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Ms Catherine Mooney
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19 December 2025

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

Dear Lady Young (and Ms Mooney),

MISS GAIA YOUNG (DECEASED)

Thank you for your letter. This letter was dictated before your more recent correspondence. I have no difficulty responding. Since adding these lines I have also now received the genetic analysis of the liver biopsy taken from the transplanted liver. First, I am not disagreeing with anything you have analysed. I was asked to look at this tragedy independently and of course if everyone agreed with your analysis, that would not be necessary.

All I have tried to do here is point out the challenges now by virtue of the absence of investigation that would help produce a diagnosis.

It was important to point out that the original CT brain scan was wrongly reported, (a clinical error - this always begs the question regarding consultant supervision) which did not help the managing clinicians.

The exercise premonitory element of Gaia leading to the initial symptoms, I thought ought to be at least considered. There is remote literature about the development of an exercise encephalopathy with raised intracranial pressure.

I in no way wanting to undermine anything that you say, but I do have a duty to try and work out if there is anything more that might contribute.

I think it would be useful to understand what you wish to achieve with this intense analysis. I have no difficulty with it. If there is a concern about a genetic diagnosis then family can be

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informed and I assume proper genetic testing can be undertaken.

Second, if there is a potential litigation process involved, then my reports are not what we call CPR 35 compliant, and there would need to be an alternative independent consultant court agreed. In any case I would say straightaway that the genetics of this situation are not my expertise. The difficulty I had right at the beginning in trying to help was that I personally did not know of anyone else who would sit down and analyse hence my agreement to at least review clinically.

I felt that the main lessons here involved the reporting of the CT brain scan and the woeful rule that was in place that people were coming into particularly A&E departments unaccompanied, which I hope will never ever happen again.

This was not being wise after the event. I had given very clear instruction to family members and friends that if there was any restriction with acute illness that they would turn up at the door with a barrister and demand access because this was just not acceptable. I have just done an audit of how many people on an outpatient basis need to be accompanied to get a proper history and it was about 60%. For acute neurology I would suspect that it is nearer 100%.

If it is accepted by yourself that OTC, hyperammonaemia and encephalopathy is the diagnosis and you have support elsewhere, then it is not for me to doubt that, it is merely indicating that there is a differential diagnosis. As you say there were no drugs or toxins involved. Alcohol certainly was not involved although that was postulated. Scanning did not show any significant anatomical malformation and that would not fit anyway with the presentation, and I do not think there was any true evidence that this was IIH. I think we are sitting between your considered diagnosis of OTC, and as yet unknown encephalopathy still to be determined, and an exercise induced encephalopathy. I do not know how much insight you have of the medical process, clearly your ability to research is excellent. What maybe not so clear is the change in medicine over the 55 years that I have been honoured to be part of the process.

There are so many diagnoses being made on a weekly basis with our beginning to unravel the genome.

I am sorry you misunderstood my comment about a clever diagnosis. This was not in any way disrespectful; it was again having worked at leading post-graduate centres over so many years, rare presentations were very common and the training that one obtained was to make sure every piece of information was available. Frequently many different specialists were asked to see a complex person and nearly always they came up with an answer that fitted their own specialty which never really helped. What we have here is a likely diagnosis sitting within the differential diagnoses, but an absence of total information to say with absolute certainty.

I could say to you in reverse if this was a scientific discussion, why was this not an exercise induced encephalopathy, but then why would that have appeared so suddenly under this circumstance which could of course be the same comment about the sudden presentation of OTC.

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I truly do not think I can add anything further to this discussion and if you and Miss Mooney feel that you need a further opinion, that would not be unreasonable, and a geneticist could be considered.

(I have also just added the following two paragraphs).

I have now seen the molecular analysis of the liver that you and the family so magnanimously in your hour of extreme distress donated in order to help save the life of another individual.

What has come out of this molecular analysis was the inability to identify a genetic cause of what might have been hyperammonaemia. I have emphasised that I am not a genetic expert. I noted how much genetic testing could be done looking for causes of hyperammonaemia and all I can say from reading the result is that there was nothing found that would for instance put the recipient under a greater risk.

Whether or not that is the whole story, I am afraid I just do not know. I can only extend again heartfelt condolences. May the memory of Gaia always be a blessing.

With kind regards

Yours sincerely

Sent unseen and unsigned to avoid delay

**Michael Gross MA MD FRCP
Consultant Neurologist**