

IRISH HAEMOPHILIA SOCIETY

TRIBUNAL NEWSLETTER

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TRIBUNAL OF INQUIRY

(Into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters)

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Mr Finlay referred Mr Lynam to inventory sheets produced by Mr Lynam from the Blood Transfusion Unit in St. James's Hospital. With respect to a note by Professor Temperley in June 1989 that more BTSB Factor IX be used, Mr Finlay referred Mr Lynam to the inventory in the two months prior to June 1989. This inventory showed the quantity of BTSB Factor IX received by the Hospital in that two month period. Mr Lynam pointed out that approximately 80,000 units were received by the Hospital in April and May 1989. In the two months subsequent to June 1989, the total number of units increased to 200,000 units.

Mr Lynam was then cross-examined by Jim McCullough for the Irish Haemophilia Society.

Mr McCullough referred Mr Lynam to draft guidelines and final guidelines issued in December of 1983 by Professor Temperley for the treatment of severe Haemophilia A. Mr Lynam said his part in implementing the guidelines was to ensure that products were well documented in relation to batch numbers and which patient got which product. Mr Lynam agreed that the implementation of the guidelines took place against a growing awareness of the threat of AIDS.

Mr Lynam said to his knowledge there was no recall of BTSB Factor IX after November 1985. Mr Lynam said he returned two batches of BTSB Factor IX to Pelican House on the 15th November 1985. These batches were returned said Mr Lynam, because the Hospital had sufficient heat treated Factor VIII to issue out to the various patients and, it returned the non-heat-treated Factor IX. However, there was no attempt to recall BTSB Factor IX issued for home therapy.

Mr Lynam agreed that the non-heat-treated BTSB FIX returned by him appeared to have been re-issued by the BTSB in November and December of 1985. Mr Lynam agreed that no sense of urgency attached to any return of BTSB Factor IX he may have made at this time.

Mr Lynam said that 85,000 units referred to by Professor Temperley appeared to be the same batch of Armour Factor VIII as was referred to in a note of consignments from Berke Pharmaceuticals which recorded the delivery of 350 vials by 230 units on the 13th January 1985.

With respect to a letter sent by Professor Temperley on the 7th June 1990, whereby Professor Temperley instructs Mr Lynam that "we should not order any further concentrates of Factor VIII which are dry heat treated unless it is a serious emergency of one sort or another". Mr Lynam said this letter referred to Factor VIII only and had no affect on the use of Factor IX.

Mr McCullough referred Mr Lynam to a letter dated November 1990. In the letter it is noted that during 1990 the National Haemophilia Treatment Centre had drastically reduced dry heat treated products and are now almost completely using solvent detergent products. Mr McCullough put it to Mr Lynam that from this letter it would appear that although dry heat treated products had been drastically reduced during 1990, they would still appear to be in use. Mr Lynam agreed with this observation and also agreed that it would concur with his recollection of events and his recollection of what the Factor VIII letter contained. Mr Lynam agreed that the letter concerning Factor VIII did not stop the use of dry heat treated Factor IX at source. Mr Lynam agreed that there was a residual use of dry heat treated Factor VIII and Factor IX into 1990.

Mr Lynam was examined by Mr Maurice Collins for St. James's Hospital.

Mr John Finlay for the Tribunal then examined Mr Liam Dunbar, former chief executive of St. James's Hospital. Mr Dunbar joined St. James's Hospital in 1981 as the chief nursing officer. In mid- 1985 he was appointed acting chief executive officer and was appointed chief executive officer in 1987, succeeding Mr Ernest Robinson. Mr Dunbar said the services at St. James's Hospital expanded considerably during his period of office. There were 14/15 Consultants in 1970 and this number was up to 70 in 1980.

Mr Finlay directed Mr Dunbar to a number of documents which indicated an increasing level of financial deficit in the 1980's. Mr Dunbar agreed that the hospital was in dispute with the Eastern Health Board concerning payment for blood products. Mr Dunbar said this was a recognised problem throughout the period and was adversely affecting the hospital's cash-flow. He said if the Department had told the hospital the disputed money was St. James's responsibility, no dispute would have ensued. In the event the hospital's auditors had to qualify the accounts of the hospital in a number of years during the mid 1980's, Mr Dunbar said from 1983 onwards it was one of the biggest difficulties faced by the hospital and strained the relations between the hospital and its bankers.

Mr Dunbar said that the annual allocation from the Department of Health to finance the activities at St. James's Hospital was not in any way related to the estimates prepared by the hospital. Mr Dunbar listed the number of services which were forced to close due to financial cutbacks during the 1980's.

With regard to providing services for those infected with HIV, Mr Dunbar said the physical environment of the hospital was totally inadequate to provide a service. Haemophilia shared space with Oncology and Haematology. Mr Dunbar said every speciality was crying out for a support service. The provision of a dedicated Haemophilia Treatment Centre was to be included in the second phase of the new Hospital.

Mr Finlay referred Mr Dunbar to correspondence between his office and the Department of Health concerning the provision of social work services. Mr Finlay also referred Mr Dunbar to the question of providing dental services at St. James's Hospital for people with Haemophilia. This correspondence commenced in December 1985 and continued until the 14th October 1992. Mr Dunbar agreed that this was an unacceptably long time for the provision of dental treatment for people with Haemophilia.

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Mr Finlay continued his examination of Mr Dunbar.

Mr Finlay referred Mr Dunbar to the provision of dental facilities at St. James' Hospital. Mr Finlay noted that negotiations for a new dental surgery within the haemophilia unit opened in 1985 and did not conclude until 1992. By 1991 the dental facilities in the haemophilia unit were obsolete. Mr Finlay asked Mr Dunbar did this mean no dental treatment was available to those with haemophilia during the 1991/92 period? Mr Dunbar said he could not answer this question.

Mr Finlay referred Mr Dunbar to the issue of body bags and the disposal of remains. Mr Dunbar said this was an on-going problem for a long time. He was advised by the infection control committee. Mr Dunbar said this vexed question was made more difficult by the nature of the layout of the hospital, where remains would have to be transported between different units. Mr Dunbar said that the nurses taking care of the patients were hyper-sensitive to see that families were accommodated. However, there was disquiet about this particular activity.

Mr Dunbar said further difficulty was experienced with respect to the lack of visiting facilities, particularly for children visiting their parents. Mr Dunbar said he could recollect the situation as described by the witness Deirdre, where the daughter of the family was unable to visit her father while on the ward. Mr Dunbar said he could remember Deirdre being very distressed by this situation. He had tried to explain the difficulties, that because many people on the ward were immune suppressed it was advisable to restrict the number of visitors, especially children, to the facility.

Mr Dunbar said the provision of ancillary services for the treatment of haemophilia, such as social work services and dental services, were delayed because of lack of resources/ He also said that the plans to introduce such services in new facilities being made available served to delay matters further.

Mr Finlay referred Mr Dunbar to the planning of Professor Temperley's retirement. Mr Dunbar said he could see that it would take at least two consultants to replace Prof. Temperley.

Mr Dunbar was cross-examined by Mr Martin Hayden for the Irish Haemophilia Society.

Mr Hayden asked Mr Dunbar, why was there such a delay in the provision of dental facilities? Why had no facilities been put in place from 1985 until 1992? Mr Dunbar said the reasons for this were that a permanent National Haemophilia Treatment Centre with all the facilities in place, was to be incorporated into the new hospital project. He said the phased basis of the project meant some facilities were delayed. Mr Dunbar said he realised the facilities in place were not adequate, but he had tried to get facilities and funds over time.

With respect to the provision of dental services, social work services and other ancillary services for people with haemophilia who had been infected with HIV, Mr Hayden asked Mr Dunbar if he thought that St. James's had made a sufficient effort to get the Department to furnish it with adequate finances to meet the requirements identified by him and the medical staff? Mr Brennan, for the Department of Health, interjected and said he was prepared to concede the Department knew. [presumably referring to the question of adequate financial facilities].

With respect to St. James's Hospital financial position during the period and the dispute on the invoices for blood products with the Eastern Health Board, Mr Dunbar agreed that he had to negotiate various agreements with bankers in order to discharge the hospital's financial needs. The hospital's accounts

were qualified by its Auditors and its financial position disimproved by £572,000. Mr Dunbar agreed that each year the amount in question increased substantially. By the time the debt was resolved in 1990, a deficit of £2 million plus had accumulated. The dispute meant that St. James' Hospital had to pay £350,000 in interest. Mr Hayden put it to Mr Dunbar that the interest on the disputed amount would have paid for the dental and social worker costs. Mr Dunbar said one would have to distinguish between capital costs and revenue costs, but he agreed that the provision of AIDS counsellors was a revenue expense. He said that if all the money had been in the possession of the hospital, so much the better.

Mr Dunbar agreed that on one occasion he had to make a personal visit to the bank to ensure that staff wages cheques would be paid. He agreed that a structural financial difficulty existed in that the hospital had to carry the cost of the disputed funds.

With regard to legal actions taken by people with haemophilia, Mr Hayden asked Mr Dunbar if Prof. Temperley told the Board of St. James's that there was any special category haemophilia B patients infected with BTV factor IX. Mr Dunbar said he had no recollection of being informed of that. Mr Dunbar said the issue of litigation was referred to the office of the Attorney General, and thereafter St. James's had no further dealings with the matter.

Mr Dunbar was cross-examined by Mr Brian McGovern for Prof. Temperley.

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Mr Ian Brennan for the Department of Health, cross-examined Mr Dunbar, former chief executive of St. James's Hospital.

Mr Dunbar agreed with Mr Brennan that during the 1980's, pressure on health expenditure was exceptional. It was a time of high unemployment and the health service was the biggest source of government expenditure. Mr Dunbar said that 1986/87 were the worst years he had been through in terms of his health service career. He said a reduction in acute hospital beds from 1,300 to around 600 to 650 had taken place. A corresponding reduction in the work force was also occurred.

Between 1986 and 1990 health service employment was reduced by 6,000. Many of the job cuts took place in the St. James's Hospital catchment area, said Mr Dunbar. Despite serious financial cut-backs, health expenditure overran its budget by £85 million. During this period Mr Dunbar said that in the face of the cut-backs, St James's building programme proceeded and was completed in or around 1990. He said the main core of the new hospital opened in 1987. This allowed older buildings to become available. Mr Dunbar said no-one was ever refused treatment at the hospital.

Mr Brennan referred Mr Dunbar to the issue of social work provision at St. James's Hospital. With respect to the redeployment of a social worker from Sir Patrick Dun's Hospital to St. James's, Mr Dunbar pointed out that the Sir Patrick Dun's social worker was obliged to care for the patients who had come from Sir Patrick Dun's to St. James's. In this regard the suggestion that the social worker be utilised to cover the needs of haemophilia patients was not workable. Mr Dunbar agreed with Mr Brennan that matters regarding social workers came to a satisfactory conclusion in 1988 with the provision of Lottery funding for a social worker/AIDS counsellor.

Mr Brennan referred Mr Dunbar to documents concerning the provision of dental facilities at St. James's Hospital. Mr Brennan pointed out that the outcome of Mr Dunbar's discussions with Mr d'Alton, was that the Department would not sanction, and the hospital would not pay for, £45,000 worth of medical/dental equipment to be installed in the old facilities at St. James's when the new facilities were about to come on stream.

Mr Dunbar was cross-examined by Ms Murphy for St. James's Hospital. Ms Murphy described an I.H.S. document opened to Mr Dunbar by Mr Hayden as, in essence, a wish list, where the I.H.S. outlined its view of what should be contained in a haemophilia treatment centre. With respect to the Craig Gardiner audit between 1986 and 1989, Ms Murphy suggested that it was fallacious to suggest that a reduction in the debt would have enabled St. James's Hospital to provide social worker, dental and other ancillary services for haemophilia. Ms Murphy said that payment of the disputed funds would have had the effect of reducing the deficit. The hospital would still have been in debt.

She also put it to Mr Dunbar that the whole issue showed the high cost of haemophilia treatment, in that half the deficit of the entire hospital was attributable to the provision of home therapy for haemophilia. Mr Dunbar agreed with Ms Murphy that cost never affected the provision of treatment.

With respect to an announcement in Dail Eireann that £700,000 would be made available for the treatment of HIV and AIDS, Mr Dunbar said he saw the Minister's statement but he did not see the money.

Ms Murphy put it to Mr Dunbar that the board of St. James's Hospital was not aware in 1989 of which product had caused infection among people with haemophilia. Mr Dunbar agreed that this was a clinical issue, within the realm of Prof. Temperley's influence. Mr Dunbar said that the board of the hospital had not known in any official way of what products had caused HIV infection.

Mr Dunbar said it was his impression that medical treatment evolved by those working in it pushing out the boundaries, and pushing beyond their original remit. He said Prof. Temperley's voluntary responsibility in establishing a Bone Marrow Transplant Unit was an example of this type of volunteer activity. Mr Dunbar said that people went out of their way to be helpful to those with haemophilia who had become infected with HIV. He said the management of the hospital supported these efforts. An example of this, said Mr Dunbar, was the priority given to these patients when possible, such as in the redeployment of a social worker and the provision of recombinant product when it came on the market.

Mr Finlay, in redirect examination of Mr Dunbar, referred him to the issue of St. James's Hospital being left to deal single-handedly with the AIDS crisis. Mr Dunbar agreed that by 1989 this was no longer the case, in that various hospitals, including Cherry Orchard Hospital, stepped in to provide respite care for AIDS patients. Mr Dunbar said the Cherry Orchard facility was a great help to them at that time.

Mr Finlay examined Ms Laurette Kiernan, former social worker at the National Children's Hospital.

Ms Kiernan described the early days of dealing with children who had haemophilia at the National Children's Hospital. She outlined how those with haemophilia would have to attend at the Meath Hospital once a year for a major check-up. Ms Kiernan said space was so restricted at the hospital in these early days, that she would sometimes have to conduct interviews with patients in the garden of the hospital. She said all of the patient's needs would have to be catered for in one day and it was an exhausting procedure for everyone concerned.

Eventually treatment for children with haemophilia was located at the National Children's Hospital. Ms Kiernan said she became involved with the Irish Haemophilia Society. She would liaise with the Society on the needs of haemophilia patients. Ms Kiernan said she was not formally aware of the problems caused by HIV infection. She would discuss these matters with parents if they were referred to her, and would carry out home visits with respect to people with haemophilia. Ms Kiernan said in the early days there was a lot of hysteria in the newspapers about HIV and haemophilia.

Ms Kiernan was cross-examined by Mr Martin Giblin SC for the Irish Haemophilia Society. Mr Giblin noted the restrictions under which Ms Kiernan worked during her time as social worker at the National Children's Hospital. He referred her to an incident where she sought approval for the purchase of a paperback book costing £5.99. Ms Kiernan said the book was considered useful and agreed that she had to have clearance to spend this sum on the book.

Ms Kiernan said she was involved in instituting the provision of overnight accommodation for parents whose children were being treated at the National Children's Hospital. This was available from the 1970's onwards. She said that from 1985 onwards, it was realised that HIV presented a very serious problem, and she responded by keeping in touch with the I.H.S, she described this as an important part of her duties.

The Tribunal then examined Ms Brenda Mehigan, who succeeded Ms Kiernan as the social worker at the National Children's Hospital. Ms Mehigan's evidence was that she was not really involved in dealing with people with haemophilia on behalf of the National Children's Hospital. She was not aware of the issues concerning people with haemophilia and was never formally told of HIV infections among the

children. Ms Mehigan said she was not aware of the issue of hepatitis when she compiled her report on social work needs for the hospital in 1993. Ms Mehigan said she only became aware of the issue of hepatitis when she read about it in the newspapers in relation to contaminated Anti-D causing hepatitis C.

The Tribunal then examined Ms Berna Reddin who was a nurse on the surgical ward at the National Children's Hospital. Children with haemophilia would have been amongst the patients treated by Nurse Reddan.

In October 1994 Nurse Reddin took up the position of Haematology Nurse Specialist. Nurse Reddin said that children with haemophilia would be treated in the same way as other children unless their illness was such that they had to be treated in isolation. Nurse Reddin said that parents did not tend to discuss the child's HIV condition, and issued instructions that the children were not to be made aware that they had HIV. However, Nurse Reddin said it was her view that many of the children knew that they had HIV and it was unfortunate that they had nobody to speak to about their condition.

As haematology nurse specialist, Nurse Reddin looked after the needs of children with haemophilia, and also children with leukaemia and other blood disorders. Nurse Reddin said she was instrumental in instructing parents how to administer concentrate to their children. She trained parents in this regard.

Mr Finlay asked Nurse Reddin, did she ever recall being informed that some children who were patients of the National Children's Hospital had been found to be hepatitis C positive. Nurse Reddin said that she was not officially informed of this.

Nurse Reddin was cross-examined by Mr Raymond Bradley for the Irish Haemophilia Society

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Mr McCann for the Tribunal, examined Ms Bruinsha McGrath, infection control sister, National Children's Hospital 1980-1998.

Sister McGrath said she was part of the infection control team of the Federated Dublin Voluntary Hospitals. Sister McGrath agreed with Mr McCann that the FDVH infection control team wrote guidelines and put in place policies and procedures in relation to infection control. There was no specific policy for haemophilia patients, a policy was developed for any patient who developed HIV and subsequently AIDS.

Sr McGrath said that all policies were based on expert advisory groups in drafting their policy documents. Sr McGrath and the infection control nurse at St. James' Hospital would have consulted with Prof. Keane and Dr Mulvihill. On being approved the document would be distributed to the infection control committees, or directly to various departments in the three different hospitals. The first infection control document relating to blood borne diseases, was drawn up in respect of hepatitis B. This policy was subsequently followed for HIV infections. In the first instance, universal precautions were adopted followed by standard precautions.

Sr McGrath said that because it was not known whether or not any individual patient may have HIV, universal precautions were adopted based on recommendations from the CDC, Atlanta, Georgia. In this way the body fluids of all at-risk patients were treated as though they might be infected. With respect to the use of body bags, as an infection control measure, Sr McGrath said a special pack was prepared to deal with these patients. Sr McGrath said there was great concern expressed by those attending the infection control committee on behalf of the NCH, at the use of such bags. Sr McGrath said such measures were felt to be totally inappropriate for these patients. Sr McGrath said that a red sticker was applied to the charts of patients in at risk groups. The red sticker was not confined to identifying those with HIV.

Sr McGrath was cross-examined by Mr Martin Giblin on behalf of the Irish Haemophilia Society.

The Tribunal then examined Mrs Bridie McNulty, the phlebotomist at the National Children's Hospital. Ms McNulty occupied this post from 1975 until the late 1990's. Ms McNulty said from the time of her appointment as phlebotomist, she would draw blood on written instructions for the purpose blood tests. From the mid-1980's onwards, she said she drew blood for tests with respect to HIV and HTLV-III.

She said the first time she heard of hepatitis C was after the Pelican House news conference. Ms McNulty said they tested regularly for hepatitis A and hepatitis B, and for raised enzymes and liver functions. They also tested for non-A, non-B hepatitis, which became hepatitis C.

The Tribunal also examined Mr Des Rogan, secretary manager of the National Children's Hospital from May 1978 until October 1985.

The Tribunal examined Ms Betty Brady, director of nursing at the National Children's Hospital from 1980 until 1988.

The Tribunal examined Ms Cathering McDaid, matron at the National Children's Hospital from December 1992 until June 1994. She said she was not aware that patients had been infected with hepatitis C. Ms McDaid said she was not aware of how patients' hepatitis C status was recorded.