Today’s piece was prepared by Brian Marcus, MD, based on a NY Times article [British Court Decides Charlie Gard Will Be Moved to a Hospice to Die](https://www.nytimes.com/2017/07/27/world/europe/uk-charlie-gard-baby-parents.html?_r=0)

Charlie Gard was born August 4, 2016 a normal healthy boy, but by October 2016 he presents to his pediatrician with failure to thrive. Within days Charlie's intubated; by Dec 2016 has had permanent brain damage from recurrent seizes and is diagnosed with Mitochondrial DNA depletion syndrome from two RRM2B mutations. Charlie's doctors explore experimental treatment but submit to the court to withdraw care by February 2017. The court sides with the hospital, but the parents appeal. An MRI scan becomes publically revealed in July in court and the parents soon thereafter withdraw their appeal to continue care. The battle continues; however, the parents appeal to the hospital to bring Charlie home. The hospital refuses, citing the ventilator required would not fit through the door. That said, a few days later, both sides agree for Charlie to be transferred to hospice. Charlie dies within a few days.

While emphasizing hope, note the paucity of facts related to Charlie's medical condition and current clinical state. This article and many throughout the course of the past year portray parents fighting for their son's life against a heartless hospital. However, it is curious as to how these articles would read if they began with Charlie's clinical condition and a description of the natural history of RRM2B mutations: 15 known cases that presented with profound disease in the first few months of life with hypotonia, lactic acidosis, failure to thrive, and tubulopathy. From there the disease progressed rapidly with death within a few months.

Charlie Gard's story from the beginning always presented two sides of the argument, hopeful parents vs faceless hospital; however, Charlie's perspective always seemed to be missing. What was Charlie's quality of life and what would have been best for him?

**RESOURCE FOR FAMILIES ON BEREAVEMENT:**

[Babyloss](http://www.babyloss.com/) *Informational and support group for those affected by the death of a baby during pregnancy, birth, or shortly afterwards*

Reference Article: Mitochondrial DNA depletion syndromes – Many genes, common mechanisms. [Suomalainen A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Suomalainen%20A%5BAuthor%5D&cauthor=true&cauthor_uid=20444604), [Isohanni P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Isohanni%20P%5BAuthor%5D&cauthor=true&cauthor_uid=20444604).[Neuromuscul Disord.](https://www.ncbi.nlm.nih.gov/pubmed/20444604) 2010 Jul;20(7):429-37. doi: 10.1016/j.nmd.2010.03.017. Epub 2010 May 4.

And that’s today’s Developmental & Behavioral Pediatrics: IN THE NEWS!