

12 January 2005

Mr & Mrs Roberts
[REDACTED]

Dear Mr & Mrs Roberts

Thank you for forwarding your questions which arose from our meeting on 7 December 2004 at the Department of Clinical Psychology, RBHSC. On receipt of your e-mail, the questions were passed for consideration to Dr Heather Steen and Professor Young.

As I discussed with you on the telephone, we appreciate that these questions were sent before you had received the minutes of our meeting and some of your questions may therefore have been answered on reviewing this record. However, as agreed, answers were sought to all of the questions raised in your e-mail.

I know that it has been difficult to fully answer some of your very specific questions as Dr Steen and Professor Young could only reply on the documentation available in the medical chart and their knowledge of the practices of the time. However, I hope that the answers provided will go some way to providing you with the information you require. I have organised the answers provided by Dr Steen and Professor Young in the format of your questions and so the following paragraphs should read in conjunction with your original e-mail (enclosed). I appreciate that reading this information may cause you some further distress and for that I wish to offer my apologies.

1. (a) When Claire arrived in A & E at 8.00 pm on the evening of Tuesday 21 October, the history given to staff was that she had been vomiting in school that day and the GP advised she should be admitted to hospital. Based on this history and Claire's clinical presentation, the admitting Registrar suspected she had possible encephalitis.
- (b) Claire's symptoms were attributed to encephalitis, which was confirmed at post mortem.
- (c) Claire's condition was not under-estimated as she was considered to be very unwell, with a diagnosis of non-convulsive status epilepticus and encephalitis/encephalopathy. Claire consequently received intensive medical intervention.

- (d) At the time of admission, Claire's sodium was only slightly below the normal serum level. At this stage hyponatraemia, as a complication of her illness, was not considered as a major component.
2. (a) While Claire's sodium level was slightly low when it was recorded as 132 mmol/l on admission, this would not have been regarded as unusual in a child presenting with an illness similar to Claire's.

Practice now would involve approximately six hourly checks and use of the CT scanner. However, in 1996, before there was such extensive knowledge about hyponatraemia, it would have been normal practice to monitor sodium level every twenty-four hours.

- (b) In hindsight, it may have been an early indicator but, at these levels, doctors would not have been particularly concerned because the level was just below the lower limit of normal.
3. (a) Claire had blood taken for two specific reasons. The first was for biochemistry, which includes sodium levels; the second to measure phenytoin levels. As soon as the sodium levels were noted, steps were taken to address the condition.
- (b) According to nursing records, Claire was seen by a doctor at 9.00 pm after being informed about a possible seizure. At this time Claire had her bloods. At 9.30 pm, a doctor erected her acyclovir infusion. As already explained, common practice in 1996 would have been to monitor sodium level approximately every twenty-four hours.
- (c) One blood test with two samples was taken on 22 October. This was taken at approximately 9.00 pm.
- (d) Output would have been difficult to measure accurately as Claire was wearing nappies. However, it was noted in the chart that the nappies were wet on 22 November at 3.00am, 11.00 am 7.00 pm and 9.00 pm. Claire's input was carefully monitored.
- (e) Urine from the 11.00 am sample was sent for culture.
4. Claire's medication was very important and was aimed at controlling her seizures. Without this medication, her condition could have deteriorated more rapidly. The combination of drugs should not have had an adverse effect on sodium levels.
5. (a) Claire was given 5th normal saline fluid, which was the most common type of fluid to be administered in 1996. Treatment has now changed. Nowadays, Claire would be given smaller amounts of a different type of fluid following admission. It is not possible to say whether a change in the amount and type of fluids would have made any difference in Claire's case as she was very ill for other reasons.

- (b) The medications which were used to manage Claire's seizures are unlikely to have interacted in any significant way with the fluids that she was given. The combination of medication with fluids is therefore unlikely to have speeded up the fall in sodium levels.
6. (a) The clinical notes reflect the serious nature of Claire's condition. Dr Webb has noted that he spoke to Mrs Roberts at 5.00 pm on 22 October, although the content of this or other conversations between medical staff and the family was not summarised.
- (b) With regard to why Claire was not moved to PICU, her hourly CNS observations had remained stable for a period of time and no clinical signs of further deterioration were noted. PICU may not have been viewed, therefore, as appropriate / necessary.
7. (a) The paediatric Registrar co-ordinated the subsequent treatment.
- (b) The correct action was taken.
- (c) It is difficult to say, but in Professor Young's opinion, it was likely that Claire had deteriorated beyond the point of recovery by this time.
- (d) Claire was admitted to PICU at 3.25 am.
- (e) By the time Claire reached PICU, the staff were unable to do anything to save her.
8. (a) Hyponatraemia was not thought at the time to be a major contributor to Claire's condition. It is noted from the post mortem report that the presence of hyponatraemia was indicated in the clinical summary provided to the neuropathologist conducting the post mortem. The post mortem was limited to brain examination only and the subsequent neuropathology report commented only on the low grade sub-acute meningoencephalitis and neuronal migrational defect.
- (b) The full post mortem report states in relation to the cerebral oedema that a metabolic cause can not be entirely excluded. This is a reference to the possible effect of the low sodium in Claire's case, although hyponatraemia is not specifically referred to.
9. Professor Young did indeed state that monitoring of sodium levels would not be more frequent (ie around six hourly). However, the management of patients with sodium levels less than 135 is dependent on the clinical condition which has led to the low sodium. In Claire's case, it was felt to be due to the syndrome of inappropriate antidiuretic hormone secretion (SIADH). The practice at that time would have been firstly, to restrict fluid intake and secondly, to consider administration of fluid with a higher content of sodium, if symptoms attributable to hyponatraemia were present.

10. Having brought Claire's case to the attention of the Medical Director, a review of Claire's case notes was carried out, with independent advice sought from Queen's University Professor of Medicine. As a result of this review, the Coroner has been fully informed of the issues of concern. It will now be up to the Coroner to further review the medical aspects of Claire's case as he feels appropriate. The Coroner had not been informed at the time as it was believed that the cause of Claire's death was viral encephalitis.

In conclusion, while I appreciate that not all of the detail you require might be included, I hope that the information provided above goes some way to answering your questions. As previously stated, it is very difficult to be precise about such complex conditions, especially with the passing of time, the benefit of hindsight and greater acquired knowledge.

Dr Steen, Professor Young and myself would be happy to meet with you to discuss the information further, if this would be helpful. However, as HM Coroner has now requested that Dr Robert Bingham, Great Ormond Street Hospital, provide him with a fully independent report, it might be better to await his opinion.

Once again, I would like to offer you my sincerest sympathy to you and your family on Claire's untimely death and apologise for any increased distress caused by the pursuit of your enquiry.

Yours sincerely



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Psychology Service manager*