

Case Study – Genetic Testing Ethics

Mother Refuses Genetic Testing



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Bioethics case study on genetic testing.

Emma is a five-year-old girl who was admitted for aggressive seizures, neuro storming and palliative care. She has had an extremely difficult life due to severe medical conditions, possibly resulting from injuries sustained at birth.

Emma has never been able to gain consciousness, open her eyes, or engage with her family. She has experienced uncontrollable seizures throughout her life, and her health has been in a continuous decline. Her mother has frequently returned to the hospital for admissions. While her prognosis has always been grim, this admission appears to be her last. Emma's mother has requested palliative care to make her as comfortable as possible.

The situation is further complicated by a legal issue. Emma's mother is currently in the process of filing a malpractice lawsuit against the hospital. This has created a tense environment, with hospital staff hesitant to engage with her.

Yesterday, the hospital geneticist discussed the possibility that Emma's medical conditions may not be the result of a birth injury but rather a genetic condition. If this is the case, there are therapies that could help treat Emma, though these would be palliative and not curative. While it is unlikely that a genetic condition is the cause, it remains a possibility.

The geneticist asked Emma's mother if the hospital could conduct a genetic test. Initially, Emma's mother agreed. However, after consulting with her attorney, she later informed the hospital that she would refuse the genetic test.

Ethics is consulted.