

IRISH HAEMOPHILIA SOCIETY

TRIBUNAL NEWSLETTER

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26th February 2002

TRIBUNAL OF INQUIRY

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

PROCEEDINGS: Wednesday 10th October 2001 - Day 174

Today, Dr. Emer Lawlor for the B T S B was recalled to give evidence. She was asked about the death of Mr John Berry, who suffered from mild haemophilia, and had been treated at St. James's Hospital for a nose bleed. Rather than being treated with cryoprecipitate which was the normal treatment, Mr. Berry had been treated with imported concentrate manufactured by Baxter Travenol.

Dr. Lawlor described how Mr. Berry had been admitted to St. James's suffering from a nose bleed. The nose bleed had subsequently stopped but at 6.45am, a Junior doctor had contacted Dr. Lawlor, the Haematology Registrar at St. James's in charge on the night in question, who told Dr. Lawlor that there was insufficient sterile water in the ward in order to prepare treatment for cryoprecipitate.

Dr. Lawlor instructed the Junior Doctor to use two bottles of Hemofil to stop the bleed. Dr. Lawlor explained how there would have been a preference for using cryoprecipitate because it was a national product and therefore sourced from volunteer donors in the Republic. Consequently, there would have been a higher risk from the imported factor concentrate. However, Dr. Lawlor was concerned, she said, about Mr. Berry's condition. She said that Mr. Berry could have collapsed and died very quickly had the nose bleed continued. Dr. Lawlor went on to say that doctors always had to balance the risks involved in administering treatment. Dr. Lawlor said she didn't know if sterile water shortages were a common occurrence in hospital, but she said she thought it was unlikely that this was a first time such a shortage had occurred.

Dr. Lawlor was also asked about the B T S B's supply of factor IX concentrate in August 1985. Dr. Lawlor accepted that factor IX manufactured by the B T S B was distributed in August 1985, and that more than normal was sent out by Pelican House in that month. She accepted that in retrospect it was clearly not wise for hospitals to be building up stocks of unheat-treated factor IX concentrate at a time when HIV safe heat-treated factor IX was shortly to become available. However, Dr. Lawlor said that the orders for factor IX concentrate were what hospitals had requested and were not manufactured or encouraged by the B T S B. Dr. Lawlor denied any allegation that the B T S B had been dumping non-heat-treated factor IX concentrate on hospitals at this time.

PROCEEDINGS: Thursday 11th October 2001 - Day 175

The personal testimony witnesses gave evidence to the Tribunal.

The witness “Eithne” gave evidence concerning her son, Simon.

Eithne’s son Simon died from AIDS on the 16th January 1993. He was 11 years old. On the first anniversary of her son’s death, Eithne’s brother, also a person with haemophilia, died from AIDS.

The Tribunal also heard the evidence of Veronica who contracted Hepatitis C from blood product used in the treatment of a deficiency of factor A1.

The Tribunal also heard the evidence of Ms. Anita Geoghegan who gave evidence in respect of her late brother, Mr. John Scallan. John Scallan died on 8th March 1994. In addition to giving her evidence concerning the circumstances of her brother’s illness and death, Anita Geoghegan read a statement made by her brother, to the Tribunal.

PROCEEDINGS: Friday 12th October 2001 - Day 176

Today, three witnesses gave personal testimony. Brigid was examined by Martin Giblin S.C. for the Irish Haemophilia Society. Brigid's husband was diagnosed with Hepatitis C in 1990 but he kept the information from her for some time so as not to upset her. Rumours started that he had AIDS, and his daughters were jeered at school. Brigid described how her daughters were called AIDS carriers.

William was examined by Jim McCullough for the Irish Haemophilia Society. William told the Tribunal how his father had been infected with Hepatitis C and HIV. William described how his father had died at home with only himself and his sister to care for him. He described an incident in his father's last days when he wiped a tear from his father's cheek, and his father shouted at him. His father believed himself to be highly contagious and did not want his children in close contact with him.

Christopher gave evidence of how his son was informed that he had been infected with Hepatitis C. The information was transmitted to him by post in an ordinary brown envelope. There was no adequate or appropriate counselling or support given to Christopher's son.

PROCEEDINGS: Tuesday 16th October 2001 - Day 177

Today, the Tribunal heard personal testimony evidence from Jack, Amanda and Terence.

Amanda said that her son, Mark was infected with HIV through the use of non-heat treated blood products manufactured by the BTSSB. He tested positive in 1986 and died in 1995 aged 17. She said that she was never told that blood products carried a risk of viral infection. She said that her brother, who also had haemophilia, had asked Prof. Temperley whether or not factor IX could transmit HIV, and that he had been reassured that it could not. She said that she only discovered that there was a danger from infection through blood products when she noticed an article in the newspaper which said that a person with haemophilia in Dublin had died from AIDS. Amanda's brother had also become infected with HIV.

Jack told the Tribunal that he had seen a file which showed that he had tested positive for Hepatitis C, although this information had never been given to him directly. Jack said that he had also been told that people with haemophilia with factor IX deficiency, like himself, could not get HIV. He said it was not until this Tribunal started that he discovered that factor IX patients had become infected with HIV and this came as an awful shock to him.

Terence gave evidence about his son who had become infected with Hepatitis C. He said he first received treatment in 1986 and he was informed in passing five to six years later of his Hepatitis C status. Terence described how in 1993 and 1994 he had become involved in a dispute with the Eastern Health Board over the termination of prophylactic treatment for his son. The apparent reason for the termination of the treatment was the high cost. It was only after contacting the Minister for Health, Mr Howlen, that Terence said he was informed that the treatment would be restored.

PROCEEDINGS: Wednesday 17th October 2001 - Day 178

Today, three witnesses called by the I.H.S. gave personal testimony evidence. The first witness, Thomas, was examined by Martin Hayden, Senior Counsel for the I.H.S. Thomas described how he had two brothers who were born with haemophilia. One of Thomas' brothers, Matthew, had contracted HIV from blood products and had subsequently died. Thomas described how both his brothers had no difficulty in working and being able to provide for their family. Thomas described how Matthew had had two children and was married when he was dying from AIDS. He said it was very difficult because there was nothing that could be done for his brother as he deteriorated. Thomas went on to describe how his brother Terry contracted Hepatitis C. Thomas was particularly angered by the way his brother Matthew's death was dealt with. He described how he went to St. James's Hospital to the morgue to pay his last respects, only to find that the coffin had been closed.

Thomas also described how two of his nephews had Hepatitis C.

Mr. Hayden then examined Anthony. Anthony has severe haemophilia A. He was tested for HIV in 1985 and received the results in early 1986. He described how his parents were devastated when he told them the news. He described how he didn't know where to turn, and that he had no support to deal with the situation he was in. Anthony was subsequently diagnosed as suffering from Hepatitis C in the early 1990s. He described the horrific experiences he had being treated with interferon.

Scott was then examined by Ciaran Lewis for the Irish Haemophilia Society. He said he was a mild haemophiliac who had contracted Hepatitis C from using factor VIII. He said he was married with two children. He had received factor VIII for dental treatment but it had not been explained to him that there was any danger associated with factor VIII.

Prior to contracting Hepatitis C, despite his haemophilia, Scott lived a very normal life. Scott explained that the only person who knew that he had Hepatitis C was his wife. Scott was angry that the situation in relation to Hepatitis C wasn't fully explained to him when he was first diagnosed. He described how his Hepatitis had affected him at work and also in his personal life. He eventually decided to give up his job and to find a less strenuous job, even though he had held a position of high responsibility.

PROCEEDINGS: Thursday 18th October 2001 - Day 179

The Tribunal heard evidence from Michael, David and Jason.

Jason told the Tribunal that he was infected with both Hepatitis C and HIV. He was infected by using BSB factor IX. He told the Tribunal that he was very angry because he realised he should not have been infected with HIV because there was a safe product available.

Michael told the Tribunal that he was infected with both HIV and Hepatitis C. He was angry because he did not know who was responsible for infecting him.

David also gave evidence, stating that his professional career had been blighted by his infection with Hepatitis C. He is a married man with three children and believes that he was infected from a contaminated clotting agent sometime in 1985.

PROCEEDINGS: Friday 19th October 2001 - Day 180

Today, Rebecca gave evidence examined by Jim McCullough B.L.. Rebecca was a witness giving personal testimony evidence having been called by the Irish Haemophilia Society. Rebecca's husband had haemophilia. They had married in the 1960s when there was no effective treatment for haemophilia. His condition deteriorated until 1973 when he had to give up his employment.

Treatment with factor VIII concentrate improved his physician condition in the late 1970s and early 1980s, but he also started to drink heavily which affected his mental health. He was informed that he had contracted HIV in 1986. His daughter had been to visit him and the nurse had told her in St. James's that her father didn't seem to understand his condition, and she was asked to explain it to him.

Rebecca described how her family were treated like lepers when her husband's HIV condition became known. Rebecca's husband died in 1993 and during all that time, his daughter had cared for him and his HIV status and the condition of AIDS was never properly explained to him. He never received any special assistance or counselling for his condition.

PROCEEDINGS: Monday 22nd October 2001 - Day 181

The Tribunal heard the evidence of Marian, Niamh and Frank.

Frank, who is 26 years old, found out in August 2001 that he was Hepatitis C positive, despite having been tested in 1994 and being told that he did not have the virus. He had originally thought after the tests in 1994 that he was extremely lucky. He described how he had lost any faith in the health care system. He said on the last few occasions when he went to St. James's Hospital he had to show the person treating him how to mix his injections and set up the intravenous line.

Niamh gave evidence that she was treated in University College Hospital Galway since she was a child, for factor VII deficiency. She contracted Hepatitis C but wasn't tested for it until 1995. She also complained that she was found positive in 1985, she wasn't referred for any specialist treatment to a Hepatologist. She described how, since her diagnosis, her relationship had broken up and she was not coping well.

Marian told the Tribunal how three of her sons who had haemophilia had been infected with HIV, and two had since died. She said that she felt her life was gone. She said it was very hard for any mother to see two sons die.