BRIEF FOR EXPERT ON PAEDIATRIC PATHOLOGY

RE: CLAIRE ROBERTS

Introduction

(1) Claire Roberts is one of four children whose deaths are the subject of a public inquiry being conducted by John O'Hara Q.C.

(2) Claire was born on 10th January 1987. She was admitted to the Royal Belfast Hospital for Sick Children ("RBHSC") on 21st October 1996 with a history of malaise, vomiting and drowsiness and she died on 23rd October 1996. Her death certificate recorded the cause of her death as Cerebral Oedema and *"Status Epilephicus"* [sic].

(3) The certification was subsequently called into question after a television documentary into the deaths of Adam Strain and two other children (Lucy Crawford and Raychel Ferguson). As a result an Inquest into Claire's death was carried out nearly 10 years after her death by Mr. John Leckey on 4th May 2006.

(4) The Verdict on Inquest found the cause of Claire's death to be: *"1(a) Cerebral Oedema due to (b) Meningoencephalitis, Hyponatraemia due to excess ADH production and Status Epilepticus"*. The Coroner also made findings, principally that the degree of hyponatraemia suffered (fall in her serum sodium level to 121mmol/L) contributed to the development of the Cerebral Oedema that caused Claire's death, but that Meningoencephalitis and Status Epilepticus were also causes albeit that he could not apportion the contribution of each to her death.

(5) The Coroner's findings gave rise to a new registration of the cause of Claire's death so as to reflect the Verdict.

Terms of Reference

(6) The Inquiry was established under the Health and Personal Social Services (Northern Ireland) Order 1972, by virtue of the powers conferred on the Department by Article 54 and Schedule 8 and it continues pursuant to the Inquiries Act 2005.

(7) The original Terms of Reference for the Inquiry as published on 1st November 2004 by Angela Smith (then Minister with responsibility for the Department of Health, Social Services and Public Safety) were revised in 2008 in response to the Crawford family's wish to have Lucy excluded from the Inquiry's work. The Revised Terms of Reference under which the Inquiry is operating are:

> *"To hold an Inquiry into the events surrounding and following the deaths of Adam Strain and Raychel Ferguson, with particular reference to:*

1. *The care and treatment of Adam Strain and Raychel Ferguson, especially in relation to the management of fluid balance and the choice and administration of intravenous fluids in each case.*
2. *The actions of the statutory authorities, other organisations and responsible individuals concerned in the procedures, investigations and events which followed the deaths of Adam Strain and Raychel Ferguson.*
3. *The communications with and explanations given to the respective families and others by the relevant authorities.*

In addition, Mr O'Hara will:

(a) Report by 1 June 2005 or such date as may be agreed with the Department, on the areas specifically identified above and, at his discretion, examine and report on any other matters which arise in connection with the Inquiry.
(b) Make such recommendations to the Department of Health, Social services and Public Safety as he considers necessary and appropriate".

The Inquiry

(8) The Inquiry has appointed Inquiry Expert Advisors[1] to assist it in its investigations in respect of all 4 children. Their work is peer reviewed by a team of international experts.[2]

(9) The Inquiry has also engaged Expert Witnesses.

Claire's clinical history prior to October 1996

(10) Claire Roberts was born on 10th January 1987. Claire was first admitted to hospital on 23rd July 1987 when she was admitted to The Ulster Hospital in Dundonald ("the Ulster Hospital"), aged 6½ months, because of seizures. Further episodes occurred during August 1987 resulting in treatment with the anticonvulsant, carbamazepine (Tegretol ®). Further convulsions occurred in September 1987, together with findings on examination of floppiness with possible abnormal posture and tone on the left side.

(11) She was referred to the RBHSC on 3rd September 1987 under the care of Dr. Elaine Hicks, Consultant Paediatric Neurologist[3]. Investigations, including brain CT scanning and electroencephalography, did not define any causative diagnosis for her epilepsy. She was prescribed the anticonvulsant sodium valproate (Epilim®) before discharge, while weaning her from her previously prescribed Tegretol[4].

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1 Dr. Peter Booker (Paediatric Anaesthesia), Dr. Harvey Marcovitch (Paediatrics), Ms. Carol Williams (Paediatric Intensive Care Nursing), and Mr Gren Kershaw (Health Service Management and Patient Safety)

2 Professor Allen Arieff at the University of California Medical School in San Francisco (Internal Medicine & Nephrology), Dr. Desmond Bohn of the Critical Care Unit at the Hospital for Sick Children in Toronto (Paediatric Anaesthesia), Ms. Sharon Kinney at the Intensive Care Unit and Clinical Quality and Safety Unit at the Royal Children's Hospital in Melbourne (Paediatric and Intensive Care Nursing)

3 Ref: 090-018-033, 034

4 Ref: 090-015-026, 027

(12) Claire's convulsions ceased at the age of 4 years (September 1991) and Claire was weaned off Epilim over 3 months from February 1995.[5]

(13) In May 1996, she was seen by Dr. Colin Gaston, Consultant Community Paediatrician in relation to behavioural problems including inattention, being easily distracted, having obsessions and constant activity. Dr Gaston noted, in his letter to Claire's GP, that he had discussed with Mrs. Roberts the option of treating Claire with a stimulant medication, such as Ritalin, Pemoline or amphetamine[6].

(14) Dr. Gaston saw the family again on 1st August 1996 and prescribed Ritalin 10 mg daily until October 2nd 1996. It is not believed that Ritalin was continued after that date. There is no mention of it in her A&E admission notes[7] which record no medication, or in the ward assessment[8].

Claire's Admission to RBHSC on 21st October 1996

Examination by G.P.

(15) On 21st October 1996, Claire's GP referred her for admission to the RBHSC. She was described as a 9-year-old girl with severe learning disability and past history of epilepsy who had been seizure-free for 3 years and had been weaned off anticonvulsant drugs 18 months previously. The referral also stated "*No speech since coming home. Very lethargic at school today. Vomited x 3 – speech slurred. Speech slurred earlier*"[9]. Claire was described as pale, not liking the light and with no neck stiffness. The GP considered her tone increased on the right side and suggested that Claire was post-seizure and had an underlying infection[10].

Examination at RBHSC Accident & Emergency

(16) Claire was admitted to the RBHSC later on 21st October 1996 exactly 4 months after the conclusion of the Inquest into Adam Strain's death at the RBHSC of cerebral oedema with dilutional hyponatraemia and impaired cerebral perfusion as contributory factors. The A&E note for Claire records non-bilious vomiting since the evening. She was drowsy, tired, apyrexial with no other abnormal signs except for increased left sided muscle tone and reflexes. At 20:45, a decision was made to admit Claire to hospital under the care of Dr. Heather Steen, Consultant Paediatrician[11].

5 Ref: 099-006-008, 099-007-009
6 Ref: 090-013-017, 018
7 Ref: 090-011-013
8 Ref: 090-022-050
9 Ref: 090-011-013
10 Ref: 090-011-013
11 Ref: 090-012-014

Claire's Admission to Allen Ward on 21st October 1996

Examination by Dr. O'Hare

(17) The admission note (timed at 20:00) refers to Claire as vomiting at 15:00 and every hour since and to her having experienced a loose bowel motion 3 days previously. The admitting doctor, Dr. O'Hare, noted that Claire had severe learning difficulties but normally had meaningful speech and referred to the recent trial of Ritalin and its apparent side effects[12]. Dr. O'Hare also noted that Claire sits-up and stares vacantly and was ataxic. She was not responding to her parents' voices and only intermittently responding to a deep pain stimulus. She had cogwheel rigidity of her right arm and increased tone in all other limbs. Tendon reflexes were brisker on the right than the left and there was bilateral ankle clonus[13].

(18) The admission diagnoses were noted as: (1) Viral illness; (2) Encephalitis (but this was subsequently scored through)[14]. Treatment was noted as "*IV fluids, IV diazepam if seizure activity*". She was to be reassessed after fluids.

Fluid management on 21st October 1996

(19) An IV prescription chart was prepared, ordering 500 ml of 0.18% sodium chloride in 4% dextrose to be given at 64 ml/h (equivalent to 65 ml/kg/24 h).[15] The nursing care plan referred to administering *'IV fluids as prescribed by doctor, according to hospital policy.'*[16] The nursing record includes a fluid balance chart. This stated that treatment was started at 21:30 with 64 ml hourly of 5/N saline. By 07:00, Claire had received 536 ml (just under 57 ml hourly). During those 9 ½ hours, she was noted by Nurse McRandal to have had 1 "*medium*" and 5 "*small*" vomits.[17] The nursing notes describe these vomits as bile-stained; this was a change from the A&E note, where vomits were described as "*non-bilious*".[18]

Review at midnight

(20) A medical note at midnight stated that she was slightly more responsive and had no meningism.[19] It was noted that she would be observed and reassessed in the morning. Directly beneath that note is an entry for the blood biochemical and haematological results:[20]

"*Sodium 132↓; Potassium 3.8; Urea 4.5; Glucose 6.6; Creatinine 36; Chloride 96;*

12 Ref: 090-022-050
13 Ref: 090-022-051
14 Ref: 090-022-052
15 Ref: 090-038-134
16 Ref: 090-043-146
17 Ref: 090-038-133
18 Ref: 090-040-140, 090-012-014
19 Ref: 090-022-052
20 Ref: 090-022-052

Haemoglobin 10.4; Packed cell volume 31; White cell count 16.5; platelets 422,000"

The white cell count result of 16.52 on admission was from a sample taken at approximately 22:00/22:30 on 21st October 1996.[21] Claire's white cell count results then dropped to 9.4 as recorded in the medical notes at 04:00 on 23rd October 1996[22] which appears to have the printed lab report result of 9.35.[23] There are also printed lab reports for white cell count results of 5.7 from a specimen on 23rd October 1996,[24] and of 5.54 from a specimen on 24th October 1996.[25]

Claire's care and treatment during the morning of 22nd October 1996

Ward round on morning of 22nd October 1996

(21) In the late morning of 22nd October 1996 Claire, who was described as usually very active, became lethargic and vacant. She was seen by Dr. Sands (Registrar, Paediatric Cardiology) who concluded "*status epilepticus – non-fitting*" and rectal diazepam given.[26] She was described in the note of the ward round as apyrexial, pale and showing little response compared to normal. Her pupils were sluggish to light. The differential diagnoses of "*encephalitis/ encephalopathy*" was seemingly added later.[27]

Fluid management during 22nd October 1996

(22) The fluid chart for 22nd October 1996[28] does not note the solution given. However, an undated prescription chart[29] referred to 500 ml of No.18 solution at 64 ml/hr. A total of 562 ml was given over eight hours from 08:00, i.e. 70 ml/h.

Claire's care and treatment during the afternoon of 22nd October 1996

Dr Webb's attendance with Claire at 14:00

(23) At 15:10 Claire was reported as having a 5-minute strong seizure at 15:25. At 16:30, her teeth tightened slightly.[30] Dr. Webb saw Claire and noted a history of vomiting and listlessness followed by a prolonged period of poor responsiveness.[31] He added that she appeared to improve after rectal diazepam, given at 12:30. She was afebrile and pale with no meningism. She

21 Ref: 090-022-052, 090-032-108
22 Ref: 090-022-057
23 Ref: 090-032-111
24 Ref: 090-032-112
25 Ref: 090-032-110
26 Ref: 090-040-141
27 Ref: 090-022-052, 053
28 Ref: 090-038-135
29 Ref: 090-038-136
30 Ref: 090-042-144
31 Ref: 090-022-055

opened her eyes to voice, was non-verbal, withdrew (limb) from painful stimulus and had (query) reduced movements on the right side. He found mildly increased tone in her arms and symmetrical brisk reflexes, sustained ankle clonus and upgoing plantar responses. Claire was sitting up with eyes open and looking vacant, not obeying commands. She did not have papilloedema[32].

(24) Dr. Webb's impression was that Claire's motor findings were probably long-standing, which should be checked with notes but that the picture was of acute encephalopathy, most probably postictal in nature. He noted the normal biochemistry profile.[33] He suggested starting Claire on the anticonvulsant phenytoin intravenously: 18 mg/kg as a first dose, followed by 2.5 mg/kg 12 hourly. He asked for hourly neurological observations and a CT scan the following day if she did not wake up.[34]

(25) The SHO noted calculations of phenytoin dose at 14:30 and ordered a dose of 18 mg x 24 h which he wrongly calculated as 632 mg rather than 432 mg. The calculation of the continuing dose of 2.5 mg/kg 12 hourly is then stated as 60 mg 12 hourly.[35]

(26) Those doses were ordered on a prescription chart.[36] The nursing notes record a stat dose of phenytoin given at 14:45,[37] with a second dose at 23:00 following blood sampling for phenytoin levels[38].

Dr Webb's second attendance with Claire

(27) The next medical entry (untimed) refers to Claire being seen by Dr. Webb and being 'still in status'. It goes on to calculate a dose of the anticonvulsant/ sedative midazolam to be given as a first dose of 0.5 mg/kg (12 mg) followed by 2 mcg/kg/minute, calculated as 2.88 mg/h. The prescription chart records the once only dose of 120mg (rather than 12mg) with the time of administration 15:25.[39] There is no signature on the drug chart to confirm that this stat dose was given[40] but the nursing notes record *'stat IV Hypnoval* [midazolam] *at 3.25pm.'*[41] No dosage was recorded against this entry. The actual dose administered to Claire is not known. The continuing infusion of midazolam was ordered as 69 mg in 50 ml normal saline to be given at 2 ml/h, which is confirmed by the fluid charts as having been given from 16:30[42]. Also from

32 Ref: 090-022-053, 054
33 Ref: 090-022-054
34 Ref: 090-022-054
35 Ref: 090-022-054
36 Ref: 090-026-075
37 Ref: 090-040-141
38 Ref: 090-040-138, 090-038-135, 090-026-077
39 Ref: 090-040-141
40 Ref: 090-026-075
41 Ref: 090-040-141
42 Ref: 090-038-135, 136

16:00, no 18 solution was continued with 452 ml given over 7 h to 23:00 (64 ml/h)[43].

Dr Webb's examination at 17:15

(28) At 17:00, Dr Webb described Claire as largely unresponsive with intermittent vomiting and chewing. He prescribed the antibiotic cefotaxime and the anti-viral drug acyclovir for 48 hours, although he noted that he did not think meningoencephalitis very likely. He noted that stool, urine, blood and a throat swab should be checked for evidence of enterovirus infection. He also suggested an additional anticonvulsant intravenous infusion: sodium valproate 20 mg/kg as an initial dose, followed by 10 mg/kg over 12 h.[44] A nursing note at 17:15 referred to Claire being given a stat dose of Epilim and being responsive only to pain, remaining pale and having the occasional episode of teeth clenching.[45] A further attack *"teeth clenched and groaned"* for *"1 min[ute]"* is recorded at 19:15.

Claire's care and treatment during the evening of 22nd October 1996

(29) At 21:00, a nurse reported that Claire had a 30-second episode of screaming and drawing up of her arms with her pulse rising to 165. A doctor was informed.[46]

Serum sodium result at 23:30

(30) At 23:30, an SHO noted that a blood sample likely to have been taken when the doctor attended at 21:00 – 21:30, showed a sodium concentration of 121 mmol. It was noted: '*Hyponatraemic - ? Fluid overdose with low sodium fluids. ? SIADH*' and '*Imp[ression]. ? need for ↑ sodium content in fluids. Discussed with registrar - ↓ fluids to ⅔ of present value – 41 ml/h. Send urine for osmolality.*'[47]

(31) The neurological observation chart, started at 13:00 on 22nd October 1996, shows that at 13:00 she was noted as *opening her eyes to speech* and at 14:30 as *opening eyes to pain*. Thereafter, hourly observations until 02:00 on 23rd October 1996 all recorded "*no eye opening*". "*Best verbal response*" was noted as "*none*" from 13:00 to 18:00 and thereafter as "*incomprehensible sounds*". Her "*best motor response*" was noted as "*obey commands*" at 13:00 and at 20:00, "*localise pain*" between those times and "*flexion to pain*" thereafter.[48]

(32) Her Glasgow Coma Scale (GCS) score was given as 9 on first assessment and thereafter 6 - 7, excepting 8 at 20:00. There was a rise in temperature from normal to between 37.5 C and 38 C from 19:00 and of pulse rate from <90 at

43 Ref: 090-038-135
44 Ref: 090-022-055
45 Ref: 090-040-141, 090-142-144
46 Ref: 090-042-144
47 Ref: 090-022-056
48 Ref: 090-039-137

13:00 to 115 at 18:00, thereafter remaining at 100-105. There was no significant change recorded in blood pressure.[49]

Respiratory arrest on 23rd October 1996

(33) At 02:30, a nurse noted "*Slight tremor of right hand noted lasting few seconds. Breathing became laboured and grunting. Respiratory rate 20 per minute. Oxygen saturations 97%. Claire stopped breathing. The medical note states that Claire 'had been stable when suddenly she had a respiratory arrest and developed fixed dilated pupils."* The doctor who attended noted she was "*Cheyne-Stoking"*. Oxygen was being administered by a facemask and *"bagging"* with oxygen saturation in the "*high 90s"* and a "*good volume pulse*."

Transfer to PICU

(34) Claire was transferred to intensive care at 03:25'[50] on 23rd October 1996 with the first ICU note at 04:00. It noted that Claire was "*now intubated and ventilated. Pupils fixed and dilated. Bilateral papilloedema [swelling of the optic discs visible using an ophthalmoscope and implying raised intracranial pressure] L>R. No response to painful stimuli*". She was given mannitol to reduce the cerebral oedema and dopamine and a brain CT scan was requested. At that time, a second serum sodium concentration was recorded at 121mmol/L, which was the same as the result recorded at 23:30 on 22nd October 1996.[51]

(35) Dr. Webb noted, at 04:40, "*SIADH* [syndrome of inappropriate antidiuretic hormone secretion] – *hyponatraemia, hyposmolarity, cerebral oedema + coning following prolonged epileptic seizures. Pupils fixed + dilated following mannitol diuresis. No eye movements*".[52]

(36) The CT scan was reported as showing "*severe diffuse hemispheric swelling with complete effacement of the basal cisterns. No focal abnormality identified*".[53]

(37) Dr. McKaigue, ICU Consultant, ordered a dopamine infusion to maintain blood pressure and a close check on serum sodium and osmolality and urine output. He changed the IV infusion fluid to 0.9% saline and at 08:10 and at 08:50 requested 2 hourly measurements of urea and electrolytes.[54]

(38) An untimed note (possibly between 08:10 and 18:25) is made by Dr. Robert Taylor, Consultant Paediatric Anaesthetist. It refers to Claire becoming hypotensive (BP 70/?) "*with DI* [diabetes insipidus]*, given HPPF 500 ml, needing DDAVP to limit polyuria"* and he further notes a "*serum sodium level of 129 (from 121)".*

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49 Ref: 090-039-137
50 Ref: 090-040-138, 139
51 Ref: 090-022-057
52 Ref: 090-022-057
53 Ref: 090-022-058
54 Ref: 090-022-059, 060

(39) Following two negative brain stem tests, ventilation was discontinued at 18:45 on 23rd October 1996. The Death Certificate issued for Claire gave the cause of death as cerebral oedema secondary to status epilepticus.[55]

Claire's Death on 23rd October 1996

Death certificate

(40) An unsigned note, apparently in the hand of Dr. Steen, was made in Claire's medical notes "*Death certificate Issued - cerebral oedema 2° to status epilepticus*".[56]

(41) A death certificate was issued dated 24th October 1996 citing the causes of death as "*1(a) Cerebral oedema and (b) status epilephicus* [sic]*".* [57] Dr. Webb states he was not consulted as to the content of Claire's death certificate.[58] Dr. Steen stated at the Inquest that at the time she thought that Claire had died from cerebral oedema due to neurological causes.[59]

Decision not to report to the Coroner

(42) An entry in the "*Diagnosis of Brain Death*" assessment, completed by Dr. Heather Steen, in response to the question "*Is this a Coroner's case*" answers "*No*".[60] This answer is consistent with Mr. Roberts' statement that Dr. Steen told him at approximately 19:00 on Wednesday 23rd October 1996 that there would be "*no need*" for an inquest.[61] Claire's death was not reported to the Coroner. The basis upon which the decision not to report Claire's death to the Coroner and the reason for it are matters that are being investigated by the Inquiry. Dr. Webb states that he was not involved in this decision and does not know why Claire's case was not referred to the Coroner.[62]

Brain only autopsy

Decision to conduct a brain-only autopsy

(43) Dr. Steen obtained consent from Mr. and Mrs. Roberts for a limited 'brain only' autopsy.[63] The Autopsy consent form was signed by Mr. Roberts on 23rd October 1996.[64]

(44) Dr. Steen completed the undated Autopsy Request Form, in which she records the clinical diagnosis as "*Cerebral oedema 2° status epilepticus ?underlying*

55 Ref: 090-022-061, 091-012-077
56 Ref: 090-022-061, 091-012-077
57 Ref: 091-012-077
58 Ref: WS-138-1 p.54 Q 35
59 Ref: 091-011-067
60 Ref: 090-045-148
61 Ref: 091-004-007
62 Ref: WS-138-1 p.53 Q34
63 Ref: 090-022-061
64 Ref: 090-054-185

encephalitis", and the clinical problems in order of importance as "*(1) Cerebral Oedema; (2) Status Epilepticus; (3) Inappropriate ADH secretion; (4) ?viral encephalitis".*[65]

(45) Dr. Webb states that he was not aware that Claire's post mortem was limited to brain only, that he had no input into the decision to have a limited post mortem nor any discussion with the Roberts family as to the nature of the post mortem and why the post mortem was limited. He would have expected there to have been a full post mortem subject to parental consent. At the time of referral for limited post mortem, he states he thought Claire had died from cerebral oedema due to SIADH following a viral meningitis.[66]

Autopsy Request Form

(46) The Autopsy Request Form is signed by Dr Heather Steen[67]. The date the form was filled in is unknown. Dr Steen noted as follows:

> "*9 ½ year old girl [with] a history of mental handicap admitted with increasing drowsiness and vomiting. Well until 72 hours before admission. Cousin had vomiting and diarrhoea. She had a few loose stools and then 24 hours prior to admission started to vomit. Speech became slurred and she became increasingly drowsy. Felt to have sub clinical seizures. Treated [with] rectal diazepam / IV phenytoin / IV valproate. Acyclovir + cefotaxime cover given. Serum Na^+ dropped to 121 @ 23-30 hrs on 22-10-96. ?Inappropriate ADH secretion. Fluids restricted. Respiratory arrest 0300 23-10-96. Intubated + transferred. ICU – CT scan – cerebral oedema. Brain stem death criteria fulfilled @ 0600 + 1815 hrs. Ventilation discontinued 18-45 hrs.*"

Autopsy

(47) An autopsy of the brain only was carried out on 24th October 1996, the brain cut was carried out on 28th November 1996 and slides were examined in or about January 1997. Dr. Herron, a Senior Registrar in Neuropathology at the time, is named as the sole pathologist in the undated, "*Provisional Anatomical Summary"* report. [68] He accepts he was likely to have been involved in the brain cut and was the author of that provisional report.[69] It is initialled by him (Dr. Herron was also the pathologist who performed the Autopsy on Raychel Ferguson in June 2001).

(48) The final Autopsy Report was not conclusive. The Report noted *"features"* of cerebral oedema with neuronal migrational defect and a low-grade sub acute meningoencephalitis. It concluded that the reaction in meninges and cortex was suggestive of a viral aetiology although viral studies were "*negative during life*

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65 Ref: 090-054-183 & 090-054-184
66 Ref: WS-138-1 p.52 Q34, p.91 Q79
67 Ref: 090-054-183 to 184
68 Ref: 090-005-007
69 Ref: WS-224-3 p.5 Q4c, p 14 Q25, p.9 Q7b

and on a post-mortem CSF". It could not rule out a metabolic cause.[70] There was no other discrete lesion identified to explain epileptic seizures.

Authorship of the autopsy report

(49) Dr. Herron has recently stated in his witness statements that he was not the author of that final Autopsy Report.[71] Dr. Herron admits that until 2011 he had assumed that he was the author of that final Autopsy Report.[72] He gave oral evidence at Claire's inquest on 25th April 2006 in relation to the examination and appearance of the brain after fixation and in his sworn Inquest deposition, he produces a copy of "*my report*" which is exhibited.[73] He states that it was only when documents were retrieved from off-site storage in 2011 to answer his Inquiry Witness Statement request that he saw the draft autopsy reports edited by Dr. Mirakhur and he realised he was not the actual author of the final autopsy report.[74]

(50) Dr. Herron states that he does *"remember specifically what was done before the Inquest in 2006, but [he] do[es] recall reviewing the case in detail.... I also read the final autopsy report and reviewed the slides... Also, following review of the case [he] agreed with the commentary and the conclusion in the case (as written in the final autopsy report)"*. [75] Dr. Herron claims that he was able to make certain comments in his oral evidence to the Coroner based on his review.[76]

(51) Dr. Herron believes that the author was in fact Dr. Meenakshi Mirakhur[77], his supervising Consultant Neuropathologist, who was Head of the Regional Neuropathology Service/Link Laboratories between February 1988 to December 2010. Dr. Mirakhur's supervision of the neuropathology trainees, including Dr. Herron, usually involved day-to-day supervision in the mortuary and case discussion with trainees and some of the clinical colleagues involved, and also a weekly organ review which took place after fixation.[78] Dr. Mirakhur was the same consultant whose involvement in the production of Dr. Armour's autopsy report on Adam is in issue.

(52) Dr. Herron has stated that in the 1990s the policy was to record the junior doctor's (and not the consultant's) name on the autopsy reports and provisional anatomical reports, but that since then the consultant pathologist is named on all reports. [79] He has also stated that the final Report would not have been sent out had it not been signed, that the signed report is the copy that goes to the clinician and that to his knowledge a final report has never left

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70 Ref: 090-003-004, 005
71 Ref: WS-224-1 p.3 Q.7
72 Ref: WS-224-3 p.15 Q13b-f
73 Ref: 091-005-015
74 Ref: WS-224-1 p.7 & 14 Q25; WS-224-3 p.14 Q13a.
75 Ref: WS-224-3 p.15-16 Q13(h)(i)-(iv); p.23 Q20h
76 Ref: WS-224-3 p.16 Q13h(ix), p.17 Q13h(vi-x)
77 Ref: WS-224-3 p.21 Q19f
78 Ref: 306-066-002
79 Ref: WS-224-3 p.4 Q2 & p.7 Q5b

neuropathology unsigned.[80] The DLS have informed the Inquiry in a letter dated 20th June 2012[81] INQ-0961-12 paragraph 3: that "*there is no copy of the signed final report in the Neuropathology Department file. Dr Herron has advised that he does not know whom it was sent*".

(53) Dr. Mirakhur states that the final Report was produced jointly with Dr. Herron.[82] She claims that it was "*not usual to put in the Consultant's name if the autopsy was carried out by a person of the status of a Senior Registrar who also drafted the report*" and that she supervised Dr. Herron as part of the team. She also accepts that it is the usual practice for the author to sign such reports.[83] Dr. Herron states that he "*may have been involved in preparing further documents or in discussions, but [he] does not remember this specifically.*"[84] Dr. Mirakhur was not asked to attend or notified by the Coroner regarding the inquest. [85] She states that Dr. Herron delivered the pathological findings of Claire's autopsy at the Inquest because his name was on the report and he was a consultant by the time of the Inquest.

Discussions with Claire's parents post-October 1996

Notification of Autopsy Report

(54) Dr. Steen's letter dated 6th March 1997 to Dr. McMillin, Claire's GP, explained Claire's post mortem results, but does not appear to have enclosed a copy of the Autopsy Report. Dr. Steen informed Dr. McMillin that the cerebral tissue showed abnormal neuronal migration [as described by Dr. Herron] would have accounted for her learning difficulties and that other changes 'were in keeping with a viral encephalomyelitis meningitis' (the basis for this diagnosis is unknown and this type of meningitis is not referred to in the autopsy report).

(55) Dr. Steen did not inform the GP of Claire's hyponatraemia, low serum sodium concentration results, and the fact that a metabolic cause could not be excluded. The autopsy Report was not placed with the medical records of Claire Roberts.

(56) Dr. Steen wrote to Mr. and Mrs. Roberts on 18th November 1996 offering to meet with them to discuss any queries they may have. She provided a leaflet about meningitis death-related issues although recognises that meningitis was not Claire's problem.[86]

(57) Dr. Webb wrote a letter to Mr. and Mrs. Roberts which purported to summarise the Autopsy facts and findings[87]. His letter does not mention:

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80 Ref: WS-224-3 p.7-8 Q5h
81 INQ-0961-12 paragraph 3
82 Ref: WS-247-1 p.6 Q8
83 Ref: WS-247-1 p.6 Q8a & c
84 Ref: WS-224-3 p.22 Q20e
85 Ref: WS-247-1 p.7 Q8g; p.17 Q35
86 Ref: 090-004-006
87 Ref: 089-001-001. The letter was dictated on 28 Feb 1997 and typed in or about 21 March 1997.

(a) Hyponatraemia.

(b) Any of Claire's low serum sodium concentration results.

(c) Inappropriate ADH secretion.

(d) No discrete lesion to explain epileptic seizures.

(e) Viral studies were negative during life and on post mortem CSF.

(f) That a metabolic cause could not be excluded.

(58) Mr. & Mrs. Roberts recall meeting Dr. Steen in March 1997 when the post mortem results were discussed. They state that Dr Steen explained that a viral infection had been identified at post mortem. Mr Roberts additionally recalls Dr. Steen stating that the virus itself could not be identified and she advised as to how an enterovirus starts in the stomach and can then spread to other parts of the body, as in Claire's case. He also recalls asking Dr. Steen if everything possible had been done for Claire and if anything else could have been done. He says that Dr. Steen reassured him that everything possible was done.

Coroner's Inquest

UTV documentary and aftermath

(59) Claire's cause of death was subsequently challenged after the UTV Live Insight documentary *"When Hospitals Kill"*, which was broadcast on 21st October 2004. The documentary dealt with the death primarily of Lucy Crawford but also the deaths of Adam Strain and Raychel Ferguson. Claire's parents watched that programme and were prompted to contact the RBHSC about the circumstances of their daughter's death[88].

(60) By letter, dated 16th December 2004, Mr. A.P. Walby, associate Medical Director of the Royal Group of Hospitals, reported Claire's death to Mr. John Leckey, H.M. Coroner. He summarised Claire's admission in 1996 and the subsequent events, consequent upon the screening of the UTV programme. He noted that Professor Young (Professor of Medicine, Queen's University Belfast) "*has examined the notes and in his opinion there was an indication that hyponatraemia had played a part in Claire's death …*"[89]

(61) The following day, Dr. Michael McBride, Medical Director, wrote to Claire's parents stating that the Trust's medical case review suggested that "*there may have been a care management problem in relation to hyponatraemia and that this may have significantly contributed to Claire's deterioration and death.*"[90]

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88 Ref: WS-253-1, p.17
89 Ref: 089-004-009
90 Ref: 089-005-010

Proceedings at Inquest

(62) The Inquest into Claire's death was carried out on 4th May 2006 by the Coroner who had engaged as experts:

(a) Dr. Robert Bingham, Consultant Paediatric Anaesthetist at Great Ormond Street Hospital ("Great Ormond Street") and

(b) Dr. Ian Maconochie, Consultant in Paediatric A&E Medicine at St Mary's, London.

(63) Dr. Bingham considered the admission diagnosis was reasonable and acute encephalopathy (viral or ictal) a likely cause of the presenting illness. He did not consider the serum sodium concentration of 132 mmol/L a likely cause. He also considered it reasonable to give Claire intravenous fluids, as she could not hydrate herself, and noted that she was given the fluid used as standard in 1996 within the recommended volume for full maintenance fluid therapy. He believed there were, however, reasons why Claire might have required fluid restriction – namely low level of metabolism related to impaired consciousness and possible reduced urinary output due to secretion of ADH which often accompanies both encephalopathy and nausea and vomiting. He concluded that if the reported sodium concentration of 121 mmol/L was accurate, then it was the likely cause of her deterioration and death. He could not exclude the possibility of an inaccurate reading given the subsequent ICU measurements, in which case acute encephalopathy was involved or even central. He considered it possible that "*aggressive treatment at 21:00 when her coma score reduced from 8 to 6, may have been effective*".

(64) In his evidence at the Inquest, Dr. Bingham stated he agreed with Dr. Maconochie's formulation of cause of death and that he considered her neurological illness caused ADH secretion. Hyponatraemia was not her presenting problem.[91]

(65) Dr. Maconochie considered the diagnosis of encephalitis / encephalopathy and that of non-convulsive status epilepticus had a high probability given her past history of seizures. He regarded management of these diagnoses was appropriate and did not comment on hyponatraemia as it was addressed by Dr. Bingham. He considered Dr. Webb and other members of the team looking after Claire gave careful and informed advice. At the Inquest, he gave his opinion as to cause of death as I(a) cerebral oedema; (b) encephalitis/encephalopathy and hyponatraemia and II status epilepticus.[92]

(66) He considered that the finding of a sodium concentration of 121 mmol/L should have led to an immediate repeat sample and clinical reassessment. In addition, a blood sample should have been taken the morning after her admission, which may have shown a decrease in serum sodium concentration.

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91 Ref: 091-006-021

92 Ref: 091-007-028

He considered her symptoms on 22nd October 1996 were consistent with a number of conditions including hyponatraemia but there was no hyponatraemia issue on presentation.[93]

(67) Dr. Webb gave evidence to the effect that when he first saw Claire he was uncertain whether there had been seizure activity on the day before admission but concluded, after speaking to Mrs. Roberts, that there had been a definite right-sided seizure the previous day. His conclusion was that Claire was having subtle non-convulsive seizure activity provoked by a viral infection, so appeared *'encephalopathic.'* He also raised other differential diagnostic possibilities. He commented that his note about her blood results as normal (when her serum sodium concentration was <135 mmol/L) was likely to be because he believed her sodium concentration was a product of her recent vomiting and diarrhoea and could not on its own have explained her current encephalopathy or seizures. He also believed he erroneously understood the result to have been from a sample taken that morning (rather than the night before) and his entry in the note was a memo to himself that it could not have explained her clinical state. He stated that he believed if he had understood the result to be from the previous evening he would have asked for an urgent repeat sample.[94]

(68) In his deposition, Professor Young noted that losses were not accurately recorded on Claire's fluid chart so that fluid balances could not be judged. He judged the possibility of an inaccurate laboratory result for sodium as negligibly small, provided an appropriate sample was taken.[95]

(69) Dr. Steen, the consultant paediatrician under whose care Claire had been admitted, stated to the Inquest that the blood test result at 23:30 on 22nd October 1996 should have led to a repeat test, reduction in fluid intake and a clinical reassessment. Her evidence did not make any reference to any attendance by her upon her patient Claire Roberts. She recalled being told that Dr. Webb had taken over her management, that she was not contacted until 03:00 on 23rd October 1996 and that the Glasgow coma score at 21:00 should have led to a discussion with a consultant.[96]

Inquest verdict and Coroner's findings

(70) The Inquest verdict gave as the cause of death 1(a) Cerebral Oedema due to (b) meningoencephalitis, hyponatraemia due to excess ADH production and Status Epilepticus.

(71) The Coroner also made findings, principally that the degree of hyponatraemia that she suffered (fall in her serum sodium level to 121mmol/L) contributed to the development of the Cerebral Oedema that caused her death, but that

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93 Ref: 091-007-028
94 Ref: 091-008-050 to 052
95 Ref: 091-010-063,064
96 Ref: 091-011-067, 8

Meningoencephalitis and Status Epilepticus were also causes albeit that he could not determine the proportionate contribution of each to her death.

(72) The Coroner's finding gave rise to a new registration on 10th May 2006 of the cause of Claire's death so as to reflect his Verdict on Inquest.[97] The revised Death Certificate does not appear to have been issued until 2nd February 2012.

PSNI Investigation[98]

(73) Following investigations into the deaths of Lucy Crawford and then Adam and Raychel, the PSNI commenced investigations into Claire's death in July 2005[99]. The PSNI engaged a number of experts to assist with its investigations:

(a) Dr. Dewi Evans, consultant paediatrician at Singleton Hospital, Swansea, provided a report at the request of the PSNI on 1st March 2008

(b) Dr. Brian Harding, consultant neuropathologist at Great Ormond Street, provided a report to PSNI on 22nd August 2007

(c) Dr. Rajat Gupta, consultant paediatric neurologist at Birmingham Children's Hospital, provided a report to the PSNI in October 2008

(d) Susan Chapman, Nurse Consultant for acute and high dependency care at Great Ormond Street, provided a report to the PSNI on 11th April 2008.

(74) Following the PSNI investigation, the Public Prosecution Service, on reviewing the evidence generated by the PSNI, took the decision, as with the other cases, not to proceed with any prosecutions against anyone involved in Claire's case.

Requirements

(75) One of the issues the Inquiry is concerned to investigate is the opportunity available at the time of or shortly after Claire's death to more fully understand how her death had been caused. The Inquiry is interested to assess whether these opportunities were properly used, and whether any shortcomings on the part of responsible persons or bodies led to a failure to accurately identify the cause of death.

(76) The Inquiry understands that the function of a pathologist is to determine the pathology causing death by striving to address and answer the questions raised by death. It appears to the Inquiry that if this function is performed effectively, the pathologist will have a key role to play in providing a coherent and accurate account of the cause of death.

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97 Claire's reissued Death Certificate – Ref: 303-015-297

98 Police Service of Northern Ireland

99 E-mail from DS Cross to DI Nicholl re: death of Claire Roberts – Ref: 097-028-271

(77) In the circumstances the Inquiry must examine how competently the post mortem was performed given the information which was or should have been available, whether it was performed to the standard expected at the time, how the pathologist could have failed to implicate hyponatraemia in the cause of death, whether there are any inconsistencies, omissions, or inaccuracies identifiable in the paperwork, the implication of inconsistencies, omissions or inaccuracies, and whether the conclusions were internally consistent and supported by the clinical and laboratory information available to the pathologist.

(78) The Inquiry team therefore requests your assistance with the following specific questions, arising out of the material received to date:

Questions

Decision not to report to the Coroner

1. Please describe the criteria governing referral of deaths such as Claire's to the Coroner. On what basis could the decision not to report Claire's death to the Coroner be justified?

2. Was Dr. Steen, in coming to the decision not to report Claire's death to the Coroner, correct in not holding discussions with, or seeking the advice of:

    (a) The Coroner;

    (b) Dr. Webb;

    (c) Dr. McKaigue;

    (d) Mr. and Mrs. Roberts?

3. In the light of PEL (93)36 Annex B, paragraph 3 (*"If a patient dies unexpectedly, the Clinician in charge of the case must report the death immediately to the Coroner")* please provide your opinion as to whether Claire's death should have been deemed unexpected/expected.

4. In all the circumstances should Dr. Steen, Dr. Webb or the pathologist have properly considered the death of Claire Roberts to be:

    (a) An unexpected death?

    (b) An unexplained death?

    (c) Complicated by a care management issue?

Decision to conduct a brain-only autopsy

5. In all the circumstances was there justification for the Autopsy to be limited to 'brain only'?

6. What information should have been conveyed to Claire's parents when obtaining consent for limited post mortem, and should the pathologist have played any part in this process?

7. Please provide any guidance extant in 1996-1997 in respect of gaining consent from next of kin for post mortem/ limited post mortem.

8. Should the reasons behind limiting the Autopsy have been entered into the medical notes or recorded in any other manner?

9. What are the potential investigative advantages/disadvantages of deciding to conduct a limited Autopsy?

Autopsy Request Form

10. Having regard to the Autopsy Request Form, and accompanying neuropathology documents, we would be grateful if you could provide comment in respect of the following issues:

    (a) The fact that the Form was neither dated nor timed, and the time request received in mortuary not specified.

    (b) Whether the Autopsy of Claire Roberts could have commenced before receipt of Autopsy Request Form.

    (c) The fact that the Autopsy day book sheet does not include hospital, ward number or hospital number, spells Claire's name incorrectly as *"Clair"* and enters a diagnosis which does not appear to be a quote from the Autopsy Request Form.

    (d) The fact that the Provisional Anatomical Summary (Ref: 090-005-007) is undated, gives an anatomical summary which does not appear to be a quote from the Autopsy Request Form, gives time of death at variance to Autopsy Request Form, and notes *"time of Necropsy 11:30am"* despite the fact that this is not recorded elsewhere.

    (e) The fact that Dr. Steen seemingly names Dr. Webb as Lead Consultant when she was the requesting and Named Consultant.

    (f) The fact that Dr. Steen omits to note that the Autopsy is limited to 'brain only'.

    (g) The fact that the date of admission is incorrect in respect of Claire's admission to either Allen Ward or PICU.

    (h) The fact that the *"History of Present Illness"* is inconsistent with the recorded history in the following respects:

        (i) *"Well until 72 hours before admission"*;

(ii) *"24 hours prior to admission started to vomit"*;

(iii) Omits to mention administration of the anti-convulsant drug Midazolam (notwithstanding the errors of calculation and administration in respect of this medication).

(i) The fact that, notwithstanding that the Form should *"list clinical problems in order of importance"* to *"enable the pathologist to produce a more relevant report"* and a history is given of low sodium, cerebral oedema, inappropriate ADH secretion and respiratory arrest; Dr. Steen does not cite hyponatraemia nor any *"other significant conditions contributing to the death but not related to the disease or condition causing it"*.

(j) The fact that the Form cites status epilepticus as a secondary cause of death on the death certificate, notwithstanding that Dr. Steen had not attended upon Claire Roberts and the suspicion of status epilepticus was unconfirmed.

(k) The fact that the Form was signed by Dr. Steen as the sole requesting Consultant (Dr. Webb did not sign it).

(l) The fact that the Autopsy Request Form does not specify the *"investigations"* performed but refers instead to a *"chart"* without indicating the content or relevance thereof.

(m) Is it possible that the Autopsy Report was written without reference to the medical records?

Autopsy Report

11. Having regard to the Autopsy Report, and the Provisional Anatomical Summary, we would be grateful if you could provide comment in respect of the following issues:

(a) The purpose of such a Report and what it might reasonably be expected to contain;

(b) The fact that the Report is unsigned, and that the Inquiry has not yet seen a signed version of this Report whether to indicate authorship or signify finalisation;

(c) The pathologist is given as Dr. Herron. This is now said not to be so. Do you find it readily understandable that Dr. Herron could have given erroneous evidence at the Inquest as to his authorship of the Report?

(d) Is it appropriate that the Autopsy Report should not be filed with the medical records of Claire Roberts?

(e) Is it appropriate that the Autopsy Report is not sent to the GP and/or Mr. and Mrs. Roberts?

(f) Would it have been appropriate to present the Autopsy Report at a mortality meeting/ audit or review meeting?

(g) Inaccuracies and inconsistencies with the medical record, namely:

(i) Time of death;

(ii) Age at death (no date of birth given);

(iii) She had no *"history of recent diarrhoea"*;

(iv) She did not have *"history of epileptic seizures since 10 months of age"*;

(v) Did not have *"similar symptoms"* to her cousin;

(vi) Did not start to vomit *"24 hours prior to admission"*;

(vii) Her fluids were not, in fact, restricted;

(viii) Her epilepsy was not *"iatrogenic"*.

(h) The difference between the Provisional Anatomical Summary and the Anatomical Summary appearing in the Autopsy Report.

(i) Whether the Anatomical Summary is sufficient/accurate/appropriate in light of the medical record?

(j) Of the 3 versions of the Report briefed, one is dated 11th February 1997 and bears Dr. Mirakhur's handwritten draft entry for *"anatomical summary"*. Is it usual to draft this after the *"comment"* section has been finalised and typed?

(k) The Report does not contain a cause of death section?

(l) Does the Report comply with the contemporaneous Guidelines for Post Mortem Reports (Royal College of Pathologists, August 1993)?

(m) Is it correct to interpret the Report as neither confirming nor rejecting viral infection, epilepsy or metabolic cause as a cause of death, and that it adds nothing to the previously understood facts surrounding her death namely cerebral oedema?

(n) The Report comments *"the features here are those of..."* How do you interpret this? Does it mean *"findings consistent with but not proof of"*? Are there conventions governing the phrasing employed in such reports?

(o) Do you agree with the conclusions expressed in the *"comment"* section given the findings described?

(p) Is there an inconsistency between the reference to *"focal collections of neuroblasts in the sub-ependymal zone suggestive of a migration problem"* and

the comment that "*the features here are those of... neuronal migrational defect*"?

(q) What, in all the circumstances, do you believe the relevance and implication of the reference to "*low grade subacute meninoencephalitis*" to be?

(r) What is your understanding of the words "*metabolic cause*" employed in the "*comment*" section?

(s) Was it appropriate, in all the circumstances, and given the information available to omit all reference to hyponatraemia? What importance should have been attached to the history given on "*serum sodium dropping to 121,? inappropriate ADH secretion, cerebral oedema and respiratory arrest*"?

(t) Should the pathologist have himself referred this case to the Coroner?

(u) Should Dr. Steen and/or Dr. Webb have considered referral to the Coroner upon receipt of the Autopsy Report?

(v) Do you agree with Dr. Steen's interpretation of the Report given to the GP on 6th March 1997 (Ref: 090-002-002)?

(w) Do you agree with the synopsis of the Report given by Dr. Webb by letter to Mr. and Mrs. Roberts (dictated 28th February 1997/ typed 21st March 1997) (Ref: 090-001-001)?

(x) Was the length of time from necropsy to Report unusually long or appropriate?

(y) Please comment on the professionalism and utility of this Report.

(z) Please comment on whether this Report is compliant with guidance and teaching in 1996/1997?

(79) It is fundamental importance to the Inquiry that it receives a clear and reasoned opinion on the matters raised here. Your report may form the basis for witness statement requests which the Inquiry will address to those who had responsibility for ascertaining the cause of Claire Roberts' death. Moreover, you are liable to be questioned in relation to the contents of your report at the public hearings of the Inquiry.

(80) If there existed any guidance or practices which are relevant to the issues you have been asked to address, please identify them, cite the references in your report and, if possible, provide copies of such documents to the Inquiry. You should refer to any available guidance in the UK generally and Northern Ireland in particular that may be salient to the issues raised and how they were applied at the time, together with an indication of how that guidance and its application have developed since then.

(81) If there are any other issues which have not been raised with you but which you regard as relevant and important in Claire's case with regard to its relationship to Adam's case, please inform the Inquiry as to these issues as soon as possible to enable the Inquiry to consider if they should be addressed in your report.

(82) If any of the issues raised fall outside your area of expertise please advise the Inquiry accordingly. Equally, if you believe that any issue may be better addressed by an expert in another field please inform the Inquiry of your view.

(83) Your assistance in compliance with the Inquiry's requirements should be provided in the form of a fully referenced Expert's Report. Your Report, and any supplemental or addendum Reports will be made public and will be peer-reviewed in accordance with the Protocol No.4 on Experts.

(84) The Inquiry has a large volume of materials available to it in relation to Claire's case. However, we consider that not all of that material is relevant to your task. Indeed not all the documents referenced in the passages set out above are being provided to you. Instead, we have provided you with what we believe are the most relevant materials for your purpose. These documents are described in the attached Appendix. If you believe that you require any additional documents the Inquiry will take steps to provide such documents to you.

APPENDIX OF KEY ACCOMPANYING DOCUMENTS

1. **File 089-001-** Letter from Dr. David Webb to Mr. and Mrs. Roberts (21st March 1997);
2. **File 090-** Royal Hospital Medical Notes and Records;
3. **File 091-** Coroner's Papers;
4. **File 236-** Dr. Waney Squier, Expert Neuropathologist;
5. **File 235-** Professor Brian Harding, Expert Neuropathologist;
6. **WS-224-1/ WS-224-2/ WS-224-3/ WS-224-4 -** Witness Statements to the Inquiry, Dr. Herron;
7. **WS-247-1/ WS-247/2 -** Witness Statements to the Inquiry, Dr. Mirakhur;
8. **Ref: 303-052** '*Report to the Inquiry into Hyponatraemia-Related Deaths*', Dr. Bridget Dolan;
9. **Ref: WS-013-2 p.5-** PEL 93(36);
10. **Ref: 091-012-077-** Death Certificate of Claire Roberts, October 1996;
11. **Ref: 303-015-297-** Death Certificate of Claire Roberts, February 2012;
12. **Ref: 112-030-045-** Discharge Advice Note
13. **Ref: 302-153-003-** Codes
14. **Ref: 302-070b-011-** Post-Mortem Consent
15. **Ref: 302-070b-010-** Second page of Autopsy Request Form
16. **Ref: 302-070b-012-18-** Draft Autopsy Report
17. **Ref: 096-006-035-** Cross Examination of Dr. Brian Herron
18. **Ref: 097-003-004-** Letter from Dr. Herron to Mr. Leckey dated 3rd February 2005
19. **Ref: 302-143-005-008-** Dr. Herron Pie-Chart and Sample Slides
20. **Ref: Transcript of Oral Hearings (Professor Cartwright) on 7th November 2012, p.87-95**
21. **Ref: Transcript of Oral Hearings (Professor Neville) on 5th November 2012, p.94-96**