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)

PROCEEDINGS: Tuesday 23rd October 2001 - Day 182

Today, Fiachra and Edel gave evidence. Both Fiachra and Edel gave personal testimony with regard to their experience of haemophilia and infection with Hepatitis C and HIV.

Fiachra is 35 years old and married to Edel. They have two children. Fiachra suffers from severe haemophilia A. He was diagnosed at birth and commenced home treatment in 1984. He described the home treatment as having a brilliant effect on his life.

In 1985 he was tested for HIV and he was subsequently told that he was HIV positive. He described how he had been at his hospital and had entered a treatment room where, as was usual, he would make up his own treatment from product which was stored in the fridge. On entering the room, he noticed another person with haemophilia talking to a junior doctor. He noted that the other person in the room was extremely irate and upset. After some time, the junior doctor approached Fiachra and informed him, as he had informed the other patient, that he [Fiachra] was also HIV positive. He said that the junior doctor had told him that he had 3-6 months to live and that he should get his affairs in order. He said he was shocked and couldn't believe it, and that he never suspected that he might have been HIV positive.

He described how he had always been expected to be able to follow his brother's success as a businessman since he had been to college. Fiachra described how he became suicidal and on one occasion tried to dive off Dun Laoghaire pier but was stopped by a Garda.

Fiachra went on to describe how one of his brothers had died in January 1994 from AIDS. He had also been infected through the use of contaminated blood products.

Edel, Fiachra's wife, was then examined by Mr. Durcan for the Tribunal. In October 1985, Edel tested positive for HIV. Edel described how she was shocked and numb when she was told of her HIV status. She said it was as if her husband had been told that he had the virus all over again. She described his guilt and the fact that they had never been informed previously that it was possible to transmit the virus through intercourse.

She went on to describe how she became pregnant in 1997. She had the pregnancy terminated because she didn't want the child to be born with the risk of HIV.

PROCEEDINGS: Wednesday 24th October 2001 - Day 183

The Tribunal heard evidence from Mr. Seamus Dooley of the Virus Reference Laboratory. This is the second occasion on which Mr. Dooley has given evidence to the Tribunal. With respect to a study conducted by Dr. Shattock of the Virus Reference Laboratory into the number of persons with haemophilia who became positive for Hepatitis B between 1970 and 1987, Mr. Dooley said that the study identified 35 people who came into this category. Of this group, 20 were identified by name and of this group 11 subsequently became positive for HIV. At this point it is referable to the hypothesis that if Hepatitis B core antibody testing had been introduced in the early 1980s as a surrogate marker for HIV, then it would have been possible to eliminate at risk donors and thus spare some of those who subsequently became infected.

Mr. Dooley went on to present an analysis of a table prepared by the Tribunal, designed to show the rate of infection of persons with haemophilia and when persons with haemophilia became infected with HIV.

Mr. Dooley discussed the difference between the IgM anti-HIV result and the P24 antigen test result with Mr. Bradley for the Irish Haemophilia Society. Mr. Dooley said that if an IgM positive result was obtained, it would indicate generally infection in the previous six months to a year. Mr. Dooley pointed out that the P24 antigen test could indicate a recent or long-standing infection.

The Tribunal heard evidence from Ms. Susan Stapleton, a Solicitor with the Firm Ivor Fitzpatrick & Co. Ivor Fitzpatrick & Co. represented persons with haemophilia in litigation which involved a number of pharmaceutical companies. In the context of that litigation certain testing was carried out on stored samples which were provided by the Virus Reference Laboratory. Testing of these samples was carried out by the Collindale Laboratory, ie. the Central Public Health Laboratory, Collindale Avenue, London. The Tribunal requested and was provided with, a copy of the test results.

PROCEEDINGS: Friday 26th October 2001 - Day 184

Today, Counsel for the Irish Haemophilia Society, Martin Hayden S.C., applied on behalf of the I.H.S. for an extension of time within which to complete the Society's Final Submissions to the Tribunal. The Tribunal had set the date for delivery of the Final Submissions as 5th November 2001. Mr. Hayden indicated that the time limit imposed by the Tribunal was restrictive, unnecessary and would prevent the lawyers for the Irish Haemophilia Society preparing full and complete submissions. He indicated that there had been correspondence between lawyers for the Irish Haemophilia Society and the Tribunal, indicating that given the detailed nature of the submissions required, that it would be impossible to complete them within the time frame proposed.

Mr. Hayden went on to point out that the I.H.S. was in a different position from other parties before the Tribunal. Of the 150 witnesses who gave evidence, 66 of them were proposed by the I.H.S. Furthermore, he said that the I.H.S. had to prepare for every element of the Tribunal and was required to cross-examine every witness who was called. Other parties before the Tribunal, working to the same time frame, were only required to deal with certain elements of the Tribunal's work.

In the circumstances, Mr. Hayden submitted that it was unreasonable to expect the I.H.S. to deliver its submissions in the same time frame proposed for other parties. Mr. Hayden indicated that of all those people who had been infected with Hepatitis C or HIV, that the I.H.S. represented 197 of them. He reminded the Tribunal that those who had been infected had waited for many, many years for an answer as to why their infection was allowed to occur. In comparison to the length of time that I.H.S. members had had to wait for the Tribunal to commence its work, it was unreasonable to rush the final stages of the Tribunal by imposing unrealistic deadlines. Mr. Hayden further emphasised that no prejudice would be caused to any other party by granting an extension of time, whereas grave prejudice indeed would be caused to the Irish Haemophilia Society.

The I.H.S. sought an extra five weeks in which to deliver its submissions.

On behalf of Prof. Temperley, Brian McGovern S.C. stated that the delay in submissions would gravely prejudice his client since allegations were being made against him of a very serious nature.

Anthony Aston, S.C. for the Irish Medicines Board, recognised that the Irish Haemophilia Society was in a different position from other parties and that it may have difficulty making submissions in the time allowed.

John Finlay, S.C. for the Tribunal, submitted that the Irish Haemophilia Society had been afforded adequate opportunity to make its submissions.

The Chairperson of the Tribunal adjourned briefly in order to consider the application, and returned to give her ruling that although she considered the period of time which had been granted to the Irish Haemophilia Society to make its submissions was sufficient, having heard the application she would extend the deadline for submissions for a further two weeks.

The Tribunal then adjourned.

PROCEEDINGS: Wednesday 31st October 2001 - Day 185

The Tribunal was scheduled to sit to hear the evidence of the witness James, who was not available to give evidence, and the Tribunal adjourned until the 9th November 2001.

PROCEEDINGS: Friday 9th November 2001 - Day 186

Today, James was due to give personal testimony evidence to the Tribunal. However, he was too ill to attend and his statement was read into the record of the Tribunal by Mr. Bradley, Solicitor for the Irish Haemophilia Society.

In his statement, James described how he had undergone a living hell as a result of his treatment for Hepatitis C. He had been put on Interferon treatment twice. He said that on the first occasion in 1994, the side effects nearly killed him. He suffered from fevers, mood swings and missed out on schooling. He said in 1999 he went on the treatment again, as a result of which he lost his wife and had to be treated with anti-depressants. James did not response to the treatment on either occasion. He said in his statement that he now faced the horror of going on the treatment for a third time. He said that all his ambitions and his career prospects had been wrecked by his infection with Hepatitis C.

James described how his brother, Mark, had been infected with HIV through the use of non-heat treated BTSB factor IX, and had subsequently died of an AIDS-related illness.

PROCEEDINGS: Wednesday 14th November 2001 - Day 187

Mr. John Finlay S.C. for the Tribunal made the closing submissions for Counsel for the Tribunal.

Mr. Finlay said that while he offered the observations of the Tribunal's Counsel, he did so in the knowledge that it was for the Tribunal Chairperson to report to the Oireachtas on the matters specified in the Terms of Reference, and to decide what issues are relevant in doing so. He put forward the observations of the Tribunal's counsel as a possible framework for the parties to examine the matters which had been heard in the previous 186 days of evidence.

Mr. Finlay noted that the Virus Reference Laboratory had given evidence through Mr. Seamus Dooley, that their records indicated a total number of 104 persons with haemophilia had been found to be positive when tested for HIV antibodies. Seven of the 104 persons infected with HIV were persons with haemophilia B. The Tribunal heard evidence that the likely source of infection of those persons was factor IX fractionated by the BTSB, and in particular batch numbers 90633 and 90753, neither of which had been subjected to heat treatment.

The Tribunal examined the issue of late factor VIII HIV seroconversion by way of Armour, Factorate Batch A28306.

The Tribunal heard that 217 persons with haemophilia had tested positive for Hepatitis C. This was the figure presented to the Tribunal by the Virus Reference Laboratory, and as other bodies were conducting hepatitis C tests it is likely that there are some more persons with haemophilia who were infected with Hepatitis C, whose samples were not tested by the VRL. It was therefore stated that this was a minimum number of people who had been so infected.

The Tribunal examined the issues of BTSB factor IX Batch No. 9885, which was identified by Dr. Emer Lawlor as the probable source of infection with Hepatitis C of an adult patient given the pseudonym Luke, and the three children given the pseudonyms, Henry, Gordon and Joseph.

Mr. Finlay made submissions on BTSB factor IX; BTSB Armour factor IX; Hepatitis B core testing; the late Mr. John Barry; the role of the National Haemophilia Treatment Centre; factor VIII Hepatitis C infections; the infection of persons born after January 1st 1985 with Hepatitis C; the issue of counselling; the I.H.S. role in the matters under investigation; and the role of the Minister and the Department of Health.

Mr. Finlay made a number of other submissions on a large number of issues examined during the course of the Tribunal.

PROCEEDINGS: Thursday 15th November 2001 - Day 188

Today, the Tribunal heard the closing submissions of parties. The Tribunal began by hearing the closing submission of James Connolly S.C. on behalf of the Kilkenny health worker. The Kilkenny health worker was infected with HIV through a blood transfusion. The infected donor had given donations after the introduction of HIV testing.

Mr. Connolly criticised the BTSB's failure to carry out a proper look-back programme. He went on to say that it was clear that the BTSB had been aware of the AIDS risk from blood transfusion since 1983 onwards, but had failed to introduce any screening procedure in a timely fashion. The BTSB adopted instead, he said, a wait and see policy. He said that had adequate screening procedures been put in place, it would have been possible to prevent the infection with HIV of the Kilkenny health worker.