

IRISH HAEMOPHILIA SOCIETY

TRIBUNAL NEWSLETTER

ISSUE 19

CONTENTS:

| | |
|----------------|--|
| Page 2 | Day 75 - Tuesday 28th November |
| Page 5 | Day 76 - Wednesday 29th November |
| Page 9 | Day 77 - Thursday 30th November |
| Page 13 | Day 78 - Friday 1st December |

6th December, 2000

TRIBUNAL OF INQUIRY

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

PROCEEDINGS: TUESDAY 28th NOVEMBER, 2000 – DAY 75

Dr Terry Walsh formerly of the B.T.S.B. was called to the witness box. While Dr Walsh is a former employee of the B.T.S.B., he is separately represented at the Tribunal. The B.T.S.B. legal team indicated that it had no further questions for Dr Walsh regarding the meeting of September 1990, which had been gone into in detail by the Tribunal.

With respect to Dr Walsh and Dr Barry's transactions in 1987 concerning the compilation of HIV positive donors, Mr McGrath for the B.T.S.B. indicated that the B.T.S.B. was not in a position to cross-examine Dr Walsh at this stage. The B.T.S.B. proposed to meet with Dr Barry and take instruction from him concerning transactions between the two in 1987. The B.T.S.B. may or may not have questions to ask Dr Walsh as a result of this information. In these circumstances, the cross-examination of Dr Walsh was deferred until the following week.

Limited representation was granted on behalf of Dr James Kirrane. Mr Butler, instructed by Arthur Cox Solicitors, applied. Dr James Walsh of the Department of Health was then called. Dr Walsh was the chief medical officer of health at the Department of Health up to his retirement in November 1988. Dr Walsh continued in office from 1988 until 1992 on a contract basis, advising the Department and the Minister on HIV and AIDS generally.

Mr Durcan questioned Dr Walsh as to his role in the introduction of testing of blood samples from donors by the B.T.S.B., commencing in 1985. Dr Walsh informed the Tribunal he attended the World Health Organisation in Atlanta in 1985. At this conference doubts were expressed as to the efficacy of anti-HTLV-III testing and the issue of false positives was identified as causing problems. Dr Walsh said the doubts expressed caused him to contact U.S. sources to discuss the efficacy of the test. Dr Walsh said by the end of May 1985 he was satisfied that anti-HTLV-III testing had reached a point of development where it was a valid test for the screening of blood. Dr Walsh said at this time he believed that testing should have been introduced in Ireland.

Mr Durcan referred Dr Walsh to a meeting in June of 1985 which discussed the implications of the introduction of testing. A report of this meeting notes that the organisation of alternative sites for testing at STD clinics would be addressed. Dr Walsh said that the absence of alternative sites did not prevent testing being introduced by the B.T.S.B. Dr Walsh said that, when he met the B.T.S.B. in and around June of 1985, adequate alternative sites were available. He said he did his best to reassure the B.T.S.B. on that point. Asked by Mr Durcan, did he enquire as to what was holding up the introduction of testing, Dr Walsh said he didn't go into that as the B.T.S.B. said it was testing six or seven packs. Further, he was pleased that the B.T.S.B. was going to test and hoped that evaluation of testing would come to a conclusion quickly, and that HIV testing would be introduced. When, by September of 1985, the B.T.S.B. had not introduced testing, Dr Walsh said he became concerned at the lack of action. He said he brought this matter to the attention of the Department of Health and testing was introduced in mid-October.

Dr Walsh said from mid-September onwards an air of urgency came into the BTSB's attitude to testing. Dr Walsh said it was his opinion that the lack of alternative sites did not prevent the BTSB from introducing testing in the early part of 1985.

Dr Walsh said the proof of the availability and success of the STD clinics was recorded in the fact that 500 positives were recorded at STD clinics in the first year of operation. Testing commenced at STD clinics in January/ February of 1985, said Dr Walsh. Dr Walsh added that STD clinics were using the test as a diagnostic tool, and not for screening. Tests were therefore in use at STD clinics before they were introduced by the BTSB. Dr Walsh said the issue of false positives was not the same problem for the STD clinics.

Dr Walsh said he met BTSB consultants in January of 1986 to discuss the issue of untested platelets to Wexford General Hospital. Mr Durcan asked Dr Walsh did the BTSB tell him in that month that three donors had tested anti-HTLV III positive by January 1986? Dr Walsh said he had not been told this. Dr Walsh said the meeting was about the positive platelet issue.

Dr Walsh was then examined by Mr Raymond Bradley for the Irish Haemophilia Society. With respect to the issue of using hepatitis B as a surrogate marker for HTLV-III, Mr Bradley asked Dr Walsh if an increased incidence in hepatitis B was recorded, would it be notified to the Department as a notifiable disease? Dr Walsh agreed that this was the case. He also agreed that no such notification has been received in and around 1985.

Mr Bradley referred Dr Walsh to a letter from Dr Terry Walsh of the BTSB concerning discrepancies between the numbers of donors notified by the Department of Health who had tested positive, and the number of donors recorded by the BTSB as testing positive.

Dr Walsh was cross-examined by the BTSB. Mr McGrath referred Dr Walsh to a radio programme on which he appeared in August 1985. On the programme, Dr Walsh pointed out that the plan to introduce screening was in keeping with the plans for most western European countries. The delay was explained by the need to subject the test kits to evaluation. Mr McGrath put it to Dr Walsh that this was the Department of Health's state of knowledge in and around August 1985. Dr Walsh said that this was the view put forward on a radio programme. Dr Walsh said he did not want to create a sense of panic. In September 1985 it was noted that a sense of urgency had been adopted by Dr O'Riordan in his communications with the Department of Health concerning the issue of testing.

The Tribunal then called Dr James Kirrane. Dr Kirrane said he assisted the BTSB in setting up a protein fractionation programme by Sephadex chromatography for the recovery anti-D immunoglobulin. This unit was established in the late 1960's early 1970's. Dr Kirrane said that he spent two hours per week in the preparatory phase of this project, and one hour a week when the project was up and running in Pelican House, advising on the recovery of anti-D.

Dr Kirrane said that he dealt with Ms Cunningham, the head of the fractionation unit, in his dealings with Pelican House. In this capacity Dr Kirrane said he attended the Scientific meetings of the BTSB. Dr Kirrane said he had no involvement in the production of factor IX. Dr Kirrane said this was produced by cellulose chromatography, and while he had some knowledge of this process, he had no practical experience, whereas he did have practical experience of Sephadex chromatography. In this regard Dr Kirrane said he did not give any advice to Ms Cunningham or anybody else in the BTSB concerning the production methods of factor IX.

Dr Kirrane said the frequency of scientific meetings declined over time, to the point where between 1983 and 1985 he didn't believe such meetings were being held. Dr Kirrane said he had no discussion with Ms Cunningham in regard to factor IX. His only concern was with anti-D. He had no discussion with respect to clotting factors and anti-HTLV-III virus. Dr Kirrane said he had no recollection of hepatitis being discussed at scientific meetings in regard to clotting factors. Any such discussion concerning hepatitis was with respect to anti-D as far as he was concerned.

Dr Kirrane agreed with Mr Durcan that his evidence could be characterised as saying he had no recollection of any discussions about HIV, or hepatitis in regard to clotting factors, and he wouldn't have had a huge interest in that particular area in any event.

Dr Kirrane said he had no participation in the production of cryoprecipitate in the BTSB or in any issue concerning donor selection or choice of products. Dr Kirrane said he knew nothing about the production of factor IX at the BTSB other than that it was run by a Dr Chung. Neither had he any knowledge concerning the issue of the Heparin project.

Dr Kirrane was then held over for cross-examination until Thursday of the following week.

PROCEEDINGS: WEDNESDAY 29th NOVEMBER, 2000 – DAY 76

The Tribunal commenced the section of its inquiry dealing with the evidence of those persons with haemophilia, parents of a child with haemophilia and the next of kin of a person with haemophilia.

The personal testimonies commenced with the evidence of Siobhan.

SIOBHAN

Siobhan met her husband, Donal in 1983 and they married in 1985. Donal was a Civil Servant and he had severe haemophilia A. In February of 1986, when Siobhan was pregnant with her first child, Donal was diagnosed HIV positive. He was initially told that the test was negative, but was then informed that it was in fact a positive test.

Siobhan said her ensuing pregnancy was most distressful, in that she had to undergo tests. Siobhan said her husband Donal did not want her to inform the maternity hospital of his HIV status. Siobhan said she received no information concerning the risk of transmission of HIV. After the positive HIV diagnosis on her husband Siobhan said she did not inform the hospital of her husband's HIV status, because he was afraid they would handle the baby with gloves and that she would be ostracised. Siobhan said she told nobody of the news of her husband's HIV positive status.

The burden attached to secrecy continued to the present day in that Siobhan has not informed her daughter of the circumstances surrounding her father's death.

Siobhan said the isolation she had first experienced with HIV continued. On the morning of her daughter's first Communion, the child cried for her father and said she wished her daddy could see her. Siobhan explained that her daughter was a carrier of the haemophilia gene, and significant issues arose in outlining to her the circumstances of her father's death and this was something she had yet to do.

In addition to contracting HIV, Siobhan's husband Donal also contracted hepatitis C. In and around July 1992 Donal's health started to deteriorate. He became ill and lost weight. He suffered from depression and had to give up his job.

During this time Siobhan said she got support from Sister O'Shea in St. James' Hospital. However her husband, while his health was in decline, did not know he was dying.

During all this time Donal and Siobhan attempted to keep his condition confidential. This proved to be difficult. Donal was taken home and cared for by Siobhan until he died.

With regard to the future, Siobhan said a lot of questions remained to be answered. She wanted to be able to tell her daughter what had happened and have her understand the circumstances of her father's death. She said she wanted justice.

BRENDAN

The Tribunal then heard the evidence of Brendan.

Brendan has severe haemophilia A and has been treated for this condition since infancy. His elder brother, Eamon, also had haemophilia, as did a younger brother, Fergal. Eamon died in 1991 as a result of AIDS contracted from his treatment for haemophilia. Brendan's younger brother, Fergal died as a result of a childhood accident at 18 months.

Brendan was treated at Harcourt Street, Baggott Street and the Meath Hospitals for his haemophilia. Up until 1982, Brendan was treated with cryoprecipitate. Thereafter he was treated with factor concentrate which was supplied to him by St. James' Hospital.

Following the completion of his secondary education, Brendan took up training in welding. However, after getting septicaemia in his right knee, which resulted in Brendan being unable to bend his right leg, he gave up this particular occupation.

In 1985 Brendan was informed he was HIV positive. Brendan said he had been treated in hospital for a forearm bleed and, when being discharged, he was asked by Dr Helena Daly to attend the treatment room. Brendan said Dr Daly told him he had been tested for HIV and had tested positive. Brendan said he didn't know he had been tested up to this point.

Brendan said Dr Daly told him HIV wasn't dangerous and it wasn't going to kill him. She said there was nothing really to worry about and asked him had he any questions about it. Brendan said that up until this time his haemophilia treatment had been supervised by Prof. Temperley, but he was informed of his HIV status by Dr Daly. Brendan said Prof. Temperley wasn't there at the time.

Counsel asked Brendan, with respect to his dealings with Prof. Temperley, what sort of relationship did he have with the professor. At this point, Counsel for Prof. Temperley interrupted, and said Prof. Temperley was not on notice of the witness's relationship with Prof. Temperley. Counsel said he had no notice of anything which may be prejudicial and therefore could not deal with it. The Chairperson said that the purpose of having the statement was to put everybody else on notice of what the witness was going to say. The Tribunal said this was not just for persons with haemophilia, but for everybody who was giving their evidence before the Tribunal.

Counsel for the I.H.S. asked the Tribunal, would it be the case that forthcoming witnesses would be fixed to their statements? The Tribunal pointed out that it hasn't been the practice of the Tribunal to do so. The Chairperson said that if there were any allegations that prior notice should have been given, so that Counsel for the person will be in a position to deal with it, the Tribunal Chairperson said it was unfair to allow allegations to be made of which parties had not been put on notice. The Chairperson said she would be obliged if Counsel could keep to the statement.

Brendan said that before he had been tested for HIV no-one had asked his permission to conduct a test. Upon receiving the news that he was HIV positive, Brendan said and following his diagnosis with HIV he stopped taking treatment for his haemophilia. In or around 1987, said Brendan, he was informed that the treatment was safe to take.

Brendan said that during this period he had taken no precautions concerning his HIV status, as he knew nothing about the disease other than what he read in the papers. Brendan said he only

began to realise that HIV was dangerous when he saw other people with haemophilia in hospital becoming sick, and it was realised that this was related to HIV. He also said that some of these people were dying because they were infected with the sickness.

Brendan's brother Eamon died in June 1991. He was five years older than Brendan. In 1995 Brendan contracted AIDS-related pneumonia. His family was informed that he had a short period to live. On being discharged from the hospital, triple therapy became available and Brendan was one of the first to embark upon anti-retroviral therapy. This involved taking a combination of drugs which resulted in what he described as devastating side-effects; nausea, loss of weight, lack of sleep, night sweats. Brendan said this also involved being house-bound and being unable to take part in ordinary social activities. In the long-term Brendan said he is managing on reduced therapy but fears resistance developing to the treatment, as there is no other treatment available.

With respect to hepatitis C, which Brendan has also contracted, he said he is unable to be treated for hepatitis C. In the recent past Brendan has started a family. He said for the future he hopes to be able to participate in the rearing of his son.

Brendan also said that during his treatment as an out-patient in St. James', he had read a folder which was marked for the doctor's attention, that the issue of AIDS should be played down if any haemophiliac asked questions regarding the dangers of HIV. Brendan said he wanted to know who was responsible for his infection with HIV. He said his brother and uncle had died from HIV and he is living a life wondering if he will see his son grow up. He said somebody must be held accountable, and he was depending on the Tribunal to do so.

Brendan was then cross-examined by Counsel for Prof. Temperley and Dr Daly. Mr McGovern said that Dr Daly would give evidence that, when she informed Brendan of his HIV status in August of 1985, that he was counselled by her and that the counselling took approximately 30 minutes. Brendan maintained that if he was counselled, it happened in the space of five minutes. Mr McGovern said that a note of a record of Brendan's visit to the hospital, going back to 23rd August 1985, would state that the patient was advised that he was anti-HTLV-III positive and was counselled accordingly. Brendan said he did not receive such counselling. Mr McGovern put it to Brendan that he was also counselled about the dangers arising from sexual activity as a result of his HIV condition. Brendan said this was not his recollection. Mr McGovern put it to Brendan that, was he aware at any time that free condoms would have been available through the hospital for people who had tested HIV Positive? Brendan said this was at a much later stage and that would have been through other haemophiliacs.

CECIL

The Tribunal then heard the evidence of Cecil.

Cecil has mild haemophilia A. He discovered in 1970, at the age of 10, that he had this condition following teeth extractions. Cecil said that haemophilia was not a significant part of his life, and he went on to enjoy an outdoor type occupation and enjoy contact sports, including inter-county hurling. He was treated with factor VIII only six or seven times in his life. On one occasion, receiving cryo from Limerick Regional Hospital, but mostly he was treated with factor VIII concentrate.

In 1992, following a minor surgical procedure which was conducted under the cover of factor VIII Cecil, on the advice of his brother, had a blood test which proved positive for hepatitis C. Cecil said that hepatitis C had had the effect of isolating him from his previous life. His

treatment for hepatitis C had serious physical side effects. Cecil said that hepatitis C had affected his advancement in his career, in that his superiors seemed to lose confidence in his ability to discharge his duties.

As a result of two bouts of treatment for hepatitis C, Cecil is now virus negative. Cecil said it was great to hear that he was virus negative, but he continues to live with uncertainty in this regard.

PROCEEDINGS: Thursday 30th November 2000 – Day 77

SHARON

The Tribunal heard the evidence of Sharon.

Sharon suffers from von Willebrands disease and other factor deficiencies. Sharon said that the diagnosis of her condition was made in the late 1960's. She had a range of treatments for her condition and was first treated with cryoprecipitate in her teens. She was also treated with whole blood, platelets, factor VIII and Haemate P. Sharon said she went right through the range of different treatments as they came on stream.

In the late 1980's and early 1990's Sharon began to feel ill on a continuing basis. She and her husband started their own business which was ultimately unsuccessful. Due to her condition, then undiagnosed, Sharon was unable to participate fully in the running of the business.

In 1995 Sharon returned to work full time. Sharon said it was apparent to her employer that she was unwell. Throughout 1995 Sharon continued to suffer from chronic fatigue. Sharon said that in 1995 there was a lot of publicity surrounding the BtSB's lookback campaign with respect to anti-D and Hepatitis C Sharon said that she assumed she would have been contacted, as a person who had received blood products. Sharon said she had been receiving similar type products for 25-30 years and considered that the BtSB would have contacted her in any lookback it was conducting. However, this was not the case.

Sharon attended her own GP for a blood test. The GP thought it was unlikely that that hepatitis C was the source of her problems. Sometime later Sharon's GP contacted her on a Sunday lunchtime and told her that her test was positive for Hepatitis C.

Sharon thereafter attended the BtSB in Cork, where she was asked a number of questions. Sharon was asked a number of lifestyle questions concerning her sexual history and her husband's history. Sharon said she kept thinking they thought she was promiscuous. She also thought that she was the only one with this condition. Sharon said while she realised this was routine questioning, it nevertheless made her feel dirty.

Central to the advice that she received was the need to take precautions concerning risk of infection. Sharon said this advice concerned her greatly because she had had this condition for years, and she was now being told that she should isolate her tooth brush to prevent any risk of infection passing to her children. Sharon said that she had breast fed her children and that blood was a feature of her life. This was a source of great anxiety for her.

Sharon commenced treatment for hepatitis C in May 1996 at St. James' Hospital. She was diagnosed with moderate to severe liver disease and embarked on a course of Interferon treatment. However, given the multiplicity of infections to which Sharon was exposed, the chances of the treatment working were less promising. Sharon continued to take the treatment for hepatitis C for a year and seven months but it has been unsuccessful in rendering her virus negative.

Sharon said she received communication from the Finlay Tribunal, and from the then Minister for Health, concerning her hepatitis C status. This letter was inadvertently opened by her daughter.

She said she didn't now how the Tribunal got her name. The letter contained a report of the Finlay Tribunal.

Sharon said it was important for her to know that she had hepatitis C. The diagnosis of hepatitis C provided an explanation for the fatigue that she had experienced. Sharon said that she felt so guilty, and she felt a disaster. She was so tired she wasn't able to do the things other mothers could do and other wives could do. She said it was a big relief to her to know what was wrong with her, but it didn't make dealing with the situation any easier. She continued to be terrified that she could contaminate her husband or children.

LINDA DOWLING

The Tribunal then heard the evidence of Ms Linda Dowling.

Ms Dowling gave her evidence in public. She described the death of her father, Joe, from AIDS as a result of his treatment for haemophilia A. Ms Dowling described how her father's illness took its toll on her family life.

In the early 1990's Joe Dowling was also diagnosed with hepatitis C. Joe, took part in the Irish Haemophilia Society Recompense Campaign. He worked for the Irish Haemophilia Society one day a week. Mr Dowling also contested the local government elections in 1991 and went public about his condition.

Ms Dowling said the political campaign was aimed at highlighting the plight of people infected with HIV and hepatitis C. Four days after Joe Dowling and three other members of the Irish Haemophilia Society declared as candidates in the local elections the Government announced the HIV recompense package.

Ms Dowling said she felt her father reckoned that the whole issue of the haemophilia community's infection was being put on the back burner by the Government, and this was the reason why he became involved in the political campaign. Ms Dowling assisted her father in campaigning door to door in the local election.

Ms Dowling said her father was ecstatic when the national government of the day fell on the issue of haemophilia. Ms Dowling said her father was bitter that he had been infected for 10 years before he died and had to spend two years on the recompense and political campaigns. He felt he should have had the opportunity to do something else in these years.

Joe Dowling died in 1995. Ms Dowling said there were a couple of points that she would like to make to the Tribunal. She said her father had spent two years of his life on the compensation campaign, and it was difficult for him to take on this work. She said it had transpired here at the Tribunal that the Department of Health was aware of infections related to factor IX deficiency. She said she thought the State authorities could have attended more readily to the issues raised in the recompense campaign.

Ms Dowling said she would like the U.S. pharmaceutical companies to be investigated, as one of them had infected her father. Mr Finlay for the Tribunal said he thought the Tribunal had shown considerable indulgence to the witness for what was, in effect, a speech. And, while he could understand her feelings and her wish to express her feelings, he thought she may be transgressing any reasonable limit. At this point Mr Bradley for the I.H.S. said he thought the witness was probably wishing to inform the Tribunal of her personal feelings in relation to many issues. The

Chairperson said she had listened carefully to the case made by Ms Dowling. She said that her points were made adequately and she had done it in a very open and fair manner, and she thought that this was sufficient.

UNA

The Tribunal then heard the evidence of Una.

Mr Martin Giblin S.C. for the Irish Haemophilia Society, took Una through her evidence. Una told the Tribunal of her two brothers, the elder of whom was born in 1931 and had been treated for haemophilia throughout his life, and for whom the advent of cryoprecipitate provided a source of great hope when he was around 40 years of age. Her other brother was also treated with cryo. When home treatment became available both brothers were trained to use home treatment kits for the self administration of factor VIII.

Sometime in the late 1980's the younger brother told Una's sister that both brothers were HIV positive. This was the only real discussion anyone had with the brothers concerning their condition. Una explained that in those early days any illness was seen as a source of shame for a rural family. Her brothers had felt a sense of disgrace at having haemophilia. The arrival of HIV meant they felt doubly shamed.

Una said her younger brother died at the age of 40 in January 1990, from pneumonia. He was admitted to a local rural hospital where he died.

Una's older brother survived for a further three and a half years. His face and hands were bruised and he was treated with platelets. Una said her younger brother had discussed his HIV positive status with his sister. He had been frightened.

Una said she wanted to thank the people who fought to get the Tribunal set up, and the fact that the Tribunal was here meant that her brothers didn't die quietly, as they did everything else connected with their condition. She said she thought it was marvellous for them and she thought that it would do a lot of good, not only for people with haemophilia, but also for the whole medical world generally.

FRANCES

The Tribunal then heard the evidence of Frances.

Frances is the sister of Cathal and Fintan, she told the Tribunal that both brothers suffered from severe haemophilia A. When she was a young teenager her brother Fintan became ill, said Frances. Fintan was admitted to hospital with pneumonia, which turned out to be the first stage of AIDS. At this stage no-one knew that Fintan was HIV positive. The first indication that Fintan was HIV positive was the manifestation of full blown AIDS through pneumonia.

Frances said there was also a lot of media coverage concerning Fintan's case at the time, particularly the day he came home from hospital. When the family visited Fintan in hospital they had to wear gloves, mask and apron because at that stage she said even the hospital didn't seem to be very well informed about how infectious AIDS was. Frances said she found this a very uncomfortable thing to have to do as her brother was frightened enough without having his family come to visit him dressed in masks, aprons and gloves. As time went on the precautions concerning her brother were relaxed by the hospital.

Frances told the Tribunal that her father was informed in the corridor of the hospital that his son had AIDS. She said he wasn't granted any privacy, nor was there any counselling made available to the family concerning Fintan's condition at this time.

Frances said Fintan recovered from this initial bout of pneumonia and returned home. However, no-one discussed his condition openly with him, and there was also concern that local people would learn of his condition. Frances said the family was concerned that they would be ostracised if it came to be known that Fintan was suffering from an AIDS-related illness. As Fintan's condition deteriorated Frances said the situation at home became worse. Frances said at this time she came to realise that AIDS was a fatal condition. And, while it was realised that Fintan was faced with a potentially fatal disease, it remained unspoken within the family. Frances said she now thinks it would have been better if the issue had been discussed openly, but there was no outside advice forthcoming.

After a brief family holiday, Fintan was re-admitted to hospital two years after his initial infection. He died shortly afterwards. Frances said that, upon his death, her young brother Cathal sat at the end of Fintan's bed, and wept.

Cathal also suffered from haemophilia and, following Fintan's death, began to act in a strange manner, in that he was obsessed with personal hygiene. He wouldn't take food from his mother. In addition, Cathal's haemophilia went untreated as his parents were concerned that he could become infected from further treatment.

At 13 years of age Cathal was diagnosed with hepatitis C. He died of a drug overdose at 18 years of age.

Frances read a note to the Tribunal. She found the note written by her brother in his room on the day he died. Frances said she missed her brothers. She said their absence was an endless source of pain and remained like a silent scream inside her head that never went away.

PROCEEDINGS: Friday 1st December 2000 – Day 78

FRED

The Tribunal heard the evidence of Fred.

Fred told the Tribunal he had mild haemophilia A and had received factor VIII treatment four or five times in his life. His haemophilia condition was diagnosed when he was 15 years old, and played an insignificant part in his activities since. He had received factor VIII for dental treatment and for injuries sustained in a road traffic accident.

In 1995 Fred was summoned to a BtSB facility in his local hospital, where he was tested for hepatitis C and HIV. A subsequent letter informed Fred that he was hepatitis C positive. Fred said he was thereafter referred to the Regional Hospital, which answered some of his questions concerning his hepatitis C status.

Fred said that it had not proven possible to treat his hepatitis C. Damage to his liver remained unassessed. Fred said he objected to the manner in which he was questioned concerning his lifestyle prior to being tested for hepatitis C. He objected to advice he received, in that he objected to using condoms. He was also concerned about transmitting his hepatitis C to his sons who might come into the bathroom after him and pick up his razor and use it. Fred said he had attempted to put facilities in place in his own home which would isolate his personal effects, but this was difficult.

Fred said his social life had been destroyed by his hepatitis C condition. He could no longer enjoy meeting his friends for a drink, and he could not inform his associates as to his hepatitis C status, as he believed he would be ostracised if he did so.

Fred told the Tribunal that two of his brothers also had haemophilia, one had since died from the effects of HIV and another had hepatitis C. Fred said his older brother had hepatitis C and looking at him, he could see what the future held in store. As for his younger brother, Fred said he found out he was HIV positive when he attended a solicitor who was preparing a compensation claim on his behalf. Fred said this information was imparted to his brother in 1992. His brother had been tested for AIDS in 1985. Fred said he could not understand why there was such a long delay in informing his brother of his HIV status, as the hospital dealt with both Fred and his elder brother. His sister was a health care worker at the hospital which dealt with haemophilia in that region, and the hospital had Fred's mother's address, which was the contact address for his brother. So it would therefore have been possible to pass the information on to him.

Fred said he had received no treatment for his hepatitis C as he could not have continued to work with the side effects of his treatment. Fred has since given up his employment as he was unable to keep awake during the day.

In addition to his brother dying from the effects of AIDS, Fred said yet another brother had died. This brother had been dependent on the man who died as a result of AIDS; he died a week after his brother.

Fred also said he felt like a death sentence had been imposed on him. He told the Tribunal that he was after getting a lethal injection. He said a fellow on death row has some chance to get out of it, but he couldn't. He said his brother had no chance. Fred said someone must be held

accountable for this. He said they were still there walking around the hospitals as if nothing had happened. Fred said he hoped someone would be held accountable for the whole situation.

LUKE

The Tribunal then heard the evidence of Luke. Luke told the Tribunal he had a mild form of haemophilia B. He had played contact sports and had received significant injuries which had healed normally with no medical intervention. Luke said he was diagnosed with Christmas Disease following an injury that his older brother had received. He was then tested and it was discovered that he too, had mild haemophilia B.

Luke told the Tribunal he had received factor IX concentrates on three occasions only during his life. Two of these treatments related to dental work carried out in 1990. Luke informed the Tribunal he had an appendix removed prior to receiving any factor IX concentrate. No bleeding disorder had been established at that time, said Luke, the operation was done without the cover of factor IX.

In April 1991 Luke was informed by Prof. Temperley that he had hepatitis C Genotype 3. Luke said he was told quite frankly that he had contracted hepatitis C through infected blood product he received in St. James' Hospital. He was told this would affect his liver, and there was a small percentage chance of harm occurring. He was told the condition was incurable and it could not be taken away - once you have it, you have it. He was told that there was a very small chance that it could kill him, and was also told that the medical profession knew very little about the disease at that time.

That was the extent of Luke's information about hepatitis C. No further appointments were fixed. Luke said he was afraid and didn't know who to tell about the news that he was hepatitis C positive. Two or three weeks later Luke said that he informed his mother.

Luke said the monitoring of his hepatitis C condition depended on him getting in touch with the clinic and making an appointment. With regards to his own infection, Luke said he understood he became infected in 1990. He said he understood there was safe product available at that time. He said he found it totally crazy that good product was available but they gave him the old, unsafe stuff, and they knew there was a very high chance of it being infected. He said it was a lottery that he didn't get HIV.

Luke said his feelings towards the future were tempered by events like talking to a person whose son had died from hepatitis C. Luke said this guy had it for 16 years and he died. Luke said he could attend the clinic and be told that his blood is up or his PCR test is not looking good for his liver. He could be in a hospital bed in six months time. Luke said the future for him was an hour's time. Time is precious. He said even sleeping in was a waste of time.

Luke said had not completed his college career and, with regards to planning for the future, he said a lot of his energy went into looking after himself and prolonging his life. Luke said his preparing for the future was to make sure he did not aggravate his condition. Luke said he planned to return to college, but he was aware in his chosen field that random blood testing was part of many employment regimes. He said he would have to lie on job application forms and, with regard to his personal relationships, he was at a loss as to when he could tell someone he was hepatitis C positive.

Luke said he was aware he became infected from BTSB Factor IX batch 9885 from following events at the Tribunal. Luke explained that he was treated with batch 9885 following treatment with solvent detergent product. He said he would like to find out who the people who infected him were. He would like to know why, when clean product was available, he was treated with infected product. He wants to know why, when clean product was available, infected product was not disposed of. He wants to know if it was money and accountants that were running the BTSB.

JACKIE

The Tribunal then heard the evidence of Jackie.

Jackie gave evidence concerning her son Rory. Rory was diagnosed with haemophilia A when he was 12 months old. Rory was born in 1973 and was treated with cryo up until 1982. Jackie explained that she was reluctant to embark upon a course of home treatment as she had a phobia about needles. However, it was suggested that she go on home treatment and she was trained to use the home treatment kit.

In 1982 Rory was treated at the local hospital with factor concentrate, and in May 1983 Jackie spoke to Prof. Temperley. Jackie told Prof. Temperley that she may be coming around to the idea of administering the factor VIII herself at home, and she asked Prof. Temperley in light of her phobia about using needles, would she be able to do it? Prof. Temperley said, yes, even you. Jackie said that's the way he said it to her.

In August 1983 Rory was spending some time in hospital and Jackie attended and learned to use the home treatment kit. Jackie said she gave Rory his first treatment in her own home on 2nd September 1983. Jackie said that when she went onto home treatment with Rory she was not aware of any risks which may attach to those concentrates. Jackie said she had received no warnings of any risks of AIDS during 1983 or 1984 arising from the use of factor concentrates.

In November 1984 Rory was called to hospital because he was shown to have hepatitis B. In January 1986 Rory was admitted to hospital for an operation on his knee. Rory was 13 years old at this time and was being treated in Harcourt Street Hospital. Rory did not recover well from his knee operation. Upon raising enquiries about Rory's hepatitis B status, Jackie was told by Prof. Temperley that he was okay. On that day a nurse told Jackie that Rory was not being treated any different because he was HIV positive. Jackie said this was the first she had heard of the HIV. She said she didn't know until that stage that he was HIV positive. Jackie said the news of Rory being HIV positive was like getting a kick in the stomach; she was left speechless.

Upon discussing Rory's condition with her husband, Jackie's husband went to see Prof. Temperley. He asked Prof. Temperley why there was so much difficulty with Rory's condition at this time. Prof. Temperley told Jackie's husband, "He has it; he has got the virus", and with that he disappeared down the corridor. Jackie said they were left to deal with the situation as best they could. Jackie said there was no further discussion with Prof. Temperley concerning Rory's HIV status.

Jackie said her fear at the time was that Rory's leg would be amputated however he eventually recovered from his knee operation. At this stage Jackie said their only source of information with regard to Rory's condition came from the Irish Haemophilia Society. Jackie said the hospital had told her to take precautions regarding hepatitis B, but not for HIV. In addition to HIV, Rory also contracted CMV and hepatitis C.

Jackie said Rory knew about his HIV condition from the age of 13. She said Rory had a girlfriend who was absolutely brilliant. They planned to get married and she continued going out with him until he died. Jackie said Rory just wanted to be like everybody else; he had a girlfriend, a lovely girl, and he wanted to get married and have a family.

In December 1994 Rory was admitted to hospital with meningitis. He returned home on Christmas Day and went back to the hospital on St. Stephen's Day. Upon returning to the hospital Rory suffered an AIDS-defining illness as CMV returned.

Jackie recalled in the early 1990's the recompense campaign conducted by the I.H.S. on behalf of its members infected by contaminated blood products. Jackie said she felt bad that in the midst of trying to cope with the rigours of HIV and her son's illness, they also had to start and raise funds to fight the campaign. Jackie said she thought the Government simply wanted to sweep them under the carpet, and that they might remain there and stay quiet. She agreed that the recompense campaign related to dietary supplements and basic essentials. During these times she was also aware that members of the haemophilia community were dying from AIDS.

Rory died in 1995 at 22 years of age. Jackie said she wants to know why her son died at this young age. She would like to thank the Irish Haemophilia Society, Margaret King and Rosemary Daly, and Sister O'Shea of St. James' Hospital, who was a great friend to her son.