

IRISH HAEMOPHILIA SOCIETY

TRIBUNAL NEWSLETTER

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6th April 2001

TRIBUNAL OF INQUIRY

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

PROCEEDINGS: Tuesday 13th March 2001 - Day 102

Ms Deirdre Murphy SC for St James Hospital cross-examined Professor Temperley.

Ms Murphy said she would rely on establishing a wider picture with Professor Temperley and would not resort to any documentation during the course of her cross-examination. Ms Murphy said it was conceded by the hospital that facilities for people with Haemophilia were spartan during the 1980's. She put it to Professor Temperley that things had improved dramatically from the early 1970's when the life expectancy of persons with Haemophilia was around 15 years? Professor Temperley agreed with Ms Murphy. He said he decided to set up a dedicated service for the treatment of Haemophilia during the 1960s. He was instrumental in establishing the Irish Haemophilia Society in 1969 and it was recognised that some form of centre for the treatment of haemophilia was required.

Professor Temperley said that the description of the unit at St James as a National Haemophilia Treatment Centre was more notional and aspirational than real. He agreed with Ms Murphy that his services and those of his secretary constituted the National Haemophilia Treatment Centre at that time.

Professor Temperley said that a milestone in the treatment of Haemophilia was the transfer of treatment from the Meath to St James Hospital and he referred to the evidence of Isabelle on day 6 of the Tribunal. Professor Temperley agreed with Ms Murphy that resources were spartan and inadequate in some ways but the facilities were comparable to those in place for the treatment of other conditions. Professor Temperley agreed that all specialisations was competing for services at that time.

In the 1980's financial cutbacks meant expanding services in the Hospital had to compete for shrinking finances. Professor Temperley described his involvement in establishing the bone marrow transplant unit. In or around 1984 it became known that people with Haemophilia were infected with HIV. Professor Temperley agreed with Ms Murphy that this manifested itself mostly from 1987 onward. Professor Temperley also agreed with Ms Murphy that during the course of the 1980's nobody was refused treatment at St James Hospital.

Professor Temperley said that the haemophilia unit felt vulnerable in the face of the extensive financial cutbacks that had been implemented by the Government. Professor Temperley said the unit was small but expensive to run. However he said that Mr. Dunbar would give evidence that the unit was never in danger of closing. Professor Temperley said that the nurses developed their own procedures in dealing with AIDS patients. They informed themselves and worked hard.

With respect of the evidence of the witness Deirdre whose daughter was prevented from visiting her father on the Hemophilia Unit, Professor Temperley said a strict policy of no children had to be implemented as many people on the unit had suppressed immune systems. The restriction on visitors was for the safety of patients, said Professor Temperley. Ms Murphy put it to Professor Temperley that he was mistaken in his earlier evidence with respect to body bags. She said that the mortuary attendants had no involvement in the policy concerning the use of body bags and the Hospital would say that this policy was adopted for sound medical reasons and overseen by the hospital's Infection Control Unit. It was a medically based policy. Professor Temperley said he could well be mistaken about the matter but in any event it was not his policy to enforce the use of body bags.

Ms Murphy said that evidence would be given that the social work and counselling services provided by St James's Hospital were extensive and greater than that realised by Professor Temperley. She also said that it could be shown that the wives and partners of persons with Haemophilia were offered screening.

Professor Temperley was cross-examined by Mr. Mel Crystal S.C. for the National Children's Hospital. Mr. Crystal referred Professor Temperley to his supplementary statement wherein he records his admiration and respect for the nursing staff at St. James's Hospital. Mr. Crystal asked Professor Temperley would he care to include the nurses at the National Children's Hospital in this observation. Professor Temperley said that he would have no hesitation in doing so. He added that it would have helped these nurses to have had had a special Haemophilia nurse during the 1980s and early 1990s. Professor Temperley also agreed that he commended the work of Ms. Lurette Kiernan the National Children's Hospital Social Worker.

Professor Temperley was then cross-examined by Mr. Frank Clarke on behalf of the BTSB. Mr. Clarke directed Professor Temperley to the retrospective study contained in Tribunal Booklet No. 4, page 7. Mr. Clarke also questioned Professor Temperley on the introduction of heat-treated Factor IX and the question of thrombogenicity. Professor Temperley agreed that the treaters were persuaded that no problem lay with thrombogenicity in advance of such a proposition being accepted by the producers. With respect to product selection and the concept of warehousing, Mr. Clarke put it to Professor Temperley that it could mean a range of thing such as would a product be imported, would it be produced. Mr. Clarke put it to Professor Temperley that the term Product Selection could mean:

1. The selection of product at a generic level.
2. Which product to import.
3. The individual treatment of the specific patient by the patients treating doctor.

Mr. Clarke said the importation of product was a matter for the Government and the NDAB and the licensing authority. Mr. Clarke put it to Professor Temperley that he was particularly involved in deciding upon product selection through the role of the National Haemophilia Coordinating Committee. If a drug was approved by the NDAB, an individual treating doctor could use it in the treatment of a patient. Professor Temperley agreed that this was correct.

Professor Temperley was cross-examined by Mr. Tony Aston S.C. for the NDAB. Mr Aston asked Professor Temperley about the use of a number of unauthorized blood products. He directed Professor Temperley to Koate, a factor VIII product by Cutter, and PPSB Factor IX by Travenol Baxter and BTSB Cryoprecipitate and BTSB Factor IX as unauthorized products used by the National Haemophilia Treatment Centre.

Professor Temperley said he believed at the time the BTSB did not require product authorization from the NDAB. He further said he believed that PPSB Factor IX was authorized. Professor Temperley said the BTSB supplied this product and as it came from the BTSB he believed it to be a licensed product.

Furthermore, Professor Temperley said he contacted the NDAB in January 1985 describing the products he would use for the coming year and as he received no notification from the NDAB that these products were not authorized he assumed they would be licensed product. Mr. Aston asked Professor Temperley if the BTSB provided a product did he assume it was all right to use? Professor Temperley agreed that this was the case.

Professor Temperley agreed that the BTSB Factor IX did not have a product authorization. He said that there was some question of the BTSB not requiring a product authorization and this was a prevalent view

at the time. Professor Temperley said he could not remember using Koate on a trial named-patient basis in or around the start of 1983, he said he may have used it.

Mr. Aston referred Professor Temperley to a trial of BSB Hepernized Factor VIII the intermediate Factor VIII produced by Mr Hanratty for the BSB in conjunction with Professor Temperley. It would appear from the documentation open to the Tribunal that the trials were successful. Professor Temperley agreed that this was the case.

Mr. Aston asked Professor Temperley had the NDAB ever been informed of the use of this product. Professor Temperley said he didn't know. Professor Temperley said he was not concerned to know if products were authorized, he said it was up to Dr. Scott to let him know. He said the niceties and detail of which products to use were lost in the need to get things going.

Professor Temperley agreed he supplied both Koate and Konyne before authorization was granted. He also agreed that Koate HS was used before the product authorization on the non-patient basis was granted and he agreed that the non-patient basis protocol was not adhered to in the use of Koate HS, the product was diverted for use among a different group of trial patients. Professor Temperley agreed that he also made use of Octapharma solvent detergent product in the early 1990s in the absence of a product authorization. Professor Temperley agreed that he was using Octapharma for two years before the product was withdrawn on the outbreak of Hepatitis A.

Professor Temperley was then cross-examined by Mr. Ian Brennan of the Department of Health. Mr. Brennan referred Professor Temperley to a communication with Dr. James Walsh of the Department.

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Professor Temperley was examined by his own Counsel Mr. Brian McGovern S.C.

Mr. McGovern took Professor Temperley through his role as Haemophilia treater. Professor Temperley said he would see up to 40 patients per week in the outpatients not all of whom had Haemophilia, in the course of the year he would see upwards of 300 haematology patients. In addition to dealing with Haemophilia he cared for other people who were seriously ill, dealing with acute Leukaemia's in both adults and children.

Professor Temperley said the lack of facilities in the 1970s and 1980s for the treatment of all conditions was well documented. A particular area of concern was the lack of specialist nurses in Haemophilia treatment, said Professor Temperley. This was particularly acute with respect to the National Children's Hospital and St. James's Hospital. He said the situation was not ideal. There was no trained Haematologist within the National Children's Hospital.

Professor Temperley said the lack of continuity with respect to treating doctors was a difficult problem to manage. He said that anyone born from 1970 onward with Haemophilia would have come under his care. He agreed with Mr. McGovern that a unique relationship existed between him and patients with Haemophilia. Professor Temperley said this was due to the ongoing treatment of persons with Haemophilia and the fact that he would be involved in their treatment he would come to know haemophilia patients much more so than other patients.

Professor Temperley said he was deeply affected by what happened to the Haemophilia patients. This was underlined by the unique relationship he enjoyed with them. With the introduction of home therapy Professor Temperley said it appeared that the treatment of Haemophilia was in good shape. This made the tragedies which occurred with respect to HIV and Hepatitis C all the more difficult to cope with.

With respect to the late John Kelly and Professor Temperley's relationship with John's father, Ray, he said it was a very difficult situation. It was one of the most difficult he had encountered with a parent and he could understand why Mr. Kelly was angry. With respect to a second opinion obtained from Dr. Jones in Newcastle, Professor Temperley agreed that Dr. Jones indicated that steroids would not help at that time but they were used for the later treatment of John Kelly.

Professor Temperley described his role in establishing the National Haemophilia Treatment Centre in 1971. Prior to the provision of adequate treatment, people with Haemophilia could die from a bleed. He could recollect all-night vigils with patients who were bleeding from simple matters such as tooth extractions. He also had to deal with inhibitor patients. Professor Temperley said this would involve working in relays for up to 36 hours trying to prevent a bleed by applying pressure on a wound left from an extracted tooth. As time went on the life expectancy of people with Haemophilia improved. This was primarily due to the availability of concentrate and blood products and improved management of patients. Home therapy was a major factor in increasing the life span of Haemophilia patients said Professor Temperley.

Professor Temperley said his role as a clinician involved the day-to-day running of the Haemophilia unit, conducting outpatient clinics once per week. Major ward rounds and minor ward rounds would be conducted. He also was involved in discharging general Haematology duties and laboratory duties. Professor Temperley said in addition to this he had teaching duties and research.

With respect to any private practice Professor Temperley said it would amount to less than 10 per cent of his total practice. He said he simply had no time to develop a private practice. Professor Temperley said he also had an advisory role with respect to blood products and the BTSB.

His different areas of expertise were in Haematology, Virology and Biochemistry. He said he had very little knowledge in the technical aspects of fractionation. He had a university knowledge of microbiology. With respect to heat treating Factor IX he had no idea how long it would take to introduce heat-treated product. He said the BSB Scientific Committee would be the body for this.

With respect to the NDAB, Professor Temperley said it was his impression that all products were licensed either in Ireland or in the U.S. He said he thought BSB products were an exception to this. With respect to departures from the named-patient basis Professor Temperley said the products came from reputable and established pharmaceutical companies and were licensed in their country of origin. Apart from one episode he did not depart from the named-patient basis.

Professor Temperley said he did not agree with the evidence of Mr. Keyes regarding positions of authority occupied by himself. He said Mr. Keyes over-emphasised his [Professor Temperley's] role and he was not in charge of the selection or nomination of contract fractionators. Professor Temperley said Mr. Keyes had placed too much emphasis on his role. He said his role was that within limited medical knowledge.

With respect to advice from the UK Haemophilia Centre directors, Professor Temperley said they were more experienced, had more patients and Haematologists, for this reason he followed the advice of the UK Haemophilia Centre directors. Professor Temperley said that he relied on freeze-dried Cryoprecipitate and commercial concentrate into the 1980s. BPL had its own concentrate at this time.

Professor Temperley said he attended the UK Haemophilia Centre Director's meeting on the 17th October 1983. There was a large attendance of Haematologists, about 15 or 20 of whom were Haemophilia treaters. Professor Temperley said it was important that the Tribunal appreciate the confusion which was abroad at this time, he said he may have taken a rose-tinted view as to what was occurring. Professor Temperley said in this sense one must distinguish guidelines and clinical judgement.

Professor Temperley said in respect of the *Lancet* article on the 24th December 1984 advocating a transfer to heat treated Factor VIII concentrate for Haemophilia A, he was coming around to this viewpoint at the time. He said the issue of heat treating FIX was less clear. The effect of heat treatment on the thrombogenic qualities of Factor IX were unknown. Professor Temperley

agreed that heat-treated commercial Factor IX concentrate was available. But, said Professor Temperley, problems and uncertainty prevailed with respect to heating Factor IX.

With respect to patients from Drogheda and Limerick Professor Temperley said they generally came to a clinic twice a year. With regard to Professor Egan, Professor Temperley said he was disenchanted with the National Haemophilia Coordinating Committee and his Haemophilia care practice was of a minor nature. For this reason he became detached from the NHSCC which left Professor Temperley and Dr. Cotter to carry on. Professor Temperley said a good professional relationship existed between Dr. Cotter and himself, this was conducive to discussions.

With respect to Professor Egan, Professor Temperley said a lot of patients from Galway came to the NHTC from the time before Professor Egan was appointed, this continued. Professor Egan got his product directly from the BTSB and in this sense Professor Temperley said criticism of him with respect to recalling product in August 1986 was unjustified. Professor Temperley said product recall was a matter for the BTSB, not him.

With respect to cost verses safety and the letter written on the 14th June 1988 setting out the options for the Board of the BTSB concerning the choice of a contract fractionator for the BTSB's Factor IX, Professor Temperley said he set out all the options, and the pros and cons to be considered by the Board. He gave the Board all the information at his disposal at the time. Balancing the issue of cost and the safety of product was one of these issues. Professor Temperley agreed that it was best to avail of a product at a cost which could be met. Professor Temperley said this letter did not consider Factor IX. He said it was legitimate to employ the safest method at the most economical cost. He said that the cost of Haemophilia treatment was considerable and large amounts of money were expended in treating individuals with concentrate. Professor Temperley agreed with Mr. McGovern that BPL FIX was not commercially available at the time, he did not apply his mind to obtaining it and never asked for it.

With respect to the issue of informed consent Professor Temperley said a different view prevailed in the 1970s. Doctors would prescribe medicine and the patient would not be burdened with concerns. Professor Temperley agreed that this was a paternalistic method of dealing with patients but this was how medicine was practised at the time. Professor Temperley said things were now different, it was now policy to explain issues to patients.

With respect to the lack of counselling facilities and helping people to cope with life threatening illnesses, Professor Temperley said this simply was not available in the 1970s and 1980s. He said they did the best with the resources they had at their disposal but did not comprehend the need to cope with the reaction of people. Professor Temperley said society itself did not expect this at the time and that is what he understood as a doctor.

Professor Temperley claimed that the incidence of Haemophilia/HIV in Ireland was comparable to that in the U.S. and the U.K. This observation applied to Factor VIII. Professor Temperley did not discuss the situation prevailing in Northern Ireland.

In the early to mid 1980s it was thought that only a small number of those who were positive for HTLV 3 would develop AIDS. It was thought that the AIDS antibody offered immunity in the early days of infection. Professor Temperley said it was a possibility HTLV 3 infection was not regarded as of major consequence. This continued into 1985. Professor Temperley said that this confusion prevailed throughout the medical world and it made it very difficult to advise patients adequately. Professor Temperley said a large number of patients with HIV remained well for a long period of time.

With respect to Hepatitis C Professor Temperley said it took up to 20 years for the disease to manifest itself and it took time for the doctors to come to terms with all these matters. Professor Temperley said throughout all this testing and the production of product and day-to-day treatment had to continue. Professor Temperley said he did not face any comparable crisis during his career as a doctor. He said they were put to the pin of their collar to cope. He claimed that other countries had the same level of HIV and Hepatitis C and they had striven to keep up with the rest of the world in terms of delivering a safe medicine.

In redirect examination Mr. John Finlay directed Professor Temperley to his June 14th 1988 letter. He also directed Professor Temperley to a note from Dr. Walsh within the BTSSB concerning the purchase of Factor IX from Elstree where Professor Temperley indicated that he would take the Elstree product if the price was right. Professor Temperley said this was corridor talk, an off-the-cuff remark, if he had given any consideration to the issue a more extensive record would exist with respect to choosing the 80 degrees by 72 hours.

Mr. John Finlay S.C. for the Tribunal examined Dr. Frederick Jackson.

Dr. Jackson is a Consultant Haematologist with the Southern Health Board and in June 1985 was a Haematology Registrar. Dr Jackson did an exchange with Dr. Helena Daly in June 1985. Dr Jackson worked in Dr Daly's post at Bristol and she worked a locum for Professor Temperley at the National Haemophilia Treatment Centre. Dr. Jackson was locum for Professor Temperley during the month of October 1985 and dealt with Haemophilia treatment and children with Leukaemia. Dr. Jackson succeeded Dr. Daly as Professor Temperley's locum in October 1985. Dr. Jackson said he took over from Dr. Daly during that month but could not remember any list being provided by Dr. Daly informing him as to who among the Haemophilia patients was HIV positive. Dr. Jackson said he was aware of lists and the existence of lists and the secrecy surrounding them and the maintenance of such lists but he could not remember receiving any.

Mr. Finlay referred Dr. Jackson to the case of "Dominic" who was treated by Dr. Jackson on the 22nd October 1985. Dr. Jackson said that the state of knowledge at this time was that not many people who were infected with HIV would advance to AIDS. With respect to the sexual transmission of the disease Dr. Jackson said patients would be advised as appropriate and if necessary their wives and partners would be tested. Dr. Jackson was referred to the cases of "Dermot", "Barry" and "Vincent". In July 1987 Dr. Jackson informed "Aongus" and "Kieran" of their HIV status.

As to why the patients were not told until 1987 they were HIV positive, when they had been tested in 1985, Dr. Jackson said the procedure was that if they didn't turn up, another appointment would be sent out to the patient and they would eventually attend.

Dr. Jackson said he could not remember any clinical trial of BTSB Factor IX being conducted in October of 1985. He did not remember meeting with Professor Temperley concerning BTSB Factor IX. Dr. Jackson said he was not involved in any quarantine or recall of product in 1985 while he was in St. James's Hospital. Dr. Jackson said he could not recall any steps taken in October 1985 to prevent the issue of non-heat-treated Factor IX to recall non-heat-treated Factor IX already issued. Dr. Jackson agreed that if such a mechanism had been in place he would have been involved in it.

After his work at St. James's Hospital in 1985 Dr. Jackson proceeded to the BTSB in order to sit his College of Pathology examinations. Dr. Jackson returned to St. James's Hospital in 1987. Dr. Jackson agreed that he was aware that BPL Factor IX A was available in 1988 and was deemed to be a safe and effective product. He said the Elstree product was the product of preference for U.K. Centre Directors. No adverse reports had come into being with respect to this product.

In 1987 Dr. Jackson returned to Dublin and St. James's Hospital as a Lecturer Registrar employed by TCD and based at St. James's.

With respect to Hepatitis C, Dr. Jackson said that in the late 1970s early 1980s Non A Non B Hepatitis was considered a benign condition. By 1990 it was known that Non A Non B was not such a benign condition. It was a matter of concern. Dr. Jackson agreed that in Whitechapel London, Elstree product was given to previously untreated patients, however there was no policy in place for Factor IX previously untreated patients in Ireland.

Mr. Finlay asked Dr. Jackson did he ever suggest to Professor Temperley that previously untreated Factor IX patients should be designated with an appropriate protocol. Dr. Jackson said he could not say for definite that he ever suggested using Elstree Factor IX for the treatment of previously untreated patients. Dr. Jackson said he could not really explain why there was no policy for previously untreated Factor IX patients other than to say there were fewer Factor IX's and the tendency was to concentrate on Factor VIII.

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Mr Finlay continued his examination of Dr Jackson.

Dr Jackson said he could not recall when he became aware of the availability of solvent detergent viral inactivated blood products, however he said by 1990 he was aware of the benefits of solvent detergent.

With respect to the treatment of “Luke” with dry heat treated Factor IX in October of 1990 Mr Finlay referred Dr Jackson to a letter in November of 1990 where he expressed concern that a possible shortage of solvent detergent product may occur. Dr Jackson said he could not remember the letter or any fears of a shortage of solvent detergent product at this time. He further observed that there was no absolute shortage of Factor IX concentrate and it did not appear to have run out at the time.

With respect to the treatment of people with Haemophilia who had developed symptoms of AIDS at the National Haemophilia Centre as opposed to the GUM Clinic, Mr Finlay put to Dr Jackson that a possible explanation of this might be that it was more appropriate given the Haemophilia condition to treat such patients at the NHTC? Dr Jackson said this may be the case as a lower platelet count meant that patients were more likely to bleed. However Dr Jackson said that he often sought help from Dr Mulcahy and the GUM service in the treatment of such patients.

Dr Jackson agreed that the fatalities among the patients with Haemophilia had an effect on the medical staff. Dr Jackson said optimism had existed concerning the treatment of Haemophilia. He said he remembered occasions when such fatalities had a profound effect upon Professor Temperley.

With respect to recording HIV/AIDS as a cause of death on death certificates Dr Jackson said that all relevant information was required to be recorded. He said that a two part death certificate could have removed the distress caused by recording AIDS and he was glad to know that in changing the death certificate some comfort was brought to “Deirdre” the widow of “Declan”.

Dr Jackson was cross-examined by Mr Martin Giblin SC on behalf of the Irish Haemophilia Society. Mr Giblin noted that in going over the events Dr Jackson appeared to have difficulty in remembering the detail of what happened 15 years ago. Dr Jackson said just because he could not remember a system it did not mean that no system was in place and he would not like the Tribunal to think that this was the case. Dr Jackson said that people were terribly sensitive about leaving details of HIV positive patients lying around. With respect to a survey of Hepatitis C patients conducted by Dr Jackson and Dr Noone, Dr Jackson said that this information could not be used to inform patients of HCV positivity as these were research tests only.

PROCEEDINGS: Friday 16th March 2001 - Day 105

Mr Pat McCann, for the Tribunal, examined Maeve Foreman, Social Worker at St. James' Hospital. Mr McCann took Ms Foreman through a number of documents which showed that, from 1985 onwards, the hospital was in touch with the Department of Health concerning the paucity of social workers. By the summer of 1985 Ms Foreman said there was a "frozen" social worker post as absent social workers could not be replaced, and even locum social workers were ruled out. By 1987 four such social worker posts had been frozen.

On 1st October 1985 Dr Helena Daly wrote to Mr Fitzpatrick at the National Children's Hospital. Dr Daly noted that medical counselling had taken place where she told patient their HIV status. The significance of this may be lost on patients, noted Dr Daly, as the impact of the news would be blocked out by a patient receiving such bad news. Dr Daly also noted that patients should be advised on the consequences and possible sexual transmission of HIV. She noted that more social workers were required.

Prof. Temperley is recorded as having contacted Mr Dunbar, chief executive of St. James' Hospital, looking for extra social work staff, on 19th November 1985.

In April 1986 Mr Dunbar wrote to the Department of Health looking for social work assistance. In late 1986 Ms Foreman was assigned to deal with people with haemophilia. In October 1986 Ms Foreman was in place and Ms Flynn was assigned to assist her on a half time basis. Ms Foreman explained that her duties were to attend the out-patients, identify the people with HIV and provide some support for those so identified.

Ms Foreman said from this point onward the social work department tried to be proactive in HIV counselling. However, she said this proactive approach had to take a non-threatening stance and she was simply trying to make contact with those who might be seeking counselling, and establish a rapport with the patient group.

Ms Foreman said a lot of patients knew about the availability of social workers, but didn't want to focus on being positive at this time. Ms Foreman said that both Sister King and, in her succession, Sr O'Shea, took an active role in referring HIV positive patients to the social workers.

Ms Foreman said that Sr King in her time was the haemophilia centre. She would refer any patient she assessed as being in need, to the social workers. Ms Foreman also said that the peer support group, organised by Mr Brian O'Mahony of the Irish Haemophilia Society, was of great importance. Ms Foreman said many of the people with haemophilia knew each other at that time and the support group was directed at preventing those with haemophilia being isolated. She said Father Paddy McGrath also worked with the support group. The liaison with the I.H.S. was very important even though the I.H.S. had no full time staff at this time. It sought to organise and support those with HIV. However, Ms Foreman said the social work service for people with haemophilia at this time was not a proactive service. Ms Foreman said if all the people with haemophilia who had HIV took up the offer at the time, they would have been overwhelmed by the large response, as they simply did not have the personnel in place to deal with great demand for their service.

Ms Foreman told Mr McCann that the denial of their positive status was a functional option and, said Ms Foreman, this was satisfactory provided it did not endanger either the person with haemophilia or anyone else. Ms Foreman said at this time HIV was of such terrifying dimensions, that many people did not tell

their close acquaintances or even members of their family or extended families, that they were HIV positive.

Ms Foreman said a lot of energy was put into keeping their HIV status secret. Many people did not want to upset their parents or their partners, and as long as they were positive and well there was no need to dwell on HIV positivity.

Initially, said Ms Foreman, many of the older men with haemophilia had dealt with the fact of having haemophilia on their own for many years, and continued to adopt this attitude towards being positive for HIV. Also, said Ms Foreman, the social workers were a hospital-based service, and as the hospital had infected these people in the first place, those infected were not inclined to use the services on offer. HIV infection was a cause of anger among people with haemophilia, and those concerned were not inclined to turn to the hospital for assistance or counselling or social work support.

Ms Foreman said that by the end of 1989 50 per cent of people with haemophilia had been counselled. The other 50 per cent of HIV positive people with haemophilia had had no contact with social work services by the end of 1988. From 1987 onwards, growing numbers of persons with haemophilia infected with HIV were symptomatic. At this stage, not all persons who were positive for HIV had been told.

In July 1987 further financial cut-backs occurred in the provision of social work services. At this time, said Ms Foreman, the work was very much in-patient based. When she would attend the out-patients each week the numbers expected to develop AIDS was slowly growing.

In July 1988 £15,000 was provided by the Department of Health for the provision of two social workers/AIDS counsellors. This money was provided from National Lottery funding. Ms Foreman said this was a watershed event in the provision of social work services. By the end of 1990, Ms Foreman said they had effectively created these services. The social work counselling aspect of their activities became more proactive.

Before the advent of triple therapy, said Ms Foreman, it was imperative for many to keep secret their HIV status. The prospect of illness and death was very real for many people, and a social work or counselling service enabled many facing these challenges to work out what they would say to their children, to plan terminal care and deal with the infectious diseases arising from HIV.

At the end of 1988, said Ms Foreman, Ms King retired from her post at the National Haemophilia Treatment Centre, and took up a counselling role with the Irish Haemophilia Society. Ms Foreman said that the Society and Ms King were a huge help in dealing with all the problems they had to face. After 1989 Ms Foreman said Trust Fund money became available, enabling the Society to employ a counsellor who could work outside the hospital environment, however she said the take-up of such services was small.