

THE ROYAL HOSPITALS
LITIGATION MANAGEMENT OFFICE
4TH FLOOR, BOSTOCK HOUSE, RVH
RVH EXT [REDACTED]

MEMORANDUM

FROM: Mr A P Walby
Associate Medical Director
Litigation Management Office

TO: Dr Nichola Rooney
Consultant Clinical Psychologist
Clinical Psychology Services
Manager
Royal Belfast Hospital for Sick
Children

REF: A.49/04/35/J

DATE: 12 January 2005

Dear Dr Rooney,

Re: Claire Roberts

I refer to your e-mail messages of 10 and 11 January 2005 regarding the above.

Please now find enclosed draft copy of your letter with my comments as requested.

I should be grateful if you would let me have a copy of your final letter for my file please.

Many thanks.

[REDACTED]
ENC

date typed: 12.01.05
/smce

✓ FAXED

FAO [REDACTED]
[REDACTED]

12/01/05
at 9 am
[REDACTED]

Dear Mr Roberts,

Thank you for forwarding your questions which arose from our meeting on the 7th 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 so some of your questions may have been answered on reviewing this record. However, as agreed, answers were sought to all of the queries raised in your e mail.

I know that it has have been difficult to get answers for some of your very specific questions as Dr Steen and Professor Young could only rely 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 be 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 would wish to offer my apologies.

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3. (a) Claire had blood taken for two specific reasons. The first was for biochemistry which includes sodium levels, the second to measure phenytoin

*Discrepancy with RLB's
133 mmol/l comment*
X

levels. As soon as the sodium levels were noted, steps were taken to address the condition.

(b) According to the nursing records, Claire was seen by a doctor at 9pm after being informed about a possible seizure. At this time Claire had her bloods. At 9.30pm a doctor erected her acyclovir infusion.

As already explained, common practice in 1996 would have been to monitor sodium level approximately every 24 hours.

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(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 the 22nd November at 3am, 11am, 7pm and 9pm. Claire's input was carefully monitored.

(e) Urine from the 11am 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, and today 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) It is not possible to say how information regarding Claire's serious condition was not adequately conveyed to you. While the clinical notes reflect the level of medical concern, there is no note summarising the content of conversations between medical staff and relatives. However Dr Webb has noted that he spoke to Mrs. Roberts at 5pm on the 22nd October.

(b) It is difficult to give an opinion on why Claire was not moved to PICU. However as Claire's 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 as appropriate/necessary.

7.(a) The paediatric Registrar co-ordinated the subsequent treatment.

(b) The correct action was taken

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(d) Claire was admitted to PICU at 3.25am

(e) By the time Claire had reached PICU the staff were unable to do anything to save Claire.

Would you consider:

As to why Claire was not moved to PICU, Claire's baby

... necessary

(I am sure this is correct but should the neuropathologist not have in fact to confirm?)

- 8 (a) Hyponatraemia was not thought at the time to be a major contributor to Claire's condition. 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 cannot 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.

but not every 1-2 hours?

9. Professor Young did indeed state that the monitoring of sodium levels would now be more frequent (i.e. around 6 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 is felt to be due to the syndrome of inappropriate antidiuretic hormone secretion (SIADH). The guidance at that time would have been, firstly, to restrict fluid intake, and, secondly, to consider the administration of fluid with a higher content of sodium if symptoms attributable to hyponatraemia were present.

Will be asked for copy of the "Guide"

(I hope it exists otherwise it might be better to say "The practice at that time")

9. 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 now been fully informed of the issues of concern. It will now be up to the coroner to review the medical aspects of Claire's care as he feels appropriate. The coroner had not been informed at the time as it was believed that the primary cause of Claire's death was viral encephalitis.

? delete

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. 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

Nichola Rooney

however as H.R. Coroner has now requested Dr. Robert Bingham from Great Ormond Street Hospital to provide him with a fully independent report, it might be better to await his assessment.

Message

A.49/04/35/J Page: 302.

To: [REDACTED]
Cc: Michael McBride; [REDACTED]; Heather Steen; Ian Young
Sent: Monday, January 10, 2005 5:23 PM
Subject: Roberts letter

Dear [REDACTED] I would be grateful if you would forward this letter to Dr Walby for his consideration as a matter of urgency, as I need to get it sent off as soon as possible. I enclose also the Roberts' questions which need to be read in conjunction with the response. Many thanks, Nichola

*Dr Nichola Rooney
Consultant Clinical Psychologist
Clinical Psychology Services Manager
Royal Hospitals Trust
Belfast*

11/01/2005

From: Ian Young [REDACTED]
Sent: 10 January 2005 20:03
To: Nichola Rooney; [REDACTED]
Cc: Michael McBride; [REDACTED] Heather Steen
Subject: Re: Roberts letter

Dear all

Having reviewed this draft, I have made a few minor changes which I have highlighted in green. I have called this version draft 3.

Yours sincerely

Ian Young

IS Young
 Professor of Medicine, Queen's University Belfast

Wellcome Research Laboratories
 Mulhouse Building
 Royal Victoria Hospital
 Grosvenor Road
 Belfast
 BT12 6BJ
 UK

tel: [REDACTED]
 fax: [REDACTED]
 Email: [REDACTED]

— Original Message —

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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 24 hours.
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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.

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Yours sincerely

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A.49/04/35/J Page: 307

[REDACTED]

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Sent: 10 January 2005 17:23
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Cc: Michael McBride; [REDACTED]; Heather Steen; 'Ian Young'
Subject: Roberts letter

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9. 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 Queens University Professor of Biochemistry. As a result of this review the coroner has now been fully informed of the issues of concern. It will now be up to the coroner to review the medical aspects of Claire's care as he feels appropriate. The coroner had not been informed at the time as it was believed that the primary cause of Claire's death was viral encephalitis.

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Yours sincerely

Nichola Rooney

Meeting held at Belfast Royal Victoria Hospital on 7 December 2004 to discuss the treatment of our daughter Claire Roberts

8 December 2004

Compiled by Mr Alan Roberts

Dr Nicola Rooney arranged the above meeting at my request to discuss concerns my wife and I have following the treatment of our daughter at the Belfast Royal Victoria Hospital for sick children. These concerns have been ongoing over the years and were highlighted following the Insight television programme broadcast on 21 October 2004, by UTV.

Claire was admitted to hospital on Monday 21 October 1996 at approx. 7:15

We had a detailed discussion with Dr N Rooney, Dr H Stein, Dr A Sands and Professor Young and as a result of this meeting we would like to raise the following questions.

1. What was Claire's initial diagnosis on admission to the hospital?
Claire's symptoms were, lethargy, vomiting and disorientation which are typical of Hyponatraemia.
Were these symptoms interpreted as a viral infection?
Was Claire's condition underestimated i.e. Were the Doctors concentrating on a viral infection, when a more serious illness was building which required early diagnosis?
Was Hyponatraemia considered at this stage?
2. Claire's sodium was checked at 8:00pm on Monday 21, reading 133mmol/l. Should this level have raised concerns and should it have been checked and monitored every 1 – 2 hours?
Was this an early indication of Hyponatraemia, which is defined as a sodium level less than 135mmol/l?
3. Claire had a blood test at 9:00pm on Tuesday 22 to check her medication levels. This was processed at 11:00pm but critically highlighted her sodium levels had dropped to 121mmol/l. This would indicate that this was not a specific test to check sodium levels and Claire's symptoms had been misdiagnosed.
Did a Doctor examine Claire between 5:00pm and 11:00pm on Tuesday 22?
Why was Claire's sodium level unchecked for 27 hours?
How many blood tests were carried out on Tuesday 22?
How were Claire's water retention and water excretion levels monitored?
Were tests carried out on Claire's urine?
4. Claire was administered a number of anticonvulsant and antibiotic drugs throughout Tuesday 22.
Did this mixture of medication compound and worsen Claire's symptoms given that her sodium levels were falling?
Should this medication have been stopped?
What impact would the medication have on Claire if she was suffering from Hyponatraemia?
5. Was the incorrect type of fluid administered to Claire?
If this were the case, what were the implications for Claire?
What impact would the combination of both strong medication used along with an incorrect fluid type have on Claire?
Did this combination speed up the process of falling sodium levels?

6. My wife and I were with Claire most of Tuesday 22 and left the hospital at 9:30pm. During that time we were not unduly worried about Claire's condition and no indication or concern was directly expressed by any Doctor. In fact I do not recall speaking to a Doctor on Tuesday 22 and took that as a positive with regard to Claire's condition.
At our meeting on the 7 December Doctor Sands indicated that on Tuesday 22 he considered Claire's condition to be serious.
If Claire's condition was considered as dangerous or serious on Tuesday 22 why was this concern not urgently highlighted to my wife or I?
Why was Claire not admitted to Intensive Care if her condition was serious?
Would parents leave a seriously ill child in hospital alone?
7. When Claire's blood test results were returned on Tuesday 22 at 11:00pm, showing a low sodium level, who co-ordinated the subsequent treatment?
Was the correct action taken with regard to the type and quantity/reduction of fluid given?
At this stage had Claire's condition deteriorated too much for remedial action?
At what time was Claire admitted to Intensive Care?
Had Claire's condition deteriorated so much in Allen Ward that the Intensive Care Unit were unable to do anything to save Claire?
8. Follow up meetings in January 1997 with Consultants and Doctors at the Royal Hospital and the Post Mortem report (our condensed version) dated 21 March 1997 defined the cause of death as Cerebral Oedema linked to a viral infection. No statements were made about Hyponatraemia.
Given that Claire's sodium levels dropped so suddenly within a 27 hour period ie. Acute Hyponatraemia, why was this condition not defined?
Does the full post mortem report make any reference to Hyponatraemia or sodium levels?
9. Professor Young explained that the fluid type administered to Claire would not be given to a patient at the Royal Hospital today who has sodium levels lower than 135mmol/l and that such patients would have their sodium levels reviewed every 1-2 hours.
What were the guidelines in October 1996 for a patient whose sodium levels were less than 135mmol/l?
10. Professor Young stated that the fluid type administered to Claire had a definite input into her death. He indicated that the input level would be difficult to quantify.
As Parents I feel that this question centres around our heartache and search for answers, therefore it is very important for us that this issue is investigated and answers given.
We have struggled for over eight years to understand and accept how an unknown viral infection could be the cause of Claire's death and are again devastated to realise that Hyponatraemia now appears to be a more accurate cause.
Will the cause of Claire's death be reviewed by the Belfast Royal Hospital?
Given that Claire's death was sudden, unexpected and without a clear diagnosis, why was the Coroner not informed or an inquest held?
Why did it take the broadcasting of a television programme to raise issues and concerns regarding the death of our daughter?

It is clear from our meeting on 7 December that senior medical staff are aware of shortcomings regarding Claire's treatment.

We therefore request that Claire's case is referred to the Coroner for further urgent investigation with the desire that the case is made part of the current ongoing inquiry led by Mr John O'Hara, QC.

Please note that as our discussions are ongoing the above questions do not form an exhaustive list.

Mr Alan & Mrs Jennifer Roberts

message

A.49/04/35/J Page: 313

[REDACTED]
From: Nichola Rooney
Sent: 11 January 2005 11:13
To: [REDACTED]
Cc: [REDACTED]
Subject: Roberts case

I understand Peter needs this file to do a letter to the coroner. I will ask my secretary to send it over to you. Also - sorry for the 3 drafts plus typo amendments! I do believe the letter is final - if Peter is happy with it I will get it typed up and sent asap. Many thanks Nichola

[REDACTED]
I spoke to Nichola Rooney's Secretary
She has arranged for a Porter
to bring the documents to us today.
[REDACTED]

/
Signed

11/01/2005