IRISH HAEMOPHILIA SOCIETY

TRIBUNAL NEWS

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TRIBUNAL OF INQUIRY

(into the infection with HIV and Hepatitis C of
Persons with Haemophilia and related matters)

Proceedings: May 8th, 2000

The proceedings continued before Her Honour Judge Lindsay on the above date at the Distillery Building, 141/145 Church Street, Dublin 7.

John Berry

Mr Berry gave his evidence in public under his own name. He is a married man of 62 years, he has three adult children and is mild haemophilia A. He told the Tribunal that he thought he was diagnosed Hep C positive in or around 1991.

Mr Berry said that he discovered he was that he had haemophilia in 1973. This discovery followed a road traffic accident in which he was injured about the face and head. He was not treated with any factor concentrate at that time.

Mr Berry's one and only treatment with FVIII followed a nose-bleeding incident in 1979. During the 1980s Mr Berry was diagnosed with cirrhosis of the liver. He was hospitalized and underwent a liver biopsy procedure. During the course of this treatment he also attended the NHTC which monitored his haemophilia. He attended the Centre in 1991 and was diagnosed Hep C postive. Initially he was told he was probably Hep C positive and this was confirmed at a later date.

When he was told he was Hep C positive he thought he was suffering from HIV and would get Aids and die. He did not ask any questions about the diagnosis because he did not know what questions to ask.

The news that he was Hep C positive had a seriously detrimental affect on his personal relationship with his wife. She too thought he had Aids. It was only after some time, mainly through the efforts of his wife to find information on Hep C, that he was able to determined that he was not in fact suffering from HIV but from Hep C. His wife has had four mental breakdowns since he was diagnosed with Hep C.

Mr Berry now suffers from liver cancer. It is untreatable, he is not suitable for a liver transplant and he is pessimistic about his future. Every time he gets a pain or ache he thinks this is it, this is the cancer. Further, there is no treatment available for his Hep C.

As regards his previous lifestyle Mr Berry now has little or no contact with his friends and acquaintances from work and from where he lives. He has retired from his job as a lorry driver, a job he loved. He cried on the first Monday he could not go to work. He can no longer do the gardening or painting or DIY which he previously enjoyed. He cannot sit down to a meal with any enjoyment. He has no appetite for food.

Mr Berry hopes the Tribunal will discover what went wrong with the system of looking after people with haemophilia, he hopes it will find out who made the mistakes and that the people responsible for the health system make sure that no-one is again treated with dangerous products.

Vincent

Vincent gave his evidence under an assumed name. He is a 34-year-old man and is married to Wendy. He is mild haemophilia and was diagnosed as such when he was nine years old.

In the summer of 1985 his appendix was removed at St James's Hospital. He was admitted to hospital with pains in his abdomen and was operated on immediately. The following day the surgeon who removed his appendix told him the appendix was healthy and that he had been suffering from gastritis. For the purposes of this operation he received large quantities of cryo. He received between 60 and 80 units of cryo. He did not know if the cryo had been virally inactivated.

Vincent tested positive for HIV in January 1986. He was informed of this state of affairs after he had requested a HIV test. He was told to take the usual precautions regarding his personal utensils and to use a condom if having sexual intercourse. He was offered no other form of counselling.

In 1990 Vincent was treated with AZT. His spleen was removed in 1990 and he is currently availing of triple therapy at St James's Hospital.

Vincent is HIV and hepatitis C positive. He is the only man in his family and his name will die out if he does not have children. This is an important issue for him. He would like to be able to hand over his family business to one of his own children.

With regard to public attitudes to HIV he told the story of being in the pub with his friends when the subject of a person who had died from HIV was raised. One of his companions, unaware that Vincent was HIV positive, said he would not drink out of the same glass as a person with HIV.

Vincent said if it was known that he had HIV his business would suffer – it would go down straightaway, he said. He told the Tribunal of how as long-standing relationship came to an end when his girlfriend learned he had HIV. He told of the difficulty in establishing a relationship. He said he had had to become a judge of character in order to know whom he could trust with the knowledge that he had HIV.

Vincent became HIV positive when in his early 20s. He recalled the Recompense campaign and while he received some money from the campaign he was dissatisfied with certain aspects of how settlement was reached. He said people were anxious to settle before they passed away, they were anxious for their families.

Vincent said he felt he had been let down by the health service. He said there were many flaws in the system.

Recalling the death of his mother Vincent said she died a relatively young woman of 58 years. He told her before she died that he had HIV. He now wishes he had not told her of his HIV infection as he believed she died blaming herself for his condition. She had passed haemophilia to him, he got HIV from untreated cryo, she thought, as did many mothers of men affected by haemophilia, that she was responsible for his condition. Vincent said if he had had any counselling he may not have told her. “I would never have told her,” he said.

If he had the chance to do things again the only person he would tell would be his partner. I have told my wife, he said, and she rallied round me.

In addition to being HIV positive Vincent is also Hep C positive. His reaction to being Hep C positive was not as severe – “I did not blow as much,” he said. However, he realized the serious nature of Hep C, he was aware of its capacity to infect other people and he took all the appropriate precautions. He said the felt under the greatest threat from HIV.

Vincent said he wants to know what went wrong. He said somebody made a mistake and as he had to answer for his mistakes then so too should those who were wrong in this matter. “I answer for my mistakes – so should they,” said Vincent. It would be much easier to deal with the whole thing if he finds out what has happened.

Albert

Albert has severe Haemophilia B, and is Factor IX deficient. He was known and has been treated for this condition since childhood. In the 1960s and early 70s he had to be treated in hospital. Factor IX concentrates brought about a big improvement in treatment. He could now be treated in his local hospital and had to go to St James’s only if there was a particularly serious problem to be dealt with. He did however attend the NHTC on a regular basis.

The 1980s were a rough time for people with haemophilia. Albert felt lucky and relieved to avoid any infection. Haemophiliacs were getting HIV and Aids but Albert remained clear of any infection.

In 1993 and again in 1995 Albert attended St James’s. Prior to this he had been getting on with his life. He got married and had a family and was happy with his wife bringing up their children in his home town.

He attended SJH in 1993 and a blood test was taken. He was told if there was anything amiss they would be in touch. He was anxious for a few weeks about the results of the test but when he heard nothing he assumed everything was OK.

He did not hear from SJH during the next six years. In 1999, following bouts of lethargy and taking a long time to complete simple tasks, Albert presented himself at the NHTC – the first question put to him was: “How is the Hep C.” Albert was stunned. He did not know until the question was asked that he had Hep C.

The last test he had had was in 1993. The hospital had known since 1993 that he was Hep C and has done nothing about it. The hospital had however contacted Albert's GP and told him of Albert's condition. No one told Albert.

Albert's main worry at this stage was having to go home and tell his wife the news. She too could be infected, as could his children. They were tested and proved negative for Hep C.

Albert said he found out about his condition on is own initiative, he found out because he was tired. He has a genotype 5 Hep C. This genotype is not commonly found in western Europe. It is more commonly found in Asia. Albert said he hopes some treatment becomes available for his condition. He also says that he hopes the system of letting people know about their illnesses or condition improves: "Somebody has to be responsible for letting people know what is going on," he said.

Joe Healy

Mr Healy told the Tribunal the story of his son Gerard who died in 1998. Gerard was diagnosed mild haemophilia A in 1963. In or around 1979 he received Factor VIII and was diagnosed HIV positive in 1985. Gerard was very shocked to be told he was HIV positive, he was 25 years old, his wife had just given birth to their third child, a daughter, and he had been handed what he considered to be a death sentence. There was no one to tell the family about HIV or to offer any form of counselling.

Mr Healy told how Gerard became involved in finding out as much information as he could about HIV and Aids. He eventually became a professional counsellor in this area and visited schools and prisons talking about Aids.

Following a trip to Dublin where Gerard visited the Cairde House he decided to go public about his own HIV condition. He received good support from the people of Cork. Looking after the interests of people with HIV became his major quest in life from this point until his death in 1998 at the age of 38.

Mr Healy told the Tribunal about the lack of resources in Cork when Gerard was first diagnosed. There was no haemophilia treatment center, there was no infectious diseases consultant, and there was no respite care for those in the final stages of the disease. People with Aids looking for respite care had to travel to London for such care.

A dispute between Marymount in Cork and the Southern Health Board appeared to be preventing the hospice from accepting Aids patients. While this dispute was going on Gerard's family sought a place for him. They were unsuccessful despite his condition that included loss of his speech, he was unable to walk and had to be assisted with every personal need.

Mr Healy read a letter to the Tribunal from Gerard's sister, Martina:

"The last of the my brothers – no-one will ever know the pain, the hurt and anger I have inside me. He was robbed of his life, left his wife and three children, mother, father and two sisters and brothers-in-law and many friends, still lost for words. Why? No help was offered. All he wanted in life was to be there for his family, to grow old together with the ups and downs of everyday living. He loved who he was, being a haemophiliac didn't stop him from anything until he got the HIV. For 13 years he did everything in his power to live. He would have been 40 years of age on the 27th of this month, May."

Brenda:

Brenda is the mother of six children and she gave evidence relating to one of her sons, Charles who was born in 1956. She told the Tribunal about the difficulties in treating haemophilia 40 years ago. She said that when cryo and Factor VIII became available a whole new life opened up for her son.

Advances in the treatment of haemophilia allowed her son to go off and establish an independent life for himself. He moved to Dublin and was got a job. At the weekends he would come home to visit his mother and father and the rest of his family. When Factor VIII came on the scene he took to it and availed of home treatment.

He kept in regular contact with his family through the late 1970s and early 1980s. In the mid 1980 he abruptly cut off contact with his family and they guessed there was something wrong.

Brenda's son wrote to his parents. He told them he was HIV positive. She told the Tribunal that he must have been one of the first to be infected. Brenda's husband carried the letter around in his pocket until the letter itself disintegrated.

In addition to the news that her son was HIV positive, Brenda was also aware from conversations with him that her had Non-A Non-B Hepatitis. Charles' mother and father tried to comfort their son. They wrote back to him telling him they supported him and were as angry as he was that he was HIV positive.

Charles, meanwhile was suffering severe mental anguish at the thought of being HIV positive. He isolated himself, he thought people knew to look at him that he was HIV positive, he thought people were avoiding him because of his condition, he did not report for work, and he would not let his sister into his house. When he did let her in he would not let her touch him, he would not let her children touch him as he was afraid of infecting them.

After the initial shock of finding out he was HIV positive Charles received psychotherapy. Therapy helped Charles cope with the reality of living with HIV. He re-established contact with his family and adopted a positive outlook on life, he bought a house and continued to work. However following the death of his father his health started to fail. In 1993 he sold his home, he resigned from his job in Dublin and returned to live with his mother.

Charles attended a local clinic for treatment, but no special arrangements were made in respect of his HIV condition. He was unable to queue all day for blood tests, he could not sit down for long periods, the place was too crowded, he could not handle it. He did not go back after the first visit.

In December 1993 Charles celebrated his 38th birthday. His family organized a party to mark the occasion. It was to be his last birthday. During his final illness Charles was cared for by him mother. His physical health was deteriorating and his behaviour was sometimes irrational.

Charles died on the 17th of January 1995. He was admitted to hospital on the 5th of January. On being told that he was unlikely to survive the night his family took him home. He did not want to die in hospital. He was cared for in his final days by his family and by Margaret King and Rosemary Daly of the I.H.S.

Ernie

Ernie was born in 1962 and has been a full-time farmer since the age of 16. He started work full-time earlier that he had expected to when his father had a serious accident on the farm.

Ernie has mild haemophilia A. He was treated with Factor VIII on relatively few occasions, once for teeth extraction, once for a surgical procedure on his back and again for a surgical procedure.

In the mid 1980s Ernie was tested for HIV. He was negative for HIV. In 1994 he was asked to test for Hepatitis. He attended hospital for the test and after that he heard no more for some time. During this period he was seriously worried. The media was carrying reports of people dying from Hepatitis C. He started to panic. He tried to contact Positive Action but was unable to do so. In October 1994 he received a letter from Dr Cotter telling him of an I.H.S. meeting in Cork. It was one of the greatest letter I have ever received, said Ernie.

In March 1995 Ernie received a letter to say he had tested positive for Hepatitis C. Other than being told that Hep C would affect his liver and that he should look after himself Ernie was given no other information on how Hep C would affect him.

When he discussed his condition with his then girlfriend she wanted to know if he had been tested for HIV and Aids. Despite Ernie’s assurance that he was free of HIV this relationship broke up, as did another subsequent relationship he was in.

Ernie in now in another relationship and has a positive attitude to the future. However his natural optimism is tempered with the reality that long term planning is overshadowed by his physical condition which curtails his ability for hard work on a farm and to raise capital for development.

He said that while he was not used to events like the Tribunal, he was happy to be able, by his testimony, to make a contribution to making the blood supply for the country safer. He was happy that he did not have HIV, he was working hard to deal with living with Hep C. He was also confident that the next time somebody put a needle into his arm that the product he received would be clean. He would be happy if his contribution to the Tribunal helped bring this situation about.

Garrett

Garrett was born in 1970. He had moderate haemophilia A. It was discovered that he had haemophilia when he was a child. He liked to play football and suffered bleeds into his ankle.

He is now HIV positive and is receiving quadruple therapy in St James’s. He takes 17 tablets a day for the treatment of HIV. Garrett discovered he was HIV positive in 1991 when he read a letter contained in a file in his parent’s bedroom from I.H.S. offering them support on their son’s diagnosis as HIV positive.

He did not tell his parents he knew about his HIV status; he expected to die. The following August his parents told him what he already knew.

Garrett described how his mother discovered his HIV status. The family were due to go on a trip to France. His mother went to Cork to fetch some Factor VIII to take on the trip. While she was there she met a doctor in a corridor of the hospital. The doctor told her that Garrett was HIV positive.

Garrett keeps his HIV condition confidential. There were little or no support services or counselling for people with HIV. Only three people outside his immediate family knew of his HIV. The romance thing just did not happed for me, said Garrett.

With regards to his education Garrett said that on discovering he was HIV positive his motivation evaporated. He did not see the point in making an effort for something that he might never enjoy. He discovered he was HIV positive in March of his Leaving Cert year. While he enjoyed some academic success it was not as much as it should have been.

Garrett received little or no support from the medical profession for his HIV. Any information he obtained came mostly from Sunday newspapers. By January 1997 Garrett’s CD4 count dropped to around 10. He was in serious danger of dying from Aids at this point. He went on triple therapy in the Spring of 1997 and has improved since.

Garrett was also diagnosed with Hepatitis C. This condition limits his effectiveness.

Garrett says he hopes for a long and healthy future. He knows that there are limits to what he can hope to achieve. His health could fail at any time; he won’t be able to have children, he won’t be able to hold down a permanent pensionable job, he won’t be able to fulfill his potential and in all the circumstances he feels that he has had something removed from his life which cannot be replaced.

Mary

Mary told the Tribunal the story of he husband, Norman. They met in 1987 and were married in 1990. She knew of his HIV status when they got married. Norman tested positive for HIV in 1986.

Norman was Factor IX deficient. He kept two bottles from the batch he thought had contaminated him with HIV in his fridge at home. The bottles were in a green and white box, labeled Heat Treated FIX, and were manufactured by the BTSB. He kept the bottles until after the recompense campaign in 1991.

In 1991 Norman was diagnosed as Hepatitis C positive. He was given general information about the effects of Hepatitis C, told to avoid alcohol, sleep well, eat well and to avoid stress. At this time Norman was attempting to set up a computer parts business and hold down his full time job.

In September 1992 Norman’s health started to fail. His CD4 count was dropping and there were signs that his white cell count was increasing. He suffered liver failure over Christmas of 1992. Norman’s mental faculties were affected by HIV in that he was behaving strangely and out of character. At Beaumont Norman received a CT scan which showed that his brain stem was shrinking. He had six months to a year to live. Norman died in August 1993. His death certificate read “Aids – 8 Years”. Mary succeeded in have this changed to the proximate cause of death. She did not want to have Aids on the death certificate.

Following her husband’s death Mary continued working for a while in Dublin. She then went abroad for a period. When she returned to Ireland in 1996 she was feeling unwell. She tested HIV positive at Beaumont Hospital in July 1996.

Mary feels lucky that triple therapy is now available. Unlike her husband she can get treatment for HIV that will sustain her. Mary said the product that killed her husband and had in turn infected her with HIV had BTSB written all over it. She wants to know who decided to issue the batch of Factor XI that killed Norman and infected her.

TRIBUNAL OF INQUIRY

(into the infection with HIV and Hepatitis C of
Persons with Haemophilia and related matters)

Proceedings May 10th, 2000

Peter

Peter gave evidence on behalf of his son Dermot who was born in 1957 and died in the early 1990s. Dermot had severe haemophilia A. He went through the range of treatments available for haemophilia and welcomed the advent of Factor VIII concentrate as a liberating product that would enable him to lead a normal life.

An optimistic person, Dermot worked locally and lived at home. Sometime in the mid-1980s he discovered he was HIV positive. He did not tell his parents immediately, Peter did not find out about Dermot’s HIV until the early 1990s.

In and around the same time Dermot discovered he also had Hepatitis C. When his health started to fail his cross-infected status ruled out a liver transplant for Dermot. He died in the early 1990s.

Dermot was told he was going to die. There were no members of his family present when he was told this news in St James's Hospital. When Peter and his family arrived to visit Dermot they discovered that he had been told a half-hour previously that he had at most three months to live. Dermot died three weeks later. Peter said he had a lot of difficulty with the fact the Dermot was alone when he was told that he would soon die. A member of his family should have been present – it was a cruel and insensitive thing to tell him such a thing without the support of his family being present.

Peter said his son did not commit suicide or die from natural causes – he was killed as surely as if someone had put a gun to his head and pulled the trigger.

Peter said blood products made from paid donations coming from the US should never have been imported into the State. He wants the Tribunal to find out the truth of what happened and who is responsible for the death of his son.

Larry

Larry told the Tribunal of the events surrounding this father-in-law's death. Larry's father-in-law, Neil, had haemophilia B. In September 1984 he had to attend St James's Hospital for an operation on his prostate gland and his spleen. He had the operation and seemed to recover from it. However he subsequently became very unwell. Despite his condition he was told he could go home.

He returned home and the following week he attended SJH for a check up, again he was told all was well and to return home. Upon returning home he was very unwell and was admitted to the local general hospital for treatment for a haemorrhage. The local hospital then sent him to SJH where he lapsed into unconsciousness and died three days later on November 8th, 1984.

Upon arriving at SJH Larry, who was organizing the funeral, was told by the undertaker that the hospital had issued instructions that no one was to touch the body of Neil. Two security guards were in place in the mortuary where the body was laid out to see that this instruction was observed. The body was in an open coffin, only the hands and face were visible, the hands were covered with a plastic material.

Larry was asked by a hospital employee if Neil and his wife had been sleeping together prior to his death. He said they had. The hospital employee informed Larry that they should not have been sleeping together.

When Neil's friends and neighbours arrived to accompany the remains back to his home-place for burial, Larry had to tell them not to touch the body.

Some days later a newspaper carried a report that a man had died from Aids in SJH.

Larry was asked if he was aware of any communication between Professor Temperley and Dr O'Riordan on blood supplied to Neil during his recent treatment. He said he had only become aware of this communication last week.

When Neil's death certificate was issued some months later, it stated: Hepatitis – 4 days. This was the first time Larry and his family were aware that Neil had had hepatitis. Larry and his family were not offered any explanation with regard to Neil's death.

The bizarre events surrounding Neil's death raised a number of questions. These questions have never been answered. Larry said he hoped the Tribunal would, after 16 years, be able to offer some answers to these questions to Neil's wife and daughter.

Felicity

Felicity told of how her three sons became infected with Hepatitis C from contaminated blood product. Felicity's children were born between 1985 and 1987. Her three boys have haemophilia B. She treats the children Factor XI at home.

In 1991 she attended Harcourt Street Hospital with the children for blood tests in light of the outbreak of Hepatitis C. She heard nothing from the Hospital.

In 1995 the youngest child who had been a lively, healthy and happy boy became depressed and was suffering from fatigue. She thought he was being bullied at school. She investigated this possibility but this was not the case. She called the NHTC and spoke to a nurse there. The nurse told her that it was probably the child's Hepatitis C that was causing the symptoms. This was the first Felicity knew that her sons were infected with Hepatitis C.

The childrens' medical records show that they were diagnosed Hep C positive in 1990. They were allowed to go untreated for five years. Felicity said they were using Factor IX batch number 9885 when they became infected with Hepatitis C. This product was supplied by the BTSB.

Felicity says she feels responsible for having administered the Factor IX which infected her sons. "I hope that my children did not end up with Hepatitis C because somebody was trying to save money."

Agatha

Agatha's husband Ronald tested HIV positive in January 1985. He was informed of this in August of that year. Agatha knew of Ronald's HIV status when they married in 1987. They were optimistic and put any thoughts of sickness to the backs of their minds.

Ronald was a very private person and did not tell many people of his HIV status, including his parents. About a month after Ronald and his brother had been diagnosed Agatha told their parents that they had HIV. After the initial shock Ronald was pleased that his parents were informed.

Despite the risks Agatha became pregnant. At seven months she did a HIV test. She was negative and therefore the baby would also be negative. The baby was born. The day after the baby was born the doctor who had delivered the child told Agatha the he had become aware that her husband had

haemophilia and was HIV positive. He had pricked his finger when he was inserting sutures after the birth; he took a blood sample from
Agatha. The results were back the following day confirming Agatha's assertion that she was HIV negative.

In and around the time their son was born Ronald's health started to fail. His T-Cell count was down leaving him susceptible to an Aids defining illness.

In 1991 Ronald was diagnosed a Hepatitis C positive. He said it didn't matter as the HIV would probably kill him before the Hep C. In view of his deterioration Ronald was commenced on Interfearon as part of a trial of the drug. This was stopped after six months.

Ronald's condition got worse. His brother died. On December 21st 1994, Ronald died.

Agatha said she wants the Tribunal to "find out the full extent of everything that occurred to be out in the open; about the treatment, about the fact that treatment was imported here and it was banned in America. For two year after it was banned in America, it was still being administered to the haemophiliacs here. Somebody had to have known, somebody isn't letting on or else their eyes were closed to what was going on, it didn't suit them to know.

Apology

Mel Cristle SC apologized to Felicity on behalf of the National Children's Hospital on the basis that she and her family were not informed of the childrens' Hep C status in 1991.

TRIBUNAL OF INQUIRY

(into the infection with HIV and Hepatitis C of
Persons with Haemophilia and related matters)

Proceedings: Thursday, May 11th, 2000

Newspaper article.

Counsel for Professor Temperley, Mr McGovern SC, made reference to the lead article in this morning's edition of the Irish Examiner newspaper. The article referred to a confidential draft memo which had been discovered by the BTSB. The newspaper article ran under the headline 'Blood staff told to cover up Aids risk'. Counsel said the article was a distortion of the content of the memo and was unfair to Professor Temperley.

The Chairperson indicated that the article bore the hallmarks of unfairness and that she would deal with it when she had had time to fully consider the article and the issues arising from its publication.

Julie

Julie is the daughter of Brenda who gave evidence earlier in the proceedings before the Tribunal. She gave evidence in relation to her brother, Charles. She gave her perspective on the story of her brother. She said she had come to the Tribunal to speak for her brother.

Julie gave a full description of how her brother had dealt with his haemophilia from his childhood in 1960s and into the 1970s. She described how he had established himself as an independent adult with his own home, career and life.

Julie described how her brother had gradually lost his independence and how he informed his parents by letter of his HIV status. She told the Tribunal of how Charles would act out of character and behave strangely, yet he was able to tell her that he knew he was in the final stages of Aids.

She described how their uncle, who also had haemophilia and was HIV positive died. She told of the devastating effect on her father of the news that his son was HIV positive. And she told how her mother had looked after Charles in his final illness.

After their father died Charles told her he also had Hepatitis C. Charles had to sell his home in Dublin and move back to his mother's place. He was 38 years old when he died in January 1995. In his last days he was nursed by his mother and sisters and by Rosemary Daly and Margaret King of the I.H.S.

Martin

Martin gave evidence in relation to his son Steven who was born in 1982. There is no history of haemophilia in Martin's family or in his wife's family. Martin first noticed small bruises on his son's ankles, he though it may be leukaemia and was relieved to discover he son had haemophilia.

In infancy, Steven's condition caused him relatively little trouble. Initially he was treated with Hemofil and was subsequently treated with cryo and then Factor VIII. Martin said that a taxi service was available to take him to hospital. But when they got to hospital they frequently has to wait for long periods before they were attended to. The wait in hospital meant that the bleed for which Steven needed treatment became worse and the benefit of getting to hospital quickly was lost.

Counsel for the Tribunal objected to this evidence being led. It was not in the statement of the witness, he said. It was agreed that if the witness wished to make any complaint on this basis that a supplemental statement could be furnished.

In Christmas week of the 1984 Steven was summoned to SJH for a HIV test. Martin contacted the hospital in early January for the results of the test but got no response.

In the autumn of 1986 during the course of a half-yearly check-up Professor Temperley asked if they had got on well at the counselling. "What counselling," they wanted to know. Professor Temperley was apparently referring to counselling which had taken place following Martin's diagnosis with HIV. Martin and his wife had had no communication about the HIV test from the time it was taken in December 1984. They were completely shocked to learn that their son had HIV.

Martin was told that there was nothing to worry about even though Steven was HIV positive. He says no counselling or information of any kind was offered.

Martin continued to treat Steven at home for haemophilia. In 1992 Steven's health started to fail. Martin noticed small red stickers on the child's medical charts. He was told the stickers were to warn doctors that Steven had haemophilia, but Martin believed that they referred to Steven's HIV status.

Steven's condition got worse. He was in hospital for 16 weeks, mostly in the ICU. He was unable to eat and had to be fed through a tube. He lost weigh, became skeletal and had to use a wheelchair to get around. He had to have a morphine pump fitted to control pain and this was how he spent the last two months of his life.

Steven died in 1993. He was eleven years old.

Counsel for Professor Temperley put it to Martin that Steven's medical charts showed they received counselling from a Ms Loretta Kiernan. Martin said he received no counselling, good, bad or indifferent. Likewise Martin rejected a suggestion that he had received counselling from the NCH in 1986. "We never got counselling of any description," he said.

Daniel

Daniel, born in 1949, gave his evidence. He described the early treatment regime for haemphoilia B. Fresh blood transfusions were the order of the day. Later he was lucky to get a supply of Factor IX from the US. This was an early version of blood concentrate.

By the time he reached adulthood the treatment regime had become less onerous. After 16 years in the family business Daniel set out to make his own fortune. He moved abroad and set up a restaurant business. The work was hard and the business thrived. He arranged to have a supply of Irish-sourced Factor IX supplied to him while he was abroad.

In 1987 Daniel suffered what he though was appendicitis. He returned to Dublin for treatment and was well received at SJH. While at SJH he had a liver biopsy. He was told he had liver damage and had NANB hepatitis. He was told he had cirrhosis and he should not drink again. He was not given any other information.

He returned to his business abroad and tried to sell it. Being unsuccessful in this he returned to London in 1990 where he was told he had Hepatitis C. At this stage he was manifesting signs of Hepatitis C. He was tired and depressed. His memory was affected. He took part in an Interferon test and reacted badly to the drug. He got a job which he enjoyed but found difficult to keep going as his condition often left him unable to leave home.

Daniel has since returned to live in Dublin. He has tried to start a business here but finds it difficult to organise all the elements of a business. Previously he would have been able to get a business going, now it seems to beyond him.

He wants the Tribunal to find out why "we were given infected product by professional medics, not just one batch that was administered to a few, no, there was a lot of infected product administered over a very considerable time which has dismayed the lives of 240 people," he said. Daniel thinks there has been a cover up, starting at the top and percolating right through the system. "This is unforgivable," he added.

Eoin

Eoin told the Tribunal that himself and his two brothers had haemophilia, two had mild and one had severe haemophilia. All three brothers had Hepatitis C and one also had HIV. He was contacted by a local hospital, he was tested and was subsequently told he had Hep C.

Being diagnosed with Hep C has had a major effect on Eoin's life. He can no longer enjoy going for a drink the way he used to, he can't play golf, his joints are swollen and he can't get dressed in the mornings. His personal relationship with his wife has been seriously affected. He cannot bring himself to use condoms and has had no sex life for the last four years.

Eoin's brother died from HIV at the age of 37 years. Eoin cannot understand why his brother should die in the prime of his life. Eoin told the Tribunal his brother had mild haemophilia, he was treated with Factor 8 in 1982 and again in 1985. He was tested for HIV in 1985 and the test was negative. Eoin's brother then when to England until 1992. When he returned he was again tested for HIV and was positive.

To Eoin's knowledge no member of his family received notification to attend the local hospital for a HIV test. Eoin himself did not receive any advice in relation to blood products.

Eoin is reluctant to tell his children he has Hepatitis C. He tells people that his brother died of a heart attack. He does not want to tell his 13-year-old son that his uncle died of Aids.

Eoin said the care he now receives is excellent. He has a medical card that was made available under the Blue Card scheme. However, he feels let down by the health care system. They knew what that they were giving me, they knew what they were giving my brother, they gave him bad Factor VIII knowing he was going to die from it, but they went ahead and gave it to him, said Eoin.

Eoin was cross-examined by Mr O'Brolchain for the Southern Health Board.

The thrust of the cross-examination was establish that the hospital had attempted to contact Eoin's brother who had died from HIV. And also that it was unfair to say that hospital had knowing given infected blood products to him.

Gary

Gary told the Tribunal the story of his brothers, Fintan and Cathal. He described how in the autumn of 1984 Fintan was suffering from breathlessness. It was initially put down to stress but was eventually diagnosed as pneumonia. It was also the onset of Aids. At this time, Gary, the youngest of the brothers was around 10 years old. His brother Fintan, who had just been diagnosed with HIV, was around 17 years old at the time.

Fintan was an energetic an intelligent person. He had ambitions of going to college and making a life for himself. He liked to play football. Following his diagnosis he understood that he would not have a life, and that he was going to die. In the later stages of his illness he was angry that the treatment he had taken to improve the quality of his life was in fact going to bring about his death.

Fintan died in 1986. He was the first person in Ireland with haemophilia to die from Aids. The medical staff wanted to put Fintan's body in a plastic bag inside a closed coffin. Gary's father would not permit this indignity to be visited on his son. He paid the men who dealt with the body.

Prior to his brother's death the Evening Herald carried a front-page report of the imminent death of a man from Aids in SJH.

Following the death of Fintan, Gary's younger brother Cathal, who also had haemophila was worried that he too would die from Aids. He was taunted at school and later when he was going out with a local girl someone told the girl's mother that Cathal's brother had died from Aids. She called to find out if Cathal had any diseases.

Cathal was 6 years old when his brother died. He though he could get the disease which killed his brother. He became compulsive, repeatedly washing his hands and taking fastidious measures with regards his personal needs.

Gary's mother reacted to her son's death by giving up on life. She had been a reformed alcoholic. When her son died she resumed drinking. She told her family she would not live to see 50 – she died when she was 49.

When Cathal was 13 years old he was diagnosed Hepatitis C positive. He became depressed. He blamed himself for his mother's death. He attempted to commit suicide. In 1996 he was found dead in the kitchen of the family home. He had died from a drug overdose.

Gary says he himself has contemplated suicide. Now, with the support of his partner and his sister he no longer has these thoughts. He wants to see the injustice which directly took the life of Fintan and indirectly took the life of Cathal, addressed.

TRIBUNAL OF INQUIRY

(into the infection with HIV and Hepatitis C of
Persons with Haemophilia and related matters)

Proceedings Friday May 12th 2000

Representation

The Chairperson granted limited representation to the South Eastern Health Board.

Newspaper Article:

The Chairperson said the article in the Irish Examiner was unfair and sensational. She warned participants in the Tribunal that discovered documents were confidential and that it would be a breach of duty to use such documents for any purpose other than that of the Tribunal.

Damien

Damien who has haemophila A, told the Tribunal of his infection with HIV and Hepatitis C. His brother, who also had haemophilia A, was also cross-infected. Damien related the difficulties he had encountered with regard to his family and work and how he was left to deal with the possibility of an early death throught HIV.

While he is now long-term, non-progressive for HIV and it appears that the HIV virus has not damaged his immune system, he is Hep C positive and was critical of the level of information he obtained regarding the effects of HIV and Hep C. He was also critical of investigative procedures such as liver biopsy for the treatment of Hep C.

He was told Hep C could damage his liver but was not told the extent of liver damage Hep C could bring about nor was he informed about the effects of cross infection with HIV. Damien was diagnosed HIV positive in 1985 after he made an appointment to have a blood test done. He discovered he was Hep C positive under similar circumstances.

Damien’s brother had HIV and Hep C. He died in December 1998.

Damien benefited from the recompense campaign in 1991. He was cross examined by counsel for the Tribunal as to what he did with the compensation he received. He told counsel that the invested the money and used it to pay off his mortgage. “It’s not like winning the Lotto where you can spend it and have a good time, because if your condition deteriorates, your family is going to need an income or security to maintain themselves.”

Arthur

Arthur told the Tribunal of his son John who was diagnosed HIV positive at the age of six years. John is a member of a large family. He was treated with Factor 8 from his birth in 1979.

Arthur and his wife were told John was HIV positive when they attended a regular check-up at NCH. Professor Temperley told them, "out of the blue" that John was HIV positive. They did not know John had been tested for HIV and knew very little about the virus. They thought that John would die from the condition. They were told by a social worker that the effects of the virus would not be felt for 10 years. They though this meant that in 10 years time he would be dead.

In the meantime they took the child home and looked after him. They thought that his blood, urine, perspiration and saliva were infective. They did not learn until much later that only blood spillages should be treated with bleach and other external bodily fluids were not infective.

Arthur instructed John's teachers not to put him under any pressure to achieve academic results. John left school without any academic qualifications. In 1995 when John was 16 years old Arthur asked a nurse at the NHTC if John was Hepatitis C positive. He was told this was the case.

John is now 21 years old. He lives at home with his parents, he has no trade or profession and Arthur worries about what John will do when his parents are not around to take care of him.

Arthur was cross-examined by counsel for the NCH as to what he understood by the effects of HIV being 10 years away. Arthur said he understood this to mean that in 10 years time his son would be dead.

Nuala

Nuala gave evidence on behalf of her sister who suffered from the blood clotting disorder
A Fibrinogen Anemia. When her sister was young it was thought that she may have some form of haemophilia – but this was impossible because she was female. The condition was however very serious and it was Professor Temperley who diagnosed and treated her sister's condition.

Nuala told the Tribunal that her sister's condition required a large amounts of blood product, blood and platelets. She was diagnosed NANB - later to be identified as Hepatitis C. Her sister's condition was painful and difficult to manage. She lived in fear of the pain brought on by the condition and had a lot of faith in SJH.

Hepatitis C damaged her sister's liver, this made pain control even more difficult. The fact that her liver was not functioning normally meant that ever greater doses of drugs were necessary to be effective. Nuala said her sister had great faith in the care given to her by Professor Temperley and SJH, she did not have faith in the treatment afforded to her in her local hospital – Galway Regional Hospital.

Nuala’s sister died from a brain haemorrhage. She was unconscious for just under six weeks. When she died the hospital proposed putting her in a body bag. This would have meant that the coffin would be sealed and this would have an awful impact on a rural community.

Nuala said the quality of her sister’s life was undermined by her Hepatitis C condition. The treatment of this condition exaggerated the deterioration in her quality of life. Nuala said she thinks the whole health system failed her sister and that is why we are here today.