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Couple fight on for genetically selected baby



A perfect tissue match is needed for Charlie Whitaker

An American fertility clinic says it's in talks with the parents of three year old Charlie Whitaker who suffers from a rare blood disorder.

The couple Michelle and Jayson Whitaker have been refused IVF treatment in Britain - they want to have a genetically selected baby to help to treat Charlie.

• **This morning Breakfast spoke to Jayson Whitaker, he confirmed that he and his wife were considering going to the US as time was running out for treatment for Charlie's condition**

“

We feel the decision is absolutely terrible and don't know why they have said no. We want to give Charlie a normal life.

We can appeal but that takes time and we don't have the time to do that. We can have more children and hope for a match - we can go abroad or keep trying for a baby. Average life expectancy for Charlie is somewhere around 30 ”

• **Breakfast also spoke to Dr Yury Verlinsky, the Chicago based fertility doctor who is talking to the Whitaker family. He says there is a very good chance of success:**

“We can select the embryo free of disease and match with the sick sibling. When the baby is born the blood can be used for the sick child with case like this we've had good success. I cannot judge the decision of the HFEA but they have allowed similar procedures. ”



"We have had success"

• **Also on Breakfast; Josephine Quintavalle from the pro-life pressure group Comment on Reproductive Ethics, she said:**

“The help given to Charlie must be ethically acceptable. I think the HFEA made the right decision but for the wrong reasons. No licence should ever be granted. We should be looking at the autonomy and integrity of the child created not the sick child.”



"The HFEA made the right decision"

The couple from Oxford have criticised the Human Fertilisation and Embryology Authority's decision not grant a licence allowing doctors to create a so called "designer baby" to help save their seriously ill son.

Michelle Whitaker, denied she was "playing God"; "My reply is that we are doing it because we want to save our son," she said.

Mrs Whitaker and her husband Jayson had asked the HFEA to allow doctors to use a "tissue-typing" IVF technique, which would have provided a perfect tissue match for their three-year-old son Charlie.

The licence would have enabled Charlie, who suffers from a rare blood disorder, Diamond Blackfan Anaemia, to have a potentially life-saving bone marrow transplant.

He needs a perfect tissue match, from a brother or sister, for the operation. Currently he must undergo painful day-long blood transfusion and daily injections of life-saving drugs.

But the HFEA said yesterday it could not approve the procedure as it would be unlawful and unethical. The HFEA Licence Committee ruled the screening procedure to ensure Charlie's sibling was a perfect tissue match, known as preimplantation genetic diagnosis, could not go ahead.

Charlie's case differed from that of Zain Hashmi, from Leeds, whose parents Shahana and Raj were granted permission to screen a new baby to save their son because Zain's rare blood condition was hereditary.

Screening the new baby would be necessary to ensure the Hashmi's new child did not have the disease, the HFEA ruled. In the Whitakers' case, the screening would be used solely to ensure a tissue match with Charlie.

Dr Maureen Dalziel, HFEA chief executive, said: "Diamond-Blackfan anaemia is an extremely serious condition and we have enormous sympathy for the affected child and his parents.

"However, the authority is unable to approve this application for PGD tissue typing because it does not meet the carefully considered criteria laid down to ensure that the procedure is lawful and ethical."

In effect, the HFEA says the procedure would mean selecting one life, or embryo, which matches Charlie's tissue type, over another life, another embryo, which does not. Michelle Whitaker broke down in tears when told by her clinic the HFEA had rejected their application to help Charlie.