in the United States



Medical aspects

Charlie was born on 4 August 2016. In October the same year, he was admitted to *Great Osmond Street Hospital (GOSH-NHS)* in London, and diagnosed with a disease that affects mitochondrial function, called mitochondrial DNA depletion syndrome (MDDS). This means that he cannot obtain sufficient energy for his muscles, kidneys, brain and other organs, which causes progressive muscle weakness and brain damage.

Although there seemed to be no specific treatment for the mitochondrial abnormality at that time, in January 2017, his mother became aware of an experimental treatment using nucleosides that was

being evaluated in the United States in patients with a disease similar to Charlie's. Consequently, his parents assessed the possibility of taking him to the US for treatment because, according to them, it might improve their son's health by at least 10%.

At the same time, British newspaper "**The Guardian**" announced that the US Hospital that had the medication offered to ship it so that Charlie could be treated immediately, but GOSH (NHS hospital) disagreed, proposing instead *to withdraw the child's respiratory support*.

In effect, *New York-Presbyterian Hospital* and *Irving Medical Center*, also in New York, published a statement saying that they were willing to admit and clinically evaluate Charlie, as they had **FDA approval for the use of an experimental treatment using nucleosides**. They also offered to send the experimental drug to GOSH, where Charlie is currently being cared for; in turn, they promised to collaborate with the doctors at the London hospital to facilitate their use of this novel treatment.

A similar case with a happy ending: Arturito

On 12 April this year, British newspaper "**The Sun**" published the story of Arthur and Olga Estopinan, parents of Arturito, a child with a disease similar to that of Charlie Gard.

Arturito, who is now 6 years old, was the first person in the US to receive the experimental nucleoside therapy, the same therapy that Charlie's parents, Connie Yates and Chris Gard, want their son to have.

This type of treatment, known as "compassionate" therapy, is a therapeutic alternative in cases in which there are no approved and tested treatments. Although they do not have sufficiently proven efficacy, nor can their undesirable effects be established with certainty, these therapies are a last hope in the approach to the treatment of these diseases.

"We feel very fortunate to be American and not British – because if we lived in the UK Arturito would surely be dead by now," declared Arthur. "My son has been on a respirator for 5 years. He couldn't move anything, only his eyes. Now he can move his hands, feet and fingers, he's a happy boy".

Arturito has TK2 mitochondrial DNA depletion syndrome, a rare genetic disease that causes muscle weakness. But Charlie's disease, known as RRM2B, is even more rare, with only 16 known cases worldwide. Despite this, American doctors, Arturito's parents and Charlie's parents believe that nucleoside treatment is an option. Connie and Chris say that "this is why we have continued our fight. All we've ever wanted is that chance for Charlie to try these drugs. Charlie will die anyway so we have nothing to lose."

However, according to doctors at the hospital, Charlie has severe irreversible brain damage, which it seems would not be reversed by nucleoside therapy. Furthermore, he has congenital deafness and a severe epilepsy disorder. His heart, liver and kidneys are also affected, although not severely. For this reason, the Supreme Court has determined, in agreement with doctors at GOSH (NHS hospital), that since *the child is in the terminal stages of his disease*, it would be "futile" and "not in Charlie's best interests" to subject him to nucleoside treatment (see **NHS official statement [HERE](#)**).

Charlie Gards parents hopes and their medical arguments

Nonetheless, Charlie's parents believe that there is hope for their son, hope that has been reinforced by what has been publicly stated by an international team of doctors, who claim to have evidence that an experimental treatment could have a positive effect on little Charlie's health. In their report, *they suggest that there is evidence that nucleoside therapy applied in vitro on human cells with mutations in RRM2B – the same as Charlie has in his mitochondria – could cross the blood-brain barrier, so it might also improve the brain damage suffered by the child*. Finally, they claim that there is strong evidence in mice and patients with TK2 deficiency – Arturito's disease – that the therapy produces "dramatic clinical improvements" (see **[HERE](#)**).² According to the letter, the letter is signed by a neurologist and a research fellow at Rome Children's Hospital, a scientist from Cambridge University's Mitochondrial Biology Unit and two investigators from **Vall d'Hebron Institut de Recerca in Barcelona**.

Legal aspects

On 3 March, bosses at GOSH wrote to Mr. Justice Francis, in charge of the case, asking him to withdraw the therapeutic support that Charlie was receiving, i.e. to withdraw assisted mechanical ventilation.

On 11 April, the same judge told doctors that they could withdraw the therapeutic measures keeping the child alive, after analysing the case at a hearing in the Family Division of the High Court in London. This meant that the life support could be withdrawn and the child moved to a palliative care regimen, all in the best interests of the patient.

- On 3 May, in the light of Mr Justice Francis's decision, Charlie's parents asked the Court of Appeal to reconsider the case.
- On 23 May, after assessing the case, three Court of Appeal judges rejected the parents' request.
- 8 June, the Supreme Court also rejected the parents' appeal.
- 11 June, judges at the European Court of Human Rights assessed the case, after lawyers representing Charlie and his parents sent written reports on the matter. The Court's spokesperson said that they would prioritise the case in light of the exceptional circumstances and the maximum urgency for its resolution.

- 27 June, they rejected the proposal, which seemed to be the end of this complex legal process
- 7 July, Mr Justice Francis, after being given new evidence by representatives of **Great Osmond Street Hospital**, asked the High Court to review the case, so its resolution was delayed until 10 July.

That day, the judge asked Charlie's parents to provide new evidence proving that nucleoside treatment might be effective for the child. As a result, the decision was postponed until 2 pm on Wednesday 12 July, in order to have time to evaluate the fresh information that was coming, and to have better grounds for his verdict; the judge also declared that the child's parents had to convince him that "something new or dramatic had changed" (**The Telegraph**).

Notwithstanding, after reviewing the case, doctors at GOSH say that nucleoside therapy is unjustified, and that the proposed treatment will not cure the baby. Likewise, lawyers from the NHS London hospital say that the information on the experimental treatment was already assessed in the previous verdict in April and that there is now no reason to dismiss what was concluded at that time, which was **to withdraw the child's life support** (**LifeNews.com 10-07-2017**).

Against this, however, lawyers for the family claim that there is a new chance of brain recovery, so in their opinion, it should be attempted. Charlie's parents also say that it has not been medically proven that their son's brain is "*catastrophically damaged*", although doctors treating him say that he has "severe and irreversible damage".

International repercussions

In relation to this, on 28 June, the *Catholic Bishops' Conference of England and Wales* opposed the withdrawal of assisted ventilation, as well as nutrition and hydration, from Charlie, claiming that these measures are not part of his treatment, but rather constitute his basic care.

Moreover, **Monsignor Vincenzo Paglia**, President of the Pontifical Academy for Life published a statement on 29 June, in which he stated that "the interests of the patient must be paramount, but we must also accept the limits of medicine and [...] avoid aggressive medical procedures that are disproportionate". In his intervention, Monsignor Paglia joined the bishops of England and Wales, adding that "we should never act with the deliberate intention to end a human life, including the removal of nutrition and hydration". At the same time, he added that "we have to recognise the limitations of what can be done, while always acting humanely in the service of the sick person until the time of natural death occurs". Based on John Paul II's encyclical letter "**Evangelium vitae**", on "the value and inviolability of human life", Monsignor Paglia restates that "all aggressive medical procedures that are disproportionate must be avoided" and that "the wishes of parents must be heard and respected". Several members of the **Pontifical Academy for Life** have also spoken along the same lines (see **HERE**)

In relation to this, on 2 July, the **Holy See** <https://w2.vatican.va/content/vatican/it.html> published a statement from **Pope Francis** (see **HERE**), where he expressed his opinion of the case and asked that the right of the parents to accompany their child to the end be respected. "The Holy Father follows with affection and commotion the situation of Charlie Gard," said Greg Burke, director of the Holy See's Press Office, "and expresses his own closeness to his parents."

Additionally, the *Bambino Gesù* paediatric hospital in Rome, the so-called Pope's hospital, has offered to care for the British baby, but according to its director, **Mariella Enoc**, in statements on Vatican Radio, unfortunately, "for legal reasons, we cannot transfer him". "This is sad news", she added. The director of the hospital explained that she had spoken with the child's mother, who is "very determined to fight until the end", and that she has asked her to verify whether there is a cure for the little boy, something which scientists at the Roman hospital are doing.

United States president **Donald Trump** has also offered to help Charlie Gard's parents. In this respect, **Helen Ferré**, one of the members of the Trump administration, has assured that the US president "has offered to help the family in this heartbreaking situation", in view of the possibility of transferring the baby to the United States to receive treatment there. Ferré acknowledges that the president has not spoken directly to the family because "he does not want to pressure them in any way", and that "he is just trying to be helpful if at all possible", but that members of his administration have spoken with them. Furthermore, these conversations have been facilitated by the British government

Ethical aspects

About the withdraw the child's life support and the possibility of an experimental treatment

The **Anscombe Bioethics Centre**, a Catholic bioethics institute for the United Kingdom and Ireland based in Oxford, considers that not transferring the baby to America may be a reasonable and ethical decision, and that it is not mandatory to initiate burdensome, dangerous or disproportionate medical treatment; at the same time, it recognises flaws in the UK court ruling which denied his parents their request to continue Charlie's medical treatment. They affirm, "*However, the final decisions in this case, which are to withdraw artificial respiration and not to seek experimental treatment, are decisions that the child's parents in this situation could take on behalf of their son, since the decisions themselves are morally defensible.*"

In the opinion of *Julian Savulescu*, professor of Practical Ethics at the University of Oxford, and *Peter Singer*, an Australian philosopher (see **HERE**), Charlie should have been allowed to go the United States to receive the experimental treatment in January 2017, when the possibility of using it was first considered. According to these authors, this is not a religious opinion or an argument based on compassion, but rather a well founded ethical argument.

Savulescu himself, responding to a comment by Manuel Zunin (see **HERE**), a member of our Bioethics Observatory, says that "the case for reconsidering Charlie's situation is even stronger now that seven of the world's experts in nucleoside replacement therapy have presented new evidence and petitioned Great Ormond St to review the case." He continues that "It is very hard to argue that someone would be better off dead, especially when there is an intervention that offers the chance of improving their life". Therefore, he insists that "giving Charlie a new opportunity by going to the US for 3-month nucleoside treatment is a promising practice, and this hope should be implemented long enough for it to be known before the Supreme Court issues its verdict".

Our assessment

In our opinion, the first aspect to consider from a bioethical point of view is whether it is correct to stop Charlie's life support, as the doctors at GOSH - NHS and the High Court have proposed.

Our opinion is that withdrawing life support, such as assisted mechanical ventilation, would only be ethically valid in the case of imminent risk of death and existence of well proven intense suffering. However, in this specific case, we do not believe there is an immediate risk of death, since the child has been ill for more than 8 months and is still living; the possibility has even been raised of sending him to the United States to undergo an experimental treatment, so if mechanical ventilation were withdrawn, we believe that this could be described as an objectively euthanasic act.

In addition, if the artificial ventilation is withdrawn, food and hydration would have to be continued, basic actions that, together with hygiene, cannot be discontinued in any patient, regardless of their situation.

We also share the opinion of *Savulescu* and *Singer*, when they say that there may also have been some medical malpractice, as the possibility of applying the experimental nucleoside treatment was not considered in January, *when the disease had already been clearly diagnosed and the use of this experimental treatment in the US was known.*

Similarly, from an ethical point of view, we must consider whether the autonomy of the parents is being violated by GOSH – NHS and the English High Court, by *denying them the right to decide how to act in the illness of their child*, by virtue of a *utilitarian principle founded on probabilistic calculations*, also taking into account that the parents demand their autonomy in favour of life and the welfare of their child. In this respect, lawyers for Charlie's family say that the **NHS hospital is violating several articles of the European Convention on Human Rights, such as the right to life, freedom, and private and family life.**

We, therefore, believe that the decision of the Supreme Court to withdraw artificial respiration and give Charlie a new chance for life should be postponed, owing to the possibility that he may undergo experimental nucleoside treatment as discussed, which is what seems to have been assumed by the High Court by delaying its decision.

See Ashya King case ([HERE](#)) we think both cases have in common the infringement patient autonomy by NHS hospitals.



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