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Gaia Young (deceased)
Born 4 March 1996
Died 21 July 2021

Dear Dr Gross (and Baroness Neuberger and Professor Probert)

Thank you for your letter dated 18 March 2026. I am impressed by your compassion and professionalism.

I note that you do not address my central inquiry: if Gaia did not die from OTC hyperammonaemia, what did she die of? Nor has the Trust addressed this question.

You state:

“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.”

Gaia did not undertake unusually strenuous exercise, nor did she drink a lot of fluid at the material time. She was a very fit and sporty young woman.

My understanding is that many cases of OTC in adult women are due to new de novo genetic mutations which NHS panel testing does not pick up. As you rightly state:

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

The present lack of genetic confirmation does not exclude OTC where *all* the evidence is either supportive or consistent, and none is inconsistent.

I take this opportunity to thank you again and for disregarding the Trust’s instruction not to reply to me.

Yours sincerely

Dorit

Lady Young of Dartington