Deposition of Witness taken on

CONOR EDWARD JOHN MITCHELL

the

day

of

(month),

(year), at inquest touching the death of

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, before me MR J LECKEY LL.B

Coroner for the District of GREATER BELFAST

as follows to wit: -

The Deposition of Joanna MITCHELL

of

who being sworn upon her

oath, saith

(Address)

Conor was born on the 12 October 1987 after an apparently normal birth with epidural assistance for approximately the last hour. However, the umbilical cord was around Conor's neck twice and I remember the Consultant saying, "You naughty boy", but there was no further mention of this. Conor weighed 7lbs 6oz and was a beautiful and healthy baby. We were concerned at about 5 months of age that Conor was not holding his head well and seemed to have visual problems when he wasn't looking to the left. At approximately 6 months our GP said Conor was blind but then a CAT Scan revealed that Conor had a brain injury. The visual problem was neurological. Within two or three weeks Conor, my mother and I were registered at a private neurological rehabilitation clinic in Somerset practising the Glen Doman method of therapy. Within three months Conor's vision was excellent and he was tracking and seeing in all directions. The regime we followed was continued for approximately 4 years and Conor did make progress but we were constantly looking for something more obviously effective. We then had a David Hart walker for Conor which gave him a degree of independent mobility. After this we did a long course of Hyperbaric Oxygen, Inflatable Limb Splints, Homoeopathic Ayervedic Therapy from India, Tomatis Sound Treatment from France and Amino Acid Therapy in Cyprus for 2 years. Our good friend, Linda Scotson, also the mother of a boy with Cerebral Palsy, was our guide and inspiration through these therapies, all of which Conor thoroughly enjoyed. Eventually last August we embarked on ANR Therapy which Linda had researched thoroughly and

P.T.O.

had developed from a previous therapy. The results were very exciting and approximately 100 families are getting extremely encouraging results from ANR. This therapy concentrates on gentle pressure around the diaphragm increasing blood supply to the body and normalising contractions in the trunk, thus allowing for proper placement of the arms and legs. Conor had mild Epilepsy and was taking Epilim (600mg 5 times a week, 400mg 2 times a week). Conor's seizures were absences where he would either have stared for a while or looked to the right or the left. These could last for between perhaps a few seconds to three minutes. Since working on Conor's diaphragm his respiration was greatly improved thus reducing the frequency of seizures. Until Conor's admission to hospital he had had only three small seizures since before Christmas, all typical little stares. These only occurred when Conor had over-exerted himself due to his exuberance and delight in crawling. extremely intelligent, loved maths, science, poetry and exciting stories. Through home teaching and facilitated communication he passed his eleven plus exam when he was 10. The result was an 'A' pass. Conor did not have formal speech but his ability to communicate non-verbally was excellent. Conor had recently started to crawl and was well on the way to creeping. Conor required physical assistance when eating and when noing to the bathroom, though he was fully continent. In spite of his disability Conor was extremely healthy and his only prior visit to hospital since birth was to have this Epilim requirements assessed at age 3. Conor never had the flu, tummy bugs or diarrhoea and rarely succumbed to the common cold.. Conor was last prescribed antibiotics seven or eight years ago for an ear infection. Although Conor was small for his age (although aged 15 Conor had the physique of an 8-9 year old and weighed approximately 25 kilos on admission to hospital), he was physically very strong and had great determination for independence and showed great enthusiasm for all high speed sports and games.

TAKEN before me this 24th day of May (month), 2504 (year).

Coroner for the District of Specific Relford

Deposition of Witness taken on

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(year), at inquest touching the death of

, before me

Coroner for the District of

as follows to wit: -

# The Deposition of

Of

(Address)

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Continued (Page 3)

Sunday 27 April 2003

Prior to his admission in hospital, Conor had been suffering from an infection of the ears and throat accompanied by vomiting. Conor first vomited on Sunday 27 April.

Monday 28 April 2003

On the morning of the 28 April Conor complained of a sore throat. Dr Patterson attended from the Moores Lane Surgery, Lurgan and stated that Conor's throat and left ear were pink. He advised Paracetomol to treat a typical upper respiratory infection and this was given.

Wednesday 30 April 2003

On the evening of 30 April, Conor was taken to the out of hours clinic at Moylinn and examined by Dr Pickering, who said that Conor's ears and throat were very red. She advised that a course of antibiotic might be helpful. A week's course of Penicillin was started that night.

Thursday 1 May 2003

On the morning of the 1<sup>st</sup> May Conor appeared a little better. Dr Pickering was contacted again by telephone to confirm that Conor did not have Tonsillitis. In the afternoon Conor vomited again. I rang and spoke to Dr Patterson, who said that he thought that the antibiotic was a bit too strong for Conor and that we should try something with a bit less Penicillin in it. Amoxycillin, in yellow liquid form, was

P.T.O.

prescribed. He said that if Conor proved unable to keep fluids down then he thought that a stay in hospital would be advisable to prevent dehydration. I asked the amount of fluid that should be administered to Conor to prevent dehydration. Dr Patterson stated that food consumption was not as important as assuring an adequate supply of fluids. Dr Patterson stated that Conor should receive 30 ml of water orally per hour. This advice was taken and Conor was administered this amount of fluid per hour until the day before he was administered to hospital, when he had begun to drink more normally. Dr Patterson said he would call the following day to see how Conor was. Throughout the days leading up to Conor's admission to hospital his temperature was regularly monitored and never exceeded 37.9 degrees Centigrade.

Friday 2 May 2003

Just before midday on Friday 2 May Dr Doyle from the Moores Lane surgery called. Conor appeared significantly improved. Dr Doyle checked Conor's ears, throat and chest and stated that the ears and throat were clear. She said that Conor would be tired for the next few days and would sleep more until fully recovered. By late Friday afternoon Conor had vomited again bringing up water and yellow liquid, after which the Amoxycillin was stopped. The out of hours clinic at Moylinn was contacted again and Dr Wilson stated that it wasn't necessary to force water into Conor but for him to have an analgesic and rest for a few hours before trying to consume more water. Dr Wilson stated that it would take at least 48 hours for Conor to dehydrate seriously as long as his hydration had been reasonable beforehand.

Saturday 3 May 2003

Conor appeared quite a bit better. Still vomiting up the remains of the yellow antibiotic.

Still receiving 30ml of water per hour. Had some yoghurt to eat.

Sunday 4 May 2003

Slight vomiting of remaining antibiotic. Conor was very tired. His stomach was upset

TAKEN before me this 24th day of May (month), 2004 (year).

M.L. Levley Coroner for the District of Speaker Reefort

Deposition of Witness taken on

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as follows to wit: -

## The Deposition of

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and he suffered from hiccups and burps. Had some yoghurt to eat.

Monday 5 May 2003

Conor appeared much better and was not sleeping during the day as much. Slight vomiting, but consumed some soup and kept down fluid. At this stage Conor was receiving 5ml of water every 5 minutes (60ml/hour).

Tuesday 6 May 2003

Conor started to eat more normally. Still extremely tired. I spoke to Dr Patterson who said that the infection that Conor had caught had been rife in the local area and that the effects could last for up to 14 days. Dr Patterson said that in his opinion Conor's symptoms were typical of this type of viral infection. That night Conor urinated in bed, which was very untypical and when his underwear was changed a cream coloured residue was observed. I rang the doctor on call at the out of hours clinic at Moylinn at approximately 3 30 am and in his opinion the residue was from Conor's bladder as a result of him not being well.

Wednesday 7 May 2003

Conor was still improved. Still receiving 5ml mater every 5 minutes and small amounts of food. From late that evening he seemed to be in periodic discomfort, mearched his legs and arched his back as if trying to escape the discomfort. We thought that he was stiff and sore after lying for so many days without his usual movement of limbs. Conor

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CM - Coroner

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did not normally suffer from spasms of any sort. My mother and I were both very concerned and we rang the out of hours clinic at Moylinn. My mother spoke to the doctor on call, described the symptoms and asked if he thought that Conor could be suffering from anything more serious than the diagnosed viral infection. He replied that he did not think so.

Thursday 8 May 2003

Conor appeared lethargic and unwell. I was very concerned and requested an immediate home visit from the GP. Dr Doyle attended and examined Conor around 10 am. She said the Conor would be best going into Hospital for some blood tests and 24 hours of observation as the hospital could process blood very quickly as opposed to the three days it would otherwise take. I informed Dr Doyle that Conor had been receiving 5ml of water approximately every 5 minutes and that he had not vomited in the last two and half days. Conor was then driven by myself and his grandparents to the Accident and Emergency Department of Craigavon Hospital. I ran into A&E and spoke to a young female doctor, whom I believe was named Dr Budd, immediately. Conor was placed into a side ward where Dr Budd briefly examined him and took blood samples. These samples showed that Conor was very slightly low in potassium. Conor was placed on a rehydration IV drip and was fitted with a urine collection bag. I recall that the drip was of the syringe type rather than a bag. Paracetomol was given orally. At this stage Conor was very sleepy and unwell. I asked the nurse how much fluid Conor was receiving and was told that Conor was receiving 110ml of fluids from the IV drip every 15 minutes. I remember looking at the syringe drip and thinking how fast it seemed to be emptying compared to other drips that I had seen. Conor's grandmother stated that the IV drip emptied very quickly and was replaced with another. She said to me that she thought that Conor's face looked swollen and puffy. Conor received approximately 440ml of IV rehydration fluids in one hour. Blood tests showed that his

TAKEN before me this 24th day of May (month), 2004 (year).

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Deposition of Witness taken on

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white cell count was up. Conor then suffered from a completely untypical seizure which was noted by a young male doctor. Conor's grandmother remarked that Conor had never had a seizure like this before. The doctor's reply was, "Just because you haven't had one, does not mean that you could not have one". I asked the nurse if Conor could be admitted to a Paediatric Ward. The nurse left and after a long telephone conversation returned and told me that Conor was too old to be admitted to the Paediatric Ward and would have to go to the adult male ward. Conor was then brought up to the Medical Admissions Unit. The urine bag fitted in A&E was now overflowing and despite numerous requests it was not removed. Conor's urine was observed to be thick and full of floating deposits. Eventually the urine bag was removed. An attempt was made to take Conor's blood pressure but the cuff was too large and would not function. A child's cuff had to be obtained before the blood pressure reading could be taken. The doctor stated that Conor was obviously suffering from a urinary tract infection. Conor was asleep at this time, though his sleep was broken by seizures, accompanied by choking. It appeared that Conor was in great distress and that the IV Canula in the crook of his left arms was causing discomfort. When the ward sister was asked about this she said that in her opinion the Canula was incorrectly positioned. The staff nurse then returned and said that another urine sample was required as the first had been incorrectly labelled. The available urine sample bags were all too big for

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Conor and a smaller child sized bag had to be sent for. A male doctor stated that it was urgent to get fluid into Conor and that they had used the first good vein they could find. A first dose of Ciproxin antibiotic was administered through the IV drip. A young female nurse named Ruth, was called on numerous occasions which Conor was suffering for these seizures. She was repeatedly informed that Conor did not normally suffer from seizures of this nature. On each occasion she stated that Conor was suffering not from seizures but from spasms and that his temperature was normal. An oxygen mask was now placed on Conor. After three or more complaints about the obvious pain being caused by the Canula, the nurse removed it but did not reposition it. Voltarol was given rectally, which seemed to settle Conor, who fell asleep. I then informed the nurses' station several times that the Canula had been removed but not replaced and we were very concerned that Conor was no longer receiving any treatment. After approximately one hour a female doctor returned and placed the Canula in the back of Conor's left hand. The male nurse who had been requested to get a doctor to replace the Canula on six occasions came to me and said that on each occasion he had requested a doctor, but that none had responded. Dr Murdoch then attended Conor. He stated that Conor had an infection and was dehydrated and that this was causing Conor's illness. িr Murdoch stated that he believed that Conor was getting all that he needed. I replied that I wasn't satisfied with the level of care that Conor was receiving and requested that he be transferred to the Royal Victoria Hospital in Belfast. Dr Murdoch then asked me if I was not satisfied with his treatment of Conor and I replied that I was not. Dr Murdoch then spoke to a Paediatrician, who agreed with the level of treatment that Conor was receiving. Conor was continuing to have seizures. My mother and I had never seen seizures like these before. They were not like the grand mal seizures that we had witnessed in other people many times before. Conor went completely stiff, corkscrewed his body sideways and pulled his fists tight up under his chin. Each seizure lasted two

TAKEN before me this 24th day of Many (month), 2004 (year).

Coroner for the District of Specific Religion.

Deposition of Witness taken on

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Coroner for the District of

as follows to wit: -

## The Deposition of

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to three minutes. He was also making dreadful strangulated choking sounds and a brown liquid was running from his mouth. A red and angry blotchy rash then appeared on his head, face, legs, tummy and arms during the next and following seizures, disappearing in between them. During the seizures, Conor's nose, eyelids and lips swelled up and became very red. Dr Murdoch stated that he was not concerned by the rash. In total, Conor suffered from some ten to twelve violent and unwholly untypical seizures between his admission around 1 pm and approximately 8 pm. At this stage Dr Murdoch had not physically examined Conor and had taken no action to attempt to alleviate Conor's obvious suffering and distress. He did nothing to attempt to calm Conor's persistent seizures, which were getting stronger and more prolonged. Dr Murdoch stated again that Conor was suffering from a urinary infection and dehydration. Conor's chest was x-rayed and shown to be clear. An ECG was performed as Dr Murdoch had stated that he thought he had heard missing heartbeats. The available adult ECG pads were too big for Conor's chest. When appropriately sized pads were obtained it was found that they did not fit the available ECG equipment properly but were used anyway. Dr Murdoch said he thought the ECG recording was unreadable because of the movements caused by Conor's seizures. He then stated that the missing heartbeats were probably, "Just him". Conor's grandmother then noticed that Conor had momentarily stopped breathing. Dr Murdoch said that he

P.T.O.

thought that Conor was holding every third breath. Dr Murdoch then left. A young female Paediatrician arrived and stated that Conor was in seizure and that his pupils were fixed and dilated. The Paediatrician was examining the area of Conor's groin when he suffered what proved to be his final seizure around 8 pm approximately and gave a loud strangulated choking cry. Shortly after this Conor's breathing stopped completely. I ran out into the ward and shouted to Dr Murdoch that Conor had stopped breathing and was going blue. Paediatric Consultant, Dr Smith arrived and he helped Dr Murdoch to ventilate Conor manually. Dr Smith stated that Conor was "very good at keeping his mouth open" and that "we can't do this all night, we're going to have to put a tube in him". Conor never recovered consciousness after this. I and my mother were then asked to leave the room. After some time Dr Smith spoke to me and told me that Conor was in status epilepticus and on a life support machine. This diagnosis was later refuted when we were informed that Conor was in a coma. We were also asked if he had been in a fall which they thought could have caused the resulting problems which they believed could have been due to a small bleed in Conor's brain. Conor had no such fall at any time. The next time we were able to see Conor he was in the Intensive Care Unit (ICU) on a life support machine. I don't know how Conor was ventilated in between him leaving the adult ward and me seeing him in the ICU. At some stage in between a CAT scan was made of Conor's head. My mother and I remained with Conor in the ICU throughout the night.

Friday 9 May 2003

On Friday mid-morning a number of doctors examined Conor over some considerable time. I met with Dr McCaghey after this, as described in my brother's statement and can corroborate what occurred. We were then called into the family room within the ICU when a Doctor McAlastair, whom we had not previously met or heard of before, came in with a number of junior doctors and nurses. My brother then questioned

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Coroner for the District of Speaker Reful

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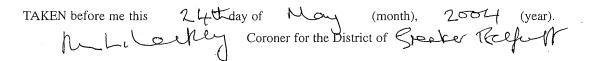
Dr McAlastair about Conor's condition and treatment and what had been determined from the CAT scan. Dr McAlastair replied that the CAT scan was unreadable. The rest of his conversation with us was that he did not appreciate the presence of my family and close friends in the room which we had been offered earlier. He said we were taking up too much room and that if anyone was interested in Conor's condition they didn't have to come and see us, they should be told. Considering the circumstances, this was unbelievably arrogant and insensitive as my son was lying supported by a ventilator with no credible explanations as to what had happened. My brother left at this point, consumed with anger and distress. On leaving the room my mother asked a junior doctor for a copy of Conor's medical notes. Shortly afterwards Dr McAlastair returned with his entourage, glared angrily at my mother and asked her the reason for requesting the notes. He asked her had she got a problem and said that the notes could not be made available to the next of kin. My mother then pointed to me and I then told him of the events leading up to Conor's distressing situation. I described what had occurred within the medical admissions unit and pointed out to Dr.McAlastair that Conor's needs had not been addressed in any way. He replied that he didn't know because he hadn't been there. I then said that he should know because I was telling him. I asked a nurse would she have been satisfied with such treatment of her child and she replied, "No". Dr McAlastiar then said that this kind of discussion was creating

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CM - Coroner

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a hostile environment within the ward. This could not have been the case as only my mother and I had discussed this. He suggested that we postpone our request for Conor's notes and concentrate on getting Conor well. At this point we agreed as Conor's recovery was the only immediate issue. After this Dr McAlastair left with his staff. Later that afternoon I was in the canteen when a nurse, called Tricia, informed me that Dr McAlastair wished to talk to me again. I called my mother, who was on the phone, and she came with me. I asked the nurse why he wanted us and asked if there was anything else wrong. She was smiling and said if there had been anything wrong she would not be smiling. Dr McAlastair came in with one or two members of staff and told us that Conor had improved since he had seen him earlier. He was progressing and would continue to make progress. He then asked me if I was happy and of course my delight was unbelievable and I impulsively hugged him. He told us that arrangements had been made to admit Conor to the Paediatric Intensive Care Unit at the RVH for Sick Children. Dr McAlastair's attitude towards us had undergone a complete metamorphoses since his earlier conversations with us when his chief concerns had been to get us to vacate the family room within the ICU and to prevent us from accessing Conor's medical notes. At around 6 30 pm I travelled up to the RVH Hospital in an ambulance with Conor and another doctor. I arrived at the Belfast Hospital for Sick Children with high hopes for Conor's recovery. Dr Seamus McKeage and another doctor, Gary, examined Conor and said that in his opinion Conor would not improve. I asked him, in horror, did he think he could die and he said he thought that he probably would. Conor's care whilst at the RVH could not have been improved upon and Dr Bothwell was particularly considerate and empathetic. After four days of attentive and professional care by all members of staff, during which Conor did not regain consciousness, Conor's physical condition began to deteriorate. On Monday 12 May Dr Taylor and Dr Bothwell advised us that in their



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### Continued (Page 13)

opinion Conor would not recover and that they would not be able to maintain Conor's blood pressure artificially for much longer. We felt that Conor had been given every chance whilst at the RVH and agreed to the removal of treatment and life support. The doctors and nurses helped us through this difficult process and treated Conor with great dignity. Myself, my mother and family were involved to the end. We removed the life support tubes and waited with him until he gently slipped away.

Mr Millar: At an early trage I applied for allowed in the round medical therapies for comod allowed for a while nound medical thereof for a while nound medical a treatment to fall the Lord a treatment to alternative treatment to have word a grand held so gaine in the children's word all congruences. I know whole's cotta trings a grand had serging Definitely I gothered by getting medical there are different to grand and a serging Definitely I have a frozen and a know the herease when a frozen and a know the herease of the cores of party.

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(shown letter of or dated 8/5/07). Drand said Drefared that Concer goes to NI HSC. I did who refuse how expressed a preference. I took comor to Crangain as it was alone to home Initially the family did not object to wantibisties. told Dr. Budd ha had a antibiotics of home and ste agreed to wait pending the home and ste agreed to vine o repused to go regular of vests, At that vine o repused to go along with the veekman progressed by the hospival. It mer netwad to a more that Court face bootend sworler and preffy. The young male doctor said Cenar had a grand nal sergire - & did not trum what it was. Both conver and petred, his body werd rigid this head correctioned round to the side. I d- in n de nor Romes how long it by Kad. I did nor Know if a serjuise or the community Coner discemfort. De Paul Kar bold na it was

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all to communa but abyrical surprise and/wity. I said it was not like anything he had had had have soon a sergione, a thought it and have soon a sergione, He did not use to words " grand not est give", (Shown Page 4650) Cranginan Heller) - My mother o I pare the mirrory to The Quinn. Conser orloop at this time, I disagree that he was having muscle sport tot attenon - they use organis. I saw orker children Lawing grand mal surguiss. Concrés surguises lastad als soot 2/3 minutes soch, d'agree ir is a dramatic priture - 10 senzurés reach getting worse, During, this period he was seen by Da Murdesch & sweet murter.

TAKEN before me this 24th day of May (month), 2004 (year).

Coroner for the District of Scarter Response

Deposition of Witness taken on

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Coroner for the District of

as follows to wit:-

# The Deposition of JOANNA MITCHELL

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Deposition of Witness taken on

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#### CONTINUATION OF DEPOSITION OF JOANNA MITCHELL

At an early stage I asked for alternative medical therapies for Conor though for a while normal medical treatment was sought I felt he had a better chance with alternative treatment. He has a grand mal seizure in the Children's Ward at Craigavon when he was about 2 or 3. Other times he had absences. I know what is meant by a grand mal seizure - stiffing followed by jerking but there are different types of grand mal seizures. Definitely I know the difference between a spasm and a seizure. Conor did make strange muscular movements because of the cerebral palsy. On the 8th May I did not say to Dr. Quinn that "spasm increasing over part week seems to be in pain", in that I did not use the word "spasm" (shown letter of GP dated 8/05/03). I had said I preferred that Conor go to the Royal Belfast Hospital for Sick Children. I did not refuse but expressed a preference. I took Conor to Craigavon as it was close to home. Initially the family did not object to IV antibiotics. I told Dr. Bodel he had 2 antibiotics at home and she agreed to wait pending the results of tests. At that time I refused to go along with the treatment proposed by the hospital. It was mentioned to a nurse that Conor's face looked swollen and puffy. The young male doctor said Conor had a grand mal seizure - I did not know what it was. Both Conor's arms jerked, his body went rigid and his head corkscrewed round to the side. I do not know how long it lasted. I did not know if a seizure or the canula was causing Conor's discomfort. Dr. Paul Kerr told me it was not the canula but a typical seizure activity. I said it was not like anything he had had previously. I thought it world have been a seizure. He did not use the words "grand mal seizure", (shown Page 4 and 5 of Craigavon notes) – My mother and I gave the history to Dr. Quinn. Conor asleep at this time. I disagree that he was having muscle spasms that afternoon - they were seizures. I saw other children having grand mal seizures. Conor's seizure lasted at least 2/3 minutes each. I agree it is a dramatic picture – 10 seizures each getting worse. During this period he was seen by Dr. Murdock and several nurses. For a period he was not getting any IV fluid when the canula was out. No one would listen to me. I never used the work "spasm" to Nurse Wilkinson. Possibly I did use that work but as far as I was concerned Conor was suffering seizures. Dr. Murdock was fumbling – he was out of his depth – and he would not get help. Dr. Williams arrived at about 8.45 p.m. and told Dr. Murdock Conor was suffering seizures. There definitely was a rash. Conor had brown liquid trickling from his mouth when he was examined by Dr. Murdock. His arms jerked, his body went rigid and his head corkscrewed round each time he had one of the seizures. Each one seemed more violent than the previous one and each lasted longer. Dr. Murdock did not examine Conor between 1,00 p.m. and 6.30 p.m. I did see him at 1.00 p.m. when he told us Conor had an infection I cannot recall if Dr. Murdock was present when Dr. Williams arrived. I do not accept Dr. Murdock was attentive. Dr. McAlastair definitely said the CAT scan was unreadable. My dealings with Dr. McAlastair were less than satisfactory. A nurse may have thought Conor moved in response to a communication and that may have been significant if correct, (shown P35 of notes). My conversation with Dr. McAlatair was taped – about 4.00 p.m. We did have a conversation at 12.45 p.m. but then the later one (shown P40 and note at 17.00).

Mr. McKillop: On 8<sup>th</sup> May I was with Conor the whole time until his condition deteriorated. My mother was with me most of the time. He had a seizure in Accident

and Emergency - fluids had been administered by them. This seizure occurred about 25/30 minutes after the fluids had been administered. (Demonstration by mother). I do not know how long it lasted. It was totally untypical. I do not think he made any noise. That was the early seizure in Accident and Emergency. He was admitted to them ward before 1.00 p.m. Initially seen by Dr. Quinn. From an open ward he was transferred to a side-room. I cannot remember where he had the second seizure. He had 10-12 seizures. At some stage he mad chocking noises – later in the day about 5.00 p.m. it sounded as if he was being strangled. The noises lasted seconds at a time. His rash started on his arms and moved to his stomach, chest and neck. He was on the bed wearing trousers and T-shirt but his trousers had been taken off. The rash first appeared on his abdomen. It was red and blotchy. I cannot remember if it appeared whilst he was having a seizure. The rash went away but came back again. It was on the upper arms, chest and neck. It changed to a blotchy, purple appearance on his scalp. On his scalp it looked like large purple bruises. At first his upper lips and eyelids swelled and then his whole face. The brown liquid coming from his mouth looked like dark blood. This was late in the afternoon – possibly 5.30 p.m./6.00 p.m. I became very concerned about Conor, because of that Dr. Murdock visited Conor about 6.30 p.m. About 7.00 p.m. he started to breathe quickly and then I thought he stopped breathing. A chest x-ray was carried out after this to rule out any chest infection. Then an ECT was carried out. I was present when the Paediatric Registrar arrived and when he stopped breathing Conor may have had 4 pints of fluid each 110 ml - definitely 3. It seemed to run very fast. The canula was removed at 2.00 p.m. and re-connected at 4.00 p.m. followed by the administration of more fluid. I think he received fluid continuously. At no time did I see a consultant until about 9.00 p.m. At that time Conor had turned blue, Joanna Mitchell.

PHONE NO. : 01818746502 FROM : HARDZONE

18 May. 2004 06:40FM P2

TOR ELAINE TAYLOR FROM
THE INSTITUTE FOR JUDY MITCHELL

18 May 2004.

### TO WHOM IT MAY CONCERN

I am at present in the final stages of writing up a PhD thesis supported by University College London Psychology Department in which evidence is provided suggesting that the metabolic assault of brain injury weakens the diaphragm muscle and so reduces the development of the strength and responsiveness of the respiratory system.

I am also the Clinical Director of the Charity Advance. In this capacity I was treating Conor Mitchell by a home exercise programme taught in stages to his mother and based upon the body of knowledge acquired over in the course of my research. The treatment approach is also being independently evaluated as the subject of a separate PhD by Bradford University Health Science Department.

- The strategy called Neuro Respiratory Therapy (NRT) focuses on developing core muscle strength and reducing superficial muscle strength. In this way it pararells the changes seen in the developing infant over its first year of life which the thesis maintains are brought about by the steady increases in the infant's respiratory strength.
- Progress is achieved by working directly on identifiably weak respiratory muscles, most importantly the diaphragm, the weakness of which is evident from the CP child's structure.
- The approach has involved making close observations of the children attending the Charity's centre taking their trunkal measurements and the identification of variations in regional blood flow through the brain, lungs and liver with Reography. (This is a non-invasive method of investigating organ blood flow supply based on observations of tissue electrical resistance),

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FROM ': HARDZONE

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18 May. 2004 06:41PM P3



As a result it appears that the existence of respiratory weakness may cause children with CP to respond rather differently from normal children when they are exposed to both external and internal influences causing metabolic stresses. These indications may throw more light on Conor's reactions in the last 2 days of his life.

To proceed adequately I need also to explain a little more of the probable causes of respiratory weakness in CP and then the possible metabolic consequences.

- 1. It is known that the metabolic stress of cerebral assault directs blood supply away from the muscles to the cerebral metabolism. This is particularly concerning for diaphragm muscle development since the diaphragm is the central respiratory muscle which is pivotal for the development of a normal respiratory system. There is reasonable evidence to suppose that respiratory system capability sets the level of homeostatic balance for the organism since evidence suggests it is responsible for levels of oxygen availability in the micro circulation of the body tissues.
- 2. During cerebral assault the diaphragm also appears to work harder to respond to increased demands by the cerebral metabolism for the period of the acute phase of after the injury.

These two factors probably combine to produce tissue fatigue by reducing diaphragm capillary blood flow thus leaving some of the diaphragm's capillary beds dysfunctional or weakened. As a result both the strength of the respiratory excursions and the diaphragm's responsiveness to herve signals appear reduced.

Children coming to our centre all demonstrate abnormalities of trunkal structure consistent with this thesis as well as steady improvement with ongoing treatment.

From a physiological point of view it follows that diaphragm weakness would affect the muscles involved in the abdominal thoracic pump which pulls the venous blood (the de-oxygenated blood) back to the heart. Reography observations and the study of our children's metabolic responses during limited stress suggest that in the case of children with C.P. there is a back up of venous blood to the detriment of capillary blood flow availability. This has a direct effect on venous outflow from the

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cerebral metabolism. The volume of blood in the cerebral metabolism remains constant. However, arterial inflow is known to be limited by venous outflow. This would mean that the children with C.P. would be more likely in this less stable situation to experience an increase in intercranial pressure or a reduction of available oxygen within the cerebral metabolism as a result of over-hydration or two zealous rehydration.

Reography readings of CP children also suggest that in many tissue areas capillary beds can be constricted or spastic so that a reduction in the efficiency of the venous return would also mean that the legs and body tissues could not be so available as a fluid reservoir during over hydration. It is more likely that there would be an increase in inter cranial pressure because the brain is encased in bone as a result of a backup of the fluids before tissue swelling was evident in other parts of the body.

There are a few other points to make with reference to the homeostatic balances that may be said to be dependent upon the respiratory system. We have noticed responses in our children that suggest that when tissue is active and therefore requiring blood oxygen the poor distribution of capillary blood supply tends to create imbalances in the system. Whereas the active tissues needs were very likely to be appropriately met this would be to the detriment of the other tissues. For example if a virus were to produce certain metabolic demands in the area of the affected tissues then the child with C.P. would be more likely to suffer from symptoms associated with a more severe level of the condition. For example, a reduction in blood supply to muscle tissue can produce muscle spasms; a reduction in blood supply to surface tissue can produce very pale skin; a reduction in blood supply to the digestive system can produce a poor ability to digest food and a loss of appetite. It is also likely that children's eyes would be affected and that they would suffer much more quickly from lethargy associated with illness. The reduction in capillary blood flow therefore means a more intense reduction in other metabolic demands so that focus can be on clearing the virus out of the system.

From this point of view we often see our children manifesting for a day as if they had a quite severe complaint and the next day they're remarkably recovered. At other times the symptoms of an illness can drag on for an abnormally long time until the

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child's residual respiratory strength returns to its normal levels. (This may have been the situation in Conor's case). In normal children where the blood flow through the micro circulation is more balanced and better available these kinds of severe symptoms could easily be associated with a much more severe assault. The other factor is that quite often the treatment such as rehydration or a heavy course of antibiotics can have an adverse effect on brain injured children who are less able to deal with the effects of invasive medical approach to disease. In my opinion such children would certainly be more liable to respond adversely to a rehydration process that wasn't very carefully balanced and slow. They would also be likely to respond badly to a routine course of antibiotics because the antibiotics themselves tend to weaken the cell walls and therefore reduce the efficiency of organ function. This in itself creates further instability in an already unstable system.

So far as I know there are no special guidelines for treating children with cerebral palsy. Insufficient is perhaps known by hospital staff about the differences in metabolic response to both symptoms and the intervention prescriptions to reduce those symptoms. However in my opinion Conor's thinness is typical of CP and reflects the weaknesses of the abdominal thoracic pump I have formally described. It should have been associated with cerebral palsy rather than with a condition of severe dehydration muscle. Spasming is a fairly typical symptom of C.P. and that since he, by his mother's own account had not been entirely without fluids the muscle spasms that may have been seen certainly was not likely to be a symptom of advanced dehydration.

It's always better when the patient presenting a condition on which the medical practitioner has little knowledge to consult some authorities in that particular situation. In this case the two Authorities that needed to be consulted in some depth were the patient's own family and the Hospital for Sick Children that had some experience treating children with C.P. To presuppose that a child with C.P. could be classed as an adult simply because he was 15 years old might be generally considered to be unwise under any circumstances and hopefully in the future better guidelines will be available for medical staff in this sort of situation.

Linda Scotson.

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