Claire Roberts

Meeting held on Tuesday 7 December 2004
in the Clinical Psychology Department, RBHSC

Present:

Mr & Mrs Roberts
Dr Nichola Rooney, Consultant Clinical Psychologist
Dr Andrew Sands, Consultant Paediatrician
Dr Heather Steen, Consultant Paediatrician
Ian Young, Professor of Medicine, Queens University of Belfast

Dr Rooney opened the meeting by introducing Mr and Mrs Roberts to Dr Steen, Dr Sands and Professor Young and reassuring them that any questions they feel still remain unanswered regarding Claire's death will be addressed, adding that the Trust will meet with them at anytime to help them in any way possible. She went on to outline what she believed were Mr and Mrs Robert's main areas of concern:

- What led to Clare's sudden deterioration after they had left the hospital and before they were called at 3.30 am?
- Was Claire's condition misdiagnosed?
- What role, if any, did Clare's fluid and sodium management play in her death?

Dr Steen, using Claire's medical notes, took the family through the sequence of events.

Claire arrived in A & E on the evening of Tuesday 21 October. The history given to staff was that she had been vomiting in school that day. The GP was contacted and he arrived at 7.00 pm. On examination, Dr Savage advised she should be admitted to hospital. Claire arrived at A & E at around 8.00 pm, where she was seen by a Senior House Officer. It was suspected at that point that she had a viral illness – there were signs of infection (encephalitis was suspected) and she had been vomiting all that evening. Only sips of fluid were taken.

Dr Sands then stated that, having seen Claire on the ward the next day, he was concerned how unwell she was. He sought information from Dr Gaston, Ulster Hospital, Dundonald, on Claire's previous history to find out what her normal behavioural pattern was. Dr Sands felt specialist care was required and discussed the case with Dr David Webb, who arrived quite promptly (lunchtime, Tuesday).

Mrs Roberts stated that during the morning both sets of grandparents were with Claire, with Mr Roberts and herself arriving in the afternoon.

Continuing from the notes, Dr Steen stated that Claire's muscles were stiff and she was fitting. She was commenced on ***Phenytoin*** to stop the fitting and was observed hourly. At 3.00 pm Dr Webb additionally prescribed ***Midazolam*** (rectal ***Diazepam*** had already been administered that morning). Dr Steen added that generally antibiotics do not help in a virus situation, but the antibiotics administered were the

most likely ones to help Claire in the circumstances. Blood levels were checked (probably around 9.00 pm) and a result of low sodium was noted in the medical chart at 11.30 pm. Less fluids were given at this point. Three medicines had already been administered at this stage to try to stop Claire's fitting and she was on hourly observation.

Mrs Roberts stated that just before 9.00 pm, she had a discussion with the nurse in relation to Claire's nappy etc as they were intending to return home. They left the ward at around 9.30 pm, not unduly concerned - hoping, in fact, that Claire may be well enough to be discharged on the Wednesday, as in the past when Claire suffered from measles etc, she would be in bed for a few days and be back to her normal self shortly after. She stated that neither she nor her husband got the impression from staff that the situation was in such a critical phase, otherwise they would not have left Claire. Dr Steen replied that medical staff would have been concerned about Claire's condition, this being evidenced by the fact that she was on hourly observation and that three different medicines had already been administered.

At 2.30 am, Claire's breathing became laboured, with her respiratory rate at 20 per minute, and she stopped breathing. She was intubated and transferred to ICU, where a CT scan showed swelling of the brain.

Dr Steen gave an explanation on how an illness such as Claire's can arise. Viruses known as an enterovirus can enter the body via the stomach and can then cause swelling of the brain.

Mr Roberts queried whether administering of fluids had influenced her condition.

Professor Young joined in at this point, firstly by emphasising that he was involved in the case purely as an independent advisor. He explained that treatment today differs from that used eight years ago and also related the sequence of events regarding Claire's illness and treatment.

- On arrival in hospital, Claire's sodium level was slightly low at 132 (normal rates vary from 135 – 145).

- The doctor gave her standard fluid intravenously – which is the text book recommendation.

- Approximately twenty-four hours later, Claire's sodium levels were rechecked.

- Twenty-seven hours after her arrival the results of the blood test indicated that Claire's sodium level had dropped to 121, which was very low. The doctor, as a result, reduced the amount of fluid given to help the sodium level. It was explained that a drop in sodium levels can cause swelling of the brain (equally, swelling of the brain can cause a drop in sodium levels). Professor Young feels this may have contributed to swelling of Claire's brain and therefore ultimately to her death but that it was not possible to say to what extent. He added that fitting and a virus infection can also cause this.

- With the sodium level at 121, the doctor had responded appropriately. However, Professor Young added that he believed the swelling of the brain had already occurred by this stage, therefore further intervention would probably not have helped.

Professor Young explained that treatment today is very different. At the Royal Hospitals, lessons have been learnt regarding management of sodium levels in

children – which is still not the case in many UK hospitals. Dr Steen added that text books still recommend previous thinking on fluids. Professor Young continued that the use of 5th normal fluid saline is in fact now banned in the Royal Hospital for Sick Children, with a different type of fluid used today to avoid fall in sodium levels. Blood tests are also taken more frequently, thereby speedily picking up on a fall in sodium levels. The Professor did add, however, that as Claire was so unwell it was not possible to say whether these new procedures would have helped her.

Dr Steen advised that it is not always the case that children with low sodium levels will result in swelling of the brain. It was explained that medicine has moved on considerably in the last ten years and, hopefully, in the next eight to ten years it will have even more to offer. Dr Sands added that a new CT scanner is in place today, which may have helped Claire had it been available in ICU eight years ago.

Professor Young advised Mr and Mrs Roberts that the Trust wants to be completely open about this case and therefore will have to approach the Coroner for advice on the best course of action. The Coroner may suggest an inquest which would be open for public scrutiny, or may suggest referring the case to the ongoing enquiry led by John O'Hara QC. Alternatively, the Coroner may feel that no additional actions are needed in this case. The Coroner may well be swayed by the wishes of the parents.

Dr Rooney briefly summarised the main issues that had been discussed and enquired if Mr and Mrs Roberts had any further questions. Mr Roberts asked if Claire's sodium level had been monitored in between arriving at hospital and twenty-four hours later. Professor Young confirmed that it had not, but this was not unusual at that time. Treatment today, however, involves approximately six hourly checks and use of the CT scanner. Mr Roberts enquired at what time the next blood check was taken and Professor Young stated that it was not possible to be sure about this. From the notes, blood tests were taken at approximately 9.00 pm, to measure levels of **Phenytoin**, and the sodium may have been checked at the same time, although we cannot be certain. A note of the result was made in the chart at 11.30 pm. After it is taken, the blood sample travels to the laboratory for processing and analysis and the results are returned to the ward, which at that time would often have taken a couple of hours.

Dr Steen also explained the process of dealing with sodium levels in the blood and that this can not be brought up too quickly. The plan was to bring Claire's fluids down gradually to enable her sodium levels to rise at an appropriate level. Treatment today differs in that if it is suspected that there is infection of the brain, or meningitis, fluids are restricted to two thirds from the outset.

It was agreed that another meeting can be arranged to give Mr and Mrs Roberts time to think about the matter and any further questions they may have. Professor Young stated that the Trust, in the meantime, would not contact the Coroner until Mr and Mrs Roberts decided what they wished to do. He added that the Coroner would obviously look at the case with a wider view. Also, it would be left to Mr and Mrs Roberts whether or not they wish to approach John O'Hara QC, or whether they would like the Trust to do so.

Mrs Roberts said that for eight years they have been looking for answers and Claire's case appeared to be similar to those being looked into by John O'Hara QC. Professor Young stated that there were significant differences in the cases and Dr Steen added that the other cases being investigated related to a surgical problem, fluid problem and kidney problem.

Dr Steen informed Mr and Mrs Roberts that a copy of the notes of today's meeting will be sent to them and they should not feel under pressure to make any immediate decisions. They should consider what is to be gained at each step and ultimately what they want to do - for example, if they feel Claire's case may help others. The Royal Hospitals, for its part, has already put in place new procedures. Professor Young added that at the time of Claire's treatment, there was a lack of awareness regarding low sodium. Today, a low sodium level is acknowledged as very important.

Mrs Roberts enquired if fluid intake also related to fluids lost. Professor Young replied that there are no accurate records of the amount of fluid lost as this would not have been done routinely at that time. The Professor added that with the viral infection, seizures and fluids administered, it is difficult to say what their relative contribution would have been. Dr Steen also added that it is very difficult to evaluate how much the fluids contributed to the situation.

Dr Sands stated that it would have helped if medical staff had spoken to Mr and Mrs Roberts before they left at 9.30 pm. Mr Roberts found it difficult to understand why the doctor did not advise them of the seriousness of Claire's condition. With regard to Claire's transfer to ICU, Dr Sands explained that eight years ago children were not transferred to ICU with the same regularity as they are today, nor was a CT used then.

The meeting closed with Dr Steen suggesting that, after reading through today's notes, Mr and Mrs Roberts could think about and write down any further questions they wish clarified.

Professor Young added that he would be happy to meet with Mr and Mrs Roberts again and reiterated that the Trust would not proceed with any action until they decide how they wish the matter to proceed.

Dr Rooney remained with Mr and Mrs Roberts to discuss the best way forward.