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## Update on Charlie Gard

19 June 2017

**A spokesperson for Great Ormond Street Hospital for Children NHS Foundation Trust said: "Great Ormond Street Hospital notes the ruling of the Supreme Court and the request of the European Court of Human Rights and we continue to provide the highest possible standard of care for Charlie Gard, working closely with his parents."**



**The Supreme Court ordered that Charlie Gard should continue to receive treatment until midnight on 10 July 2017, or until such earlier date as the European Court of Human Rights determines the application by Charlie Gard's parents.**

**Following the Supreme Court ruling on Thursday 8 June 2017, a spokesperson for Great Ormond Street Hospital NHS Foundation Trust said:**

"This is a very sad day for Charlie's parents and family and our thoughts are with them and Charlie.

It is never easy when medical and judicial opinion goes against the wishes of the parents but our first responsibility at Great Ormond Street Hospital remains to put the interests of the child first and foremost. It is also hugely difficult for any clinically-trained professional to be asked to treat a child who has no chance of survival or even improvement in their quality of life.

We are led by the legal process and when the time comes for a change in treatment, we will support the parents in every way that we can, aiding them through next steps. This would normally take place over at least a number of days.

For now, our priority is to ensure Charlie remains well cared for and to offer our support to Charlie's devoted parents at this distressing time."

[Frequently Asked Questions \(FAQs\) about the Charlie Gard court case](#)

### Background

**Information drawn from the judgment delivered by Mr Justice Francis in the High Court of Justice Family Division on Tuesday 11 April 2017**

#### Charlie's condition:

- Charlie's condition is exceptionally rare. He suffers from an inherited mitochondrial disease called infantile onset encephalomyopathic mitochondrial DNA depletion syndrome, referred to generally as "MDDS". He suffers specifically from the RRM2B mutation of MDDS.
- In Charlie's case, his brain, muscle and ability to breathe are all severely affected. In addition, he has congenital deafness and a severe epilepsy disorder. His heart, liver and kidneys are also affected but not severely.

- Charlie has severe progressive muscle weakness and cannot move his arms or legs or breathe unaided. No one can be certain whether or not Charlie feels pain.
- One of the leading experts in the world with a special interest in mitochondrial diseases has concluded that Charlie has infantile onset RRM2B deficiency which is the most severe form.

### Possible treatment

- Charlie's parents have applied to take him to the United States for nucleoside therapy treatment. The doctor in the United States has not had the opportunity of examining Charlie but, based on the medical information available to him, has acknowledged that he thinks Charlie "is in the terminal stage of his illness".
- Great Ormond Street Hospital did apply for ethical permission to attempt nucleoside therapy on Charlie - a treatment that has never been used on patients with this form of MDDS. By the time that decision was made, Charlie's condition had greatly worsened and the view was that his epileptic encephalopathy was such that his brain damage was severe and irreversible that treatment was potentially painful but incapable of achieving anything positive for him.
- Nucleoside therapy has been referred to as "pioneering treatment". In fact, this type of treatment has not even reached the experimental stage on mice let alone been tried on humans with this particular strain of MDDS.
- It is the view of all those who have treated and been consulted in relation to Charlie such treatment would be "futile". This was specifically stated by the Judge who adjudicated in the High Court Trial, Mr Justice Francis, that the treatment: "would be of no effect but may well cause pain, suffering and distress to Charlie."
- Ms Butler-Cole, who represented the Guardian appointed to legally represent Charlie in court, stated in her closing submissions that:  
"The Guardian has listened closely to the oral evidence during the hearing this week and has concluded that it is not in Charlie's best interests to travel to America to receive nucleoside therapy. This is not pioneering or lifesaving treatment, but a purely experimental process with no real prospect of improving Charlie's condition or quality of life."
- The Guardian's view is that it cannot be in Charlie's best interests to subject to him to experimentation and the pain that this will cause in circumstances where there is no prospect of benefit.
- The Judge in the High Court trial concluded:  
"The prospect of the nucleoside treatment having any benefit is as close to zero as makes no difference. In other words, as I have already said, it is futile."  
"In my judgment, it is putting it far too high to say that there is an available treatment with potential materially to improve Charlie's quality of life."
- He also added:  
"There is a consensus from all of the consultants and doctors who have examined Charlie that nucleoside treatment is futile."

[Access full judgment information from Tuesday 11 April 2017.](#)

## Contact Information

For further information please contact the GOSH-ICH Press Office on 020 7239 3039.

For genuine and urgent out-of-hours queries call switchboard on 020 7405 9200.

## Notes to Editors

Great Ormond Street Hospital for Children NHS Trust is the country's leading centre for treating sick children, with the widest range of specialists under one roof.

With the UCL Great Ormond Street Institute of Child Health, we are the largest centre for paediatric research outside the US and play a key role in training children's health specialists for the future.

## Supreme Court update on Charlie Gard



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