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Lady Dorit Young of Dartington
67 Gibson Square
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18 March 2026

Our Ref: MG/SP.G.YOUNG
Your Ref:

Dear Lady Young,

MISS GAIA YOUNG (DECEASED)

The misery of your loss is palpable. The cause of Gaia's death in simplest terms, unremitting cerebral oedema with raised pressure inside the skull. The point about that one case I found was that the transplanted liver revealed the genetic abnormality. The situation with Gaia was that her transplanted liver did not reveal the anomaly and all the genetics studies that were carried out, did not find evidence of a metabolic disorder.

Looking back over so many decades of medical practice, I can remember young people presenting all those years ago before MRI scanning with cerebral oedema syndromes and medicine at that time not being able to determine the mechanism. These poor people were hugely frustrating to specialist doctors who seemed impotent to help. In spite of those pointers towards OTC, that were not confirmed with the genetics studies that were carried out.

Could this have been a rare genetic disorder yet to be determined causing cerebral oedema? It is remarkable to think that the group of conditions now known as the autoimmune encephalitides were not known about a few years ago and new antibodies to the brain are being found all the time. A similar comment can be made, although not applicable to Gaia, is the detection of the genetically determined epilepsies which do not respond to normal anti-epilepsy drugs.

The detection of these disorders without any disrespect meant, is a bit like bus spotting and ticking off all of the different numbers in a book.

We do have such a long way to go in order to work out all of the genetics.

Perhaps another analogy is the way in which horrid individuals are being found out decades later by virtue of the advances in DNA technology.

I did wonder whether the exercise which was one of the consistent features with Gaia might have been responsible for that tiny number of people who do get exercise induced cerebral oedema.

If you rightly said that this was so uncommon as to make it unlikely, I would have to respond by saying that OTC without any kind of genetic support is equally unlikely.

I just do not think I have got any more to add even though I would want to if at all possible in order to assist within your tragedy.

With kind regards

Yours sincerely

A handwritten signature in black ink, consisting of several loops and a long horizontal stroke extending to the right.

**Michael Gross MA MD FRCP
Consultant Neurologist**