INV/25/04

From: Ruth Fisher
Eastern Board Unit
Secondary Care Directorate

Date: 17 November 2004

1. Andrew Browne – *agreed/AB/18.11.04*
2. Angela Smith

Issue:	**MEETINGS WITH THE CRAWFORD, FERGUSON AND SLAVIN FAMILIES TO DISCUSS THE INDEPENDENT INQUIRY.**
Timing:	**The meetings will take place on 23/25 November.**
Presentational Issues:	**The setting up of the Inquiry into the issues raised by the recent UTV Insight programme 'When Hospitals Kill' continues to attract considerable media interest.**
Recommendation:	**That you note the attached briefing material and lines to take.**

Background

You wrote to Mr and Mrs Ferguson on 9 November and to Mr and Mrs Crawford and Mr and Mrs Slavin on 10 November agreeing to a meeting to discuss the Independent Inquiry into Hyponatraemia Related Deaths. The families have since requested separate meetings. These will take place on 23/25 November.

2. In light of the allegations raised in the UTV Insight Programme, broadcast on Thursday 21 October, you announced an independent inquiry into the deaths of Lucy Crawford, Raychel Ferguson and Adam Strain (whose mother is now Mrs Slavin). This is to be conducted by Mr John O'Hara QC. Mrs Ferguson has advised that her solicitor will

be attending the meeting. The Permanent Secretary and Noel Kelly, Departmental Solicitor, will support you at the meetings.

3. Detailed briefing is attached as follows:

Pen Pictures	Tab A
Background Note	Tab B
Key Issues	Tab C
Lines to Take	Tab D

4. You are invited to note and agree the attached briefing and lines to take.

Ruth Fisher
[redacted]

Copy Distribution:
Secretary
CMO
CNO
Andrew Hamilton
Dr Miriam McCarthy
Dean Sullivan
Philip Maguire
Noel Kelly

Pen Pictures

The Ferguson Family

Raychel Ferguson, a nine-year-old, died in June 2001.

Raychel was one of four children. She is survived by 2 elder brothers and 1 younger brother.

Mrs Ferguson is known to spend a lot of time at her daughter's grave, often very late at night. She appeared on GMTV, within the last eighteen months, after having contacted a medium concerning the loss of her daughter. Mrs Ferguson has had an admission to Altnagelvin Hospital since the death of Raychel.

The Crawford Family

Lucy Crawford, a 17-month-old, died in April 2000.

Lucy was the youngest of three children. She is survived by an elder brother and sister, some ten and twelve years older respectively.

The Slavin Family

Adam Strain, a four-year-old, died in November 1995.

Adam was the only child of Mrs Slavin (nee Strain). At the time of Adam's birth his mother was single and lived with her parents. His father had no knowledge of Adam.

Adam was born in the Ulster Hospital in 1991. Soon after birth it became clear that he had abnormal kidney function. He was initially managed by Mr Brown in the Ulster Hospital but brought to the Royal Belfast Children's

Hospital for surgery. He had five operations in his first year. As well as kidney and bladder problems he had acid reflux and wasn't eating well so he had surgery to enable him to be tube fed.

In 1994 he was put on dialysis because his kidney function was not viable. His mother was taught how to do the dialysis. He was also put on the transplant list at this point. In 1995 a kidney became available, however he died following surgery.

His mother and her parents took on the care of his very complex clinical situation with great bravery. Following Adam's death his mother would not take any form of support or bereavement counselling. Her parents were extremely concerned about her wellbeing. Several of the nurses on the ward kept in contact with her and did what they could to provide support. This informal contact was maintained until the point at which she became engaged to be married.

Background Note

1. In April 2000, Lucy Crawford, a 17-month-old child, died following admission to the Erne Hospital and subsequent transfer to the Royal Belfast Hospital for Sick Children. The cause of death as recorded on the death certificate issued shortly after her death was "cerebral oedema, gastroenteritis, dehydration". Subsequently a Coroner's inquest into her death, completed on 19 February 2004, concluded that Lucy died from: (a) cerebral oedema, (b) acute dilutional hyponatraemia, (c) excess dilute fluid.

2. Hyponatraemia (a low sodium level in the blood) is known to be a risk in any child receiving prescribed fluids. It is potentially extremely serious, with a rapid fall in sodium leading to cerebral oedema, seizures and possible death. Hyponatraemia most often reflects a failure to excrete water. Stress, pain, nausea and vomiting are all potent stimulators of a hormone, ADH, that inhibits water excretion. Therefore a sick child, if given excess fluids, may not be able to excrete water adequately. The retention of water may, in severe cases, lead to cerebral oedema (swelling of the brain) and ultimately death.

3. Lucy Crawford was admitted to the Erne Hospital on the evening of 12 April 2000 with poor oral intake, fever and vomiting. At that time a presumptive diagnosis of a viral infection was made. She was dehydrated and required intravenous fluids, which were commenced about 10.30pm. At about 3.00am on 13 April Lucy collapsed, and was transferred to RBHSC at 6.00am, but in a moribund state. She was pronounced dead at 13.15pm on 14 April.

4. Lucy's death was reported to the coroner's office. Advice was sought from the State Pathologist's Department regarding the need for a coroner's post-

mortem examination. Following discussion between the state pathologist and a consultant paediatrician at the RBHSC, it was agreed that a coroner's post-mortem was not required and a death certificate could be issued. A Hospital post-mortem was conducted.

5. The Sperrin Lakeland Trust conducted an internal review into Lucy's death, concluding that neither the post-mortem nor an independent medical report could fully explain Lucy's deterioration. Specifically the review commented that the fluids Lucy received were, in both type and amount, within the accepted range, but cited poor record keeping as leading to confusion over prescribed fluids.

6. It was only in February 2003 following the inquest into Raychel Ferguson's death that the coroner was alerted to the similarities between Lucy Crawford's case and that of Raychel Ferguson, a nine-year-old who had died from hyponatraemia at Altnagelvin Hospital in June 2001. Subsequently an inquest was opened into Lucy's death and held in February 2004. In the context of these deaths, a further death of a child, Adam Strain, has been referred to. Adam Strain a four-year-old child died in November 1995, following renal transplant surgery. His autopsy confirmed cerebral oedema due to dilutional hyponatraemia and impaired cerebral perfusion as cause of death. To summarise, the sequence of events were as follows:

November 1995	Adam Strain died, following renal transplant surgery; autopsy confirmed cerebral oedema due to dilutional hyponatraemia and impaired cerebral perfusion as cause of death.
April 2000	Lucy died
June 2001	Raychel Ferguson died.
	Death reported to coroner.

March 2002	CMO issued guidance on prevention of hyponatraemia.
February 2003	Inquest into Raychel Ferguson's death.
March 2003	Links between Raychel's and Lucy's death identified.
February 2004	Inquest into Lucy's death.

7. Details of the conduct of the consultant paediatrician involved in Lucy's management has been referred to the General Medical Council, which will, through its normal procedures, consider the case and whether there are grounds for disciplinary action.

8. In 2000, at the time of Lucy's death, the statutory Duty of Quality on HPSS providers had not been introduced. The Trust did however take steps to investigate the reason for Lucy's death. A case review was conducted and a paediatrician from Altnagelvin Hospital was invited to act as a medical assessor.

9. The UTV Insight Programme broadcast on Thursday 21 October raised a number of allegations about the treatment of Lucy Crawford and the subsequent investigation into her death. These included specific references to the actions of individual doctors, the management of Sperrin Lakeland Trust and the Department's Chief Medical Officer.

10. In light of the allegations contained in the 'Insight' programme you announced an independent investigation into the issues raised by it on 1 November.

11. As you are aware, the PSNI are currently conducting investigations into some aspects of the matters to be considered by the Inquiry. The PSNI may

ask John O'Hara to suspend all or part of his Inquiry until such times as they complete their own investigation.

Key Issues

Introduction

1. There is considerable interest in the terms of reference of the Inquiry and the way in which it will be taken forward. A number of PQs have been tabled by Iris Robinson and she has also written to you on the subject. In addition, John Hume has also tabled PQs and written to you on behalf of Mrs Ferguson. He has stated that it is very important that the terms of reference, personnel and conduct of the Inquiry are such that they will lead to public confidence in its process and findings. Mrs Ferguson feels strongly that the Inquiry should be independent, public and transparent, and that the families and their legal representatives should be involved in all aspects of the Inquiry. The Western Health and Social Services Council has urged that the Inquiry should be sufficiently wide to encompass all of the issues raised by the Insight Programme. In particular, the Council has emphasised that the Inquiry must have the power to call on all of the key people involved and that it should be a full public independent Inquiry.

Independence of the Inquiry Team

2. The Inquiry is independent from Government and is to be chaired by John O'Hara QC. He has considerable freedom in making the detailed arrangements for the conduct of the review.

3. An Inquiry secretariat has been established. Team members have been freed from their current duties, and are located in non-departmental accommodation in Adelaide Street, Belfast.

Scope and Terms of Reference of the Inquiry

4. The Terms of Reference of the Inquiry are attached at Annex A. It is thought that they provide the necessary breadth to enable the concerns of the families and wider public to be fully addressed so as to restore public confidence in our health care system.

Powers of the Inquiry

5. The powers of the Inquiry to compel relevant people to give evidence and furnish documents are also a matter of public interest. The Inquiry is being established under Article 54 and Schedule 8 of the 1972 Health and Personal Social Services (NI) Order 1972. Under this legislation John O'Hara has wide ranging powers to require any person to attend and give evidence or to furnish information on any matter in question at the Inquiry. This should help to allay public concerns, as the Inquiry has the power to call on all of the key people involved.

Conduct of the Inquiry

6. The Inquiry will gather all available documentary evidence, obtain written submissions and then decide who needs to give oral evidence to the Inquiry. It is anticipated that, save in exceptional circumstances, this evidence will be given in public.

7. In addition to the proceedings being conducted in public, all formal statements provided to the Inquiry are to be placed in the public domain. The final report of the Inquiry will be published.

Legal Representation

8. The families have requested access to some form of legal representation and advice in preparing their case and to protect their interests during the course of the Inquiry. The proceedings will allow for this and, in accordance with Cabinet Office guidance, the involvement of legal

representation during the course of the proceedings is a matter for the discretion of the Inquiry.

9. Cabinet Office guidance provides for the cost of legal representation to be met from public funds, and principles and procedures will need to be established governing the claiming and approval of legal expenses incurred by witnesses. Mr O'Hara will have discretion, within parameters agreed in advance, to determine the degree to which such costs incurred by witnesses should be met. He can recommend to the Department that it should pay for legal representation where it is necessary and where there are not other means by which that representation can be funded.

Provision of Expert Advice to Inquiry

10. Mr O'Hara will require access to professional paediatric and NHS general management advice. The Department has provided him with a list of appropriate candidates from both disciplines. To avoid any possible conflict of interest, this advice will be obtained from outside Northern Ireland and the source of advice will be determined by Mr O'Hara himself.

Guidance on the Prevention of Hyponatraemia

11. Following the inquest into Raychel Ferguson's death, the Chief Medical Officer convened a small working group to develop guidance on the prevention of hyponatraemia in children as a matter of urgency. The Guidance, issued in March 2002, emphasised that every child receiving intravenous fluids requires a thorough baseline assessment; that fluid requirements should be assessed by a doctor competent in determining this; and that fluid balance should be regularly monitored. Following this advice will prevent children from developing hyponatraemia.

12.The guidance has been issued as an A2 sized poster for display in all hospital units where children may receive IV fluids or rehydration.

13.CREST has also issued guidance on the management of hyponatraemia in adults (June 2003).

14.Following a review of this guidance, the CMO has set up a group to develop a care pathway for fluid management in children.

Procedures for the Investigation of Hospital Deaths

15. All deaths that are not due to natural disease must be referred to the Coroner. The Coroner will investigate all such deaths, which will include circumstances such as:

- sudden or unexpected deaths;
- deaths where the cause of death is unknown or a doctor is unable to issue a medical certificate stating the cause of death (death certificate);
- all unnatural deaths (including accidents, suspected suicide or suspicious deaths);
- deaths thought to be due to negligence;
- deaths occurring during surgery or anaesthesia; and
- deaths from any cause other than natural disease.

16.The Coroner will decide on the need for a post mortem examination and subsequently if an inquest is required. The Coroner's investigation is supported by the Police Service for Northern Ireland.

17.A Safety in Health and Social Care Steering Group was established by the Department following the publication of the consultation document "Best Practice, Best Care" in April 2001. In July it issued interim guidance (HSS (PPM) 06/04) to the HPSS and Special Agencies on the

reporting and management of serious adverse incidents. This includes a requirement for all HPSS organisations and Special Agencies to have nominated a senior manager at Board level who will have overall responsibility for the reporting and management of serious adverse incidents within the organisation. In addition, if the senior manager considers that the incident is likely to:

- be serious enough to warrant regional action to improve safety or care within the broader HPSS;
- be of public concern; or
- require an independent review,

then he/she is required to provide the Department with a brief report within 72 hours of the incident being discovered. These reports are shared with the Chief Medical Officer and other professional and administrative staff as appropriate.

18. The Department has also established a multi-agency group comprising Departmental officials and representatives from the Police Service of Northern Ireland, the Health and Safety Executive (HSE), and the Coroners' service to develop a memorandum of understanding for the investigation of death and serious incidents in hospitals. This will take account of a recent memorandum of understanding issued for consultation in England and Wales: "Investigating patient safety incidents (unexpected death or serious untoward harm): a protocol for liaison and effective communications between the NHS, Association of Chief Police Officers and HSE".

Lines to take

Expression of Sympathy

- The death of a child is one of the worst things that can happen to any parent. I appreciate that the death of your child (use name) in a hospital setting and the subsequent investigation and publicity must be very difficult for you as parents and for your wider family circle as well. I want to offer you my most sincere sympathy and assure you that the Independent Inquiry that I have set up will rigorously examine all the issues.

Inquiry – Independence and Terms of Reference

- I regard it as very important that the general public should have confidence in the health service and in the standards of performance of all who work in it. That is why I have appointed John O'Hara QC to conduct an independent Inquiry into the issues raised by the recent UTV Insight programme.

- I am confident that the Terms of Reference of the Inquiry provide the necessary breadth to enable your concerns and those of the wider public to be fully addressed so as to restore public confidence in our health care system and help bring closure for those most affected by these tragic deaths.

- The Inquiry is independent from Government and the hearing of oral evidence will be conducted in public, save in exceptional circumstances as may be determined by the Chairman. All formal statements provided to the Inquiry are to be placed in the public domain and the final report will be published.

Powers of the Inquiry

- The Inquiry is being established under Article 54 and Schedule 8 of the Health and Personal Social Services (NI) Order 1972. This legislation gives John O'Hara wide-ranging powers to require any person to attend and give evidence or to furnish information on any matter in question at the Inquiry.

Length of the Inquiry

- I have asked Mr O'Hara to report by 1 June 2005, but if he requires additional time to complete his investigations I will consider this. Obviously it is in everybody's best interests to complete this investigation as quickly as possible. I am aware of the investigation being conducted by the PSNI and there is a possibility that it could have an impact on the progress of Mr O'Hara's work, but I know it is his intention to proceed as efficiently and speedily as possible.

Provision of Expert Advice

- The Inquiry will have access to whatever professional advice the chairman deems necessary, including clinicians and NHS general management advice. To avoid any possible conflict of interest, this advice will be secured from outside Northern Ireland and the source of advice will be a matter for Mr O'Hara.

Legal Representation

- The proceedings will allow families to have access to appropriate legal representation and advice in preparing their case and to protect their interests during the course of the Inquiry. The involvement of legal representation during the course of the proceedings is at the discretion of John O'Hara. Within

parameters agreed in advance, he will be able to determine the degree to which costs incurred by witnesses should be met, but it is anticipated that the Department will meet all reasonable costs.

Procedures for the Investigation of Hospital Deaths

- The current system provides for the coroner to investigate all unexplained or unexpected deaths. Following a Home Office review and the ongoing work of the Shipman Inquiry, proposals are being considered for the reform of the coroner and death certification service.

- We are continuing to take steps to ensure the very highest safety and quality standards in our health services. In July the Safety in Health and Social Care Steering Group issued interim guidance to the HPSS and Special Agencies on the reporting and management of serious adverse incidents. In addition, my Department has also established a multi-agency group comprising Departmental officials and representatives from the Police Service of Northern Ireland, the Health and Safety Executive, and the Coroners' Service to develop a memorandum of understanding for the investigation of death and serious incidents in hospitals.

Guidance on the Prevention of Hyponatraemia

- Following the inquest into the death of Raychel Ferguson, the Chief Medical Officer acted immediately to develop guidance that would prevent a similar incident happening again. This

guidance has been incorporated into clinical practice since March 2002. Guidance has also been issued to prevent hyponatraemia in adults.

- However we are not complacent and we regard the death of any child in hospital as a tragedy from which every possible lesson must be learnt and acted upon. That is why I have set up this Inquiry and will act upon its findings.