



A Case in Genomic Medicine

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Rapid progression in genomic medicine...



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**Gene editing saves girl dying
from leukaemia in world first**



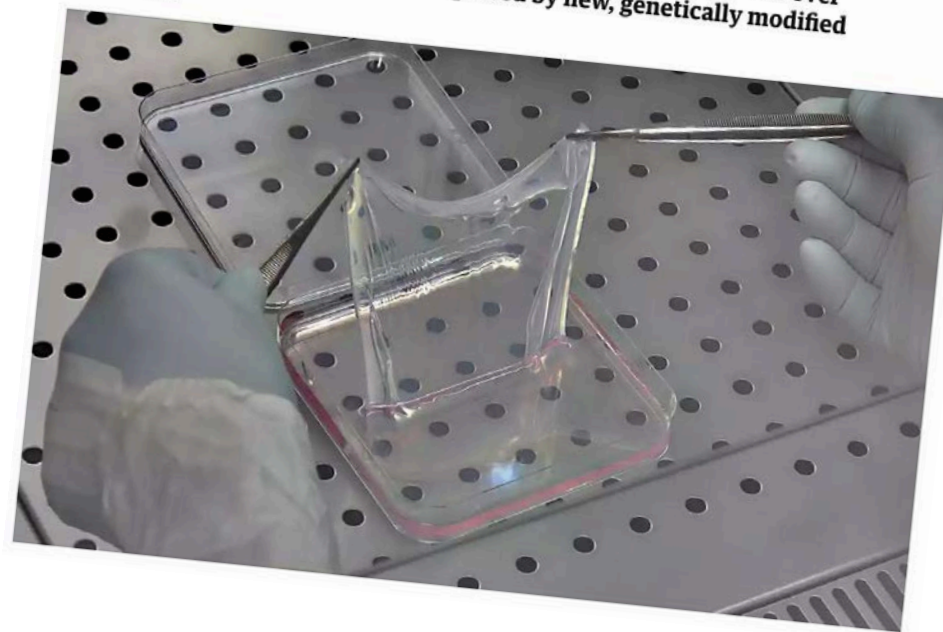
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Scientists grow replacement skin for boy suffering devastating genetic disorder

Seven-year-old boy suffering illness causing untreatable wounds over 80% of his body has had his skin replaced by new, genetically modified epidermis



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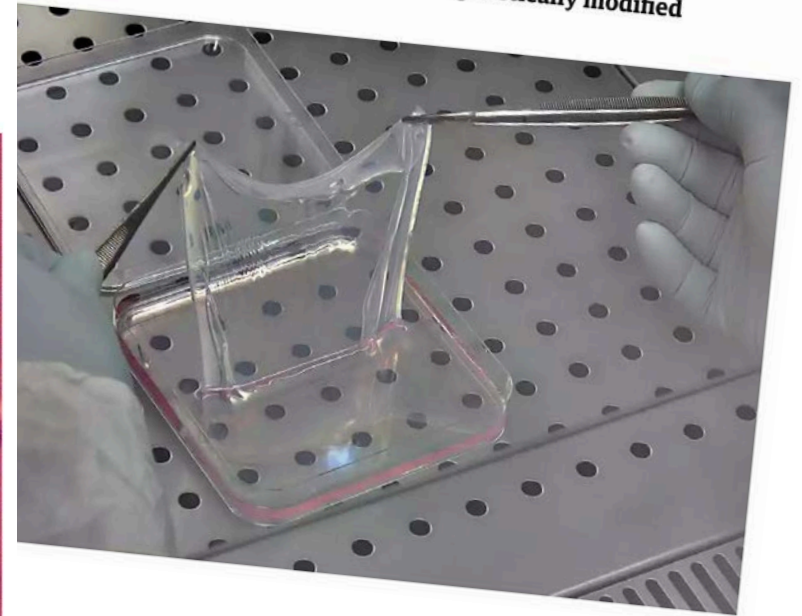
First UK licence to create three-person baby granted by fertility regulator

IVF technique uses DNA from three people to prevent genetic diseases being passed on, and could be offered by Newcastle clinic from this summer



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Jack, aged 4 – voted as having the world's best genome*



*by my family

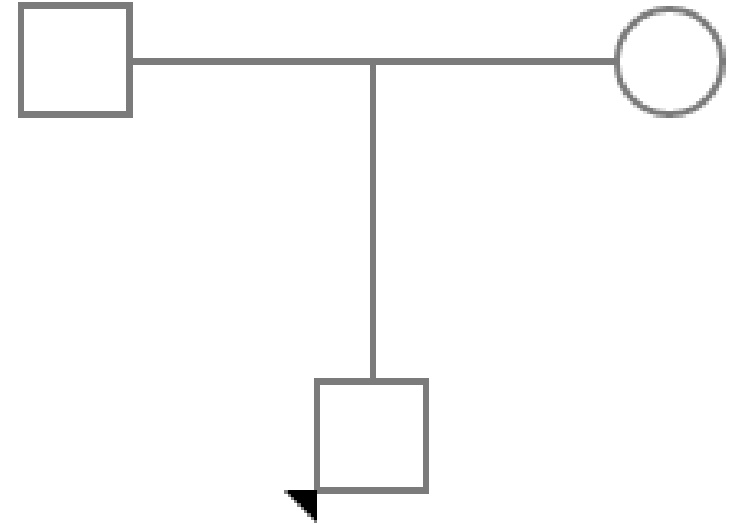
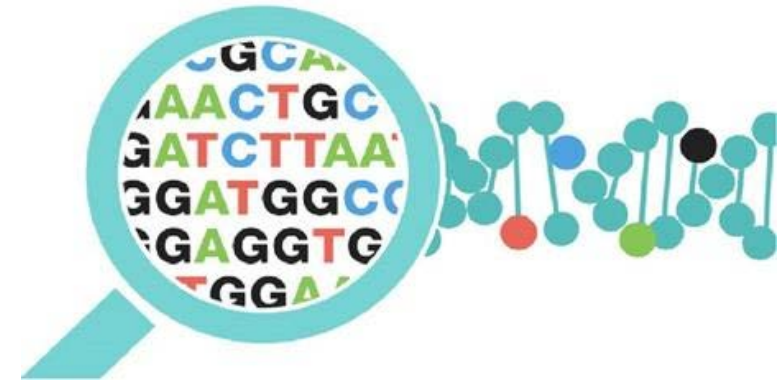
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- Infant male with developmental delay – rare disease suspected



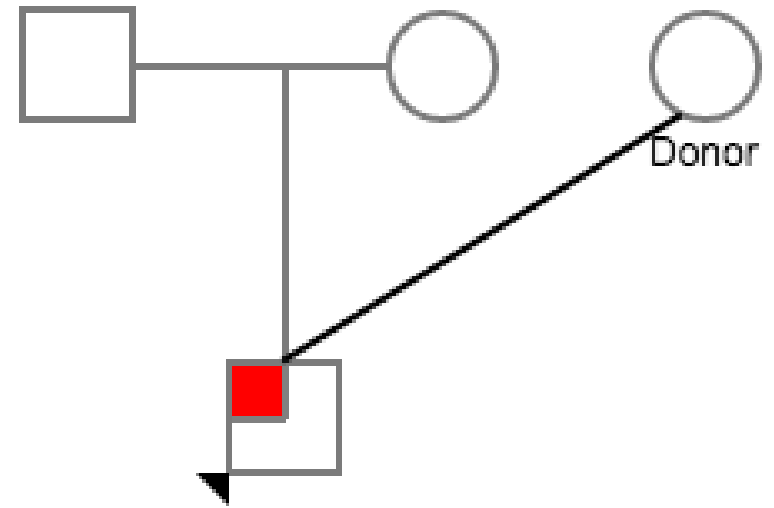
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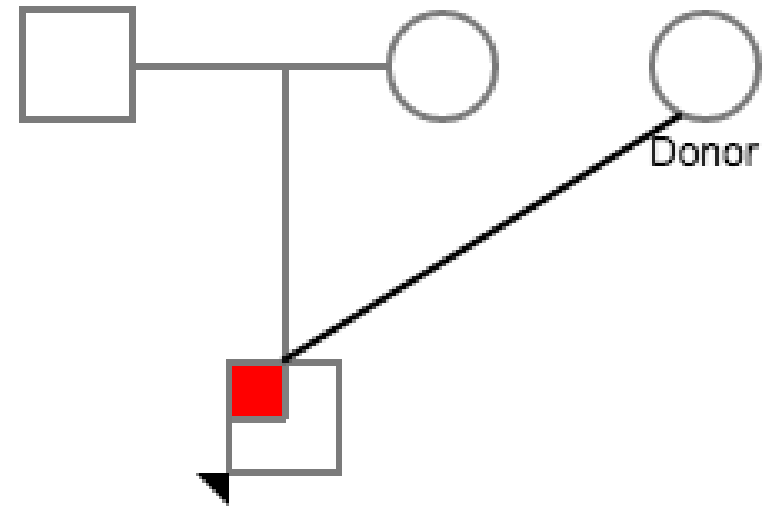
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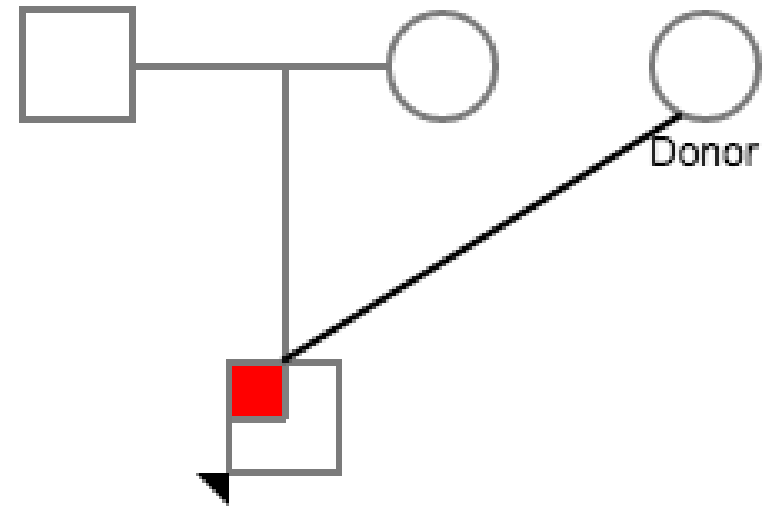
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- Referred for whole genome sequencing (WGS) - trio testing is most informative
- Child born from a donated ovum
- Fertility clinic denies contact to donor
- Human Fertilisation and Embryology Authority (HFEA) regulates





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- Wider implications for donor and other offspring
 - Could they become patients too?





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- Consent process should be updated
- WGS could be included in donor screening
- Privacy of genetic data may need to be flexible





Thank you – any questions?

Autonomy - too broad for an advanced decision?

vi) **NOTIFICATION OF GENETIC DISEASE**

Please tick
your answer:

I wish to be notified if [REDACTED] learns (e.g. through the birth of an affected child) that I have a previously unsuspected genetic disease, or that I am a carrier of a harmful inherited condition.

Yes No

Where you have answered "Yes" above:

I wish my GP to be informed in this case.

Yes No