

# **IRISH HAEMOPHILIA SOCIETY**

## **TRIBUNAL NEWSLETTER**

### **ISSUE 20**

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**14<sup>th</sup> December, 2000**

## **TRIBUNAL OF INQUIRY**

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

**PROCEEDINGS: TUESDAY 5<sup>th</sup> DECEMBER, 2000 – DAY 79**

HERBERT

The Tribunal heard the evidence of Herbert.

Herbert told the Tribunal he has two sons, both of whom have haemophilia A. A third boy does not have haemophilia.

Herbert's first son was born in 1984 and is factor VIII deficient to a level of between 4 per cent and 9 per cent. He was diagnosed with haemophilia in Crumlin Hospital and was originally treated with cryoprecipitate. He was then referred on to Prof. Temperley at the National Children's Hospital. He received his first concentrate in early 1985.

Herbert's second son with haemophilia was born in 1985 and received his first factor VIII concentrate in May 1986. Herbert said both children had been infected with hepatitis C and both were now antibody positive.

Herbert told the Tribunal Hepatitis C had created problems for the boys, in that it was difficult to keep their condition confidential. Herbert said he had not fully discussed all the issues that would arise from Hepatitis C with his sons at this stage. Herbert said that various lifestyle issues had to be addressed, such as the consumption of alcohol and any effect that it might have on progressing liver infection.

Herbert said both boys were now PCR negative and virus negative, and antibody positive. As to their future prognosis, he was aware that Hepatitis C may or may not return. Herbert said that one son had displayed high antibody levels and there may be virus activity attached to this reading.

As the boys grew older more questions presented themselves to be answered, said Herbert, and he did not think that they had fully grasped the medical implications of their condition. As for their career choices, Herbert said any employer who required them to disclose their condition, and any career which may have this requirement, may not be open to them. As for life assurance and future financial arrangements and commitments, into which his children might have to enter, Herbert said that insurance companies will now take on Hepatitis C antibody positive clients but only at three times the premium.

As regards the circumstances in which Herbert found out that his sons were hepatitis C positive, he said he attended the Wednesday clinic at Harcourt Street Hospital for their normal check-up. Herbert said there were two doctors present. One, who was speaking to him, opened the file on his elder son, and asked him did he appreciate that the boy was hepatitis C positive? Herbert said he had never known this to be the case and it had never registered on him that it may have been a possibility. He said the doctors explained they had known for some time that his elder son was hepatitis C positive, but he hadn't been told. In due course both children were diagnosed as

hepatitis C positive. Herbert said there was no assistance forthcoming in helping the children come to terms with the information he had received. Herbert said he received assistance from the Irish Haemophilia Society as regards counselling, but no other assistance.

As to why he was giving evidence to the Tribunal, Herbert said he was taking the opportunity to speak on behalf of his family, and anyone else that was infected. He said he was very disappointed in what had happened, and was particularly disappointed with Prof. Temperley and the trust he had placed in him.

At this point Herbert was interrupted in his evidence by Counsel for Prof. Temperley, Mr McGovern. Mr McGovern said there was no mention whatever of Prof. Temperley in the witness' statement and "this gratuitous type of reference which is creeping into a number of cases is quite unwarranted and should not be made". Mr Bradley, representing the Irish Haemophilia Society, pointed out that the witness was giving his personal testimony. Mr McGovern continued, "the witness may well be giving his personal testimony, but it is more than a coincidence as we are about to embark on phase three, we get these gratuitous references to practitioners about to give their evidence when there is no reference in the statements".

The Chairperson said that the position was that anyone who wanted to make a supplemental statement, or has any allegations he wishes to make, may so do, so that the allegation may be distributed to all the parties concerned. The Chairperson added that there would be fairness for all concerned because then they will know what is going to be said.

Herbert continued his evidence, saying that he understood that his children would have difficulties in the sense that they must trust the medical profession as they grew up. Herbert said he hoped the difficulties that had arisen would be sorted out, and that the trust formerly placed in the medical profession could be restored. Herbert said he would like the truth to emerge so that the same thing did not happen again.

Herbert was cross-examined by Mr McGovern counsel for Prof. Temperley, Dr Helena Daly and Dr Fred Jackson. Mr McGovern asked Herbert, had he been counselled by any party other than the Irish Haemophilia Society. Herbert said he did not recall being so counselled. Mr McGovern put it to Herbert that he and his wife had been counselled regarding their sons' hepatitis C by a Dr Joan Fitzgerald, who would give evidence to that effect. Herbert said he did not recall being counselled by Dr Fitzgerald.

## SHIRLEY

The Tribunal then heard the evidence of Shirley. Shirley gave evidence of raising her four sons with haemophilia B during the 1950's, 1960's and 1970's. Shirley said that during the 1950's and early 1960's no treatment was available. They were treated with plasma and the slow infusion of plasma would take hours to complete. The children would then be detained in hospital for weeks as they recovered. She said her children were big when concentrate came in, and they were able to treat themselves.

Shirley told the Tribunal of her son Hugh, who suffered a bleed into his brain in infancy and as a result she said he was always slow and required more care than the others. She says he grew up and was looked after by all the members of her family. Hugh went to a special school until he was 15 years old. Shirley said when concentrate became available she thought it was great because it eased the suffering of her sons and other people with haemophilia.

Shirley recounted that during his childhood, Hugh suffered jaundice on two occasions. Shirley said she was told indirectly that Hugh had HIV. She said she met a doctor in St. James' Hospital who told her that she should take care of any spillages of blood or body fluids, and to clean them up with bleach. She said she was not aware of the full consequences of HIV at this time.

Hugh started to deteriorate on his 27<sup>th</sup> birthday, said Shirley. She said he had a lung infection and was put on a ventilator. He spent three weeks in St. James' Hospital. Shirley said she thought Hugh overheard hospital staff saying he had AIDS and this had an adverse effect on him, and he knew he was going to die. Shirley said she took him to Lourdes and Medjugorje. Hugh died in 1991 and Shirley thought that his visits to the shrines of the Virgin Mary were of assistance to him, as she thought she was there with him.

Shirley said she did not know what particular factor IX concentrates infected her son. She said it was very sad to lose him at 28 years of age. He was such a quiet little lad and lived for his music and his work. Shirley said she was never told what products were responsible for the death of her son. The only thing they were told was that it was contaminated blood that had come from America. But, said Shirley, she didn't really think it came from America at all. But that's what she had been told.

#### DEIRDRE

The Tribunal then heard the evidence of Deirdre.

Deirdre was independently legally represented and attained limited representation for the duration of her evidence. The Chairperson said that if any other witness who was not being proffered by the I.H.S., and wishes to give evidence, they may do so by contacting Mr John Nolan, Solicitor for the Tribunal, and arrangements would be made.

Deirdre described meeting and getting married to her husband, Declan in the early 1980's. She said he was a very clean-living person. He played soccer, he liked music and was an accomplished runner. She said his soccer activities resulted in a number of haematomas occurring. Upon investigation it was discovered he had mild haemophilia. He was then referred to Prof. Temperley at St. James' Hospital. This diagnosis was made sometime in and around 1982.

Deirdre said her husband was disappointed to have to give up soccer and other contact sports, but he continued to run and train and did in fact participate in the Dublin City Marathon. Deirdre said both herself and her husband trained together and were interested in running.

In or around 1984 Declan developed a problem with an in-growing hair follicle. Deirdre said that this was sore; it was a minor inconvenience. It became inflamed and required antibiotic treatment. It developed into an abscess and it was indicated that he should have it surgically removed. This operation took place in April 1984.

Immediately after the operation, Deirdre said Declan was unwell. He was discharged from hospital but re-admitted at the end of April 1984. Deirdre said he was concerned he had been treated with blood products as he wasn't used to them. As time progressed he continued to complain about tiredness and fatigue. Declan was unable to return to work for the following 15 months. Describing the treatment Declan received at the time of the operation to remove the in-growing hair follicle, Deirdre said he was initially treated with DDAVP and then cryoprecipitate for about 3-4 days. Deirdre said he got a 90 per cent rise on the cryoprecipitate. She knew this

from his medical records. On his fourth day post-operative Declan was treated with factor concentrate, factor VIII. Mr Durcan indicated that Declan's medical treatment would be examined in the next phase of the Tribunal.

Deirdre then described how Declan developed glandular fever, from which hepatitis appeared to develop. Deirdre said her husband understood the surgery he had undergone to be elective surgery, to facilitate his running activities. As to any risk, he received no advice that any product he may be treated with would be hazardous in any way to his health. Deirdre said he would not have had the operation if he had been told there was a risk, and he had never been treated with any blood products prior to this date.

Deirdre said her husband read about the dangers of the HTLV-III virus and blood products in the newspapers. He said to her he hoped he didn't have anything like that. Declan continued to attend clinics and it was noted that his blood enzymes were raised. He continued to have his blood monitored by his GP and by St. James' Hospital.

In or around December 1984, Declan was summoned to St. James' Hospital, where he saw Prof. Temperley. At this time, said Deirdre, they were very interested in starting a family. Deirdre said Prof. Temperley told Declan that his hepatitis had subsided and it was safe to consider starting a family. On that same day, Deirdre said bloods were taken from Declan for an HTLV-III test. This was taken without his consent. He was also told it was safe to start a family. Prof. Temperley extended his best wishes to Declan's wife. Deirdre said she learned this when she picked Declan up from the train station that night.

Declan's next contact with St. James' Hospital was in July 1985. He received a letter and was asked to attend and advised to bring someone with him. The couple travelled to Dublin where they met Dr Helena Daly, and she told them that her husband was HTLV III positive. She also said it was inadvisable to get pregnant at that time. However, at that stage Deirdre was already five months pregnant. Deirdre said they were both devastated by this news. She had to be tested then for HIV, and waited six weeks to find out that the test was negative. Deirdre said living with the news that her husband was HIV positive was like living with a time bomb. She said it was the first thing she would think of in the morning when she woke up. However, her husband tried to be optimistic and said with the advance of medicine he hoped to survive, and would in any event give it his best shot. However, Deirdre said that he remained under a cloud for the rest of their life together.

Her pregnancy was very difficult, she said, and she didn't remember much about it. When the baby was born Deirdre said she should have been tested. However, they refused to allow the baby to be tested. The child had a difficult infancy and developed fevers, and was prone to infection. However, Deirdre said they would rather live not knowing her HIV status than knowing it at this time.

Deirdre said her husband had to resign from his work and give up his hobbies at this time, as his energy levels had dissipated. As his health deteriorated, Deirdre said his last year was one of inactivity. They told nobody that he was HIV positive at the time. A few weeks prior to his death Declan told his father that he was HIV positive. She had also been told since then that he was positive for hepatitis C. Deirdre said that he received some support from the Irish Haemophilia Society, but none otherwise apart from that offered by the local GP.

Deirdre said her husband was prescribed with AZT and Interferon. However, in the last stages of his illness, in the year before he died, he stopped taking medicines. Deirdre said her husband was

referred for psychiatric assessment. Deirdre said her husband was very upset to be sent for a psychiatric consultation. She said he had gone in with raised liver enzymes and was feeling very unwell, and was referred for a psychiatric consultation.

With respect to his relationship with Prof. Temperley, Deirdre said her husband found Prof. Temperley to be cold and very disassociated from the reality of his illness. Deirdre recalled that at one clinic attended by her husband with Prof. Temperley, he complained of being tired. She said Prof. Temperley leaned back in the chair and said, we are all tired. Deirdre said she was at that clinic. Deirdre said the visiting facilities for herself and her daughter at St. James' Hospital were completely inadequate. Children were not allowed on the ward and she had to visit her husband on a small draughty landing.

Deirdre said she felt particularly aggrieved that the hospital that had caused her husband's problems could not now address the issue of visiting someone who was dying. Deirdre said she went to Mr Dunbar, Chief Executive of the hospital, and highlighted these problems to him. He advised her to be optimistic. Facilities were made available to allow the family to visit, but in the event they only availed of these facilities on one occasion as her husband's condition deteriorated rapidly thereafter.

Prior to her husband's death, it had been arranged that he would go home to die. Deirdre said her daughter was excited at the thought of her father returning home, and she talked to him on the telephone. However, Declan declined further and died before he could be discharged from hospital. Deirdre refused to allow a post mortem to take place, but did consent to a biopsy of Declan's liver being conducted post mortem. However, the person scheduled to conduct the biopsy didn't show up. No biopsy took place. Declan was buried two days later.

In the years of Declan's illness Deirdre said their family was left in very poor financial circumstances. Because they were unable to adequately heat the family home Declan suffered more from the cold than he would otherwise have done. Deirdre said the family received assistance from the Irish Haemophilia Society at the time.

With respect to her husband's death certificate, Deirdre expressed the wish that she did not want HIV on the death certificate. However, when he died she was informed that this would have to be appended to the death cert. Deirdre said she phoned Prof. Temperley at his home at the time on this matter, and was told that if she hadn't created such a fuss the cert. might have been able to have been sorted out. Deirdre said she did not want the stigma of HIV attaching to her husband's death. She wanted the cause of death to be recorded as hepatitis. When a death certificate was eventually issued HIV was not on it.

Deirdre said she wanted to know why her husband had been given factor VIII concentrate when a safer treatment was 90 per cent effective. She wanted to know why his treatment was changed, and who changed it.

Deirdre was then cross-examined by Mr McGovern for Prof. Temperley. Mr McGovern asked Deirdre, had she found Prof. Temperley to be rather detached from everything. Deirdre said that this could be substantiated by the fact that Prof. Temperley took sabbatical leave after the time her husband was tested, in December, and that the test had been carried out without his knowledge. She said Prof. Temperley was not around to give the results of the test which he had not even asked to do, or told her husband he was doing. Mr McGovern said the reasons for Prof. Temperley's sabbatical would be forthcoming at a later stage of the Tribunal. Deirdre said she

did not think her husband would have refused consent if he had been asked at the time the test was taken.

With respect to her husband's visit to Prof. Temperley in December 1984 Mr McGovern asked, was Prof. Temperley's expression of good wishes for the future not at odds with the cold person she was describing? Deirdre said Prof. Temperley had wished them well while he was taking an AIDS test. He wished them well in starting a family while doing an AIDS test, without even having the results of the test. He was saying good luck with starting your family, which meant that she also could have been infected.

Mr McGovern asked Deirdre, was her understandable anger directed at Prof. Temperley because her husband had been given an infected product? Deirdre said she was angry at Prof. Temperley for not telling them there were risks attached to the surgery undertaken by her husband, and to the products used, and also attached to the administration of factor VIII concentrate when cryo was working for her husband. Mr McGovern said Prof. Temperley had never prescribed anything other than DDAVP and cryo, and that he was particularly upset because her husband had been given something other than cryo. Mr McGovern asked Deirdre, would it change her feelings towards Prof. Temperley if she realised he was not the one who changed her husband's treatment from cryo to concentrate? Deirdre said she would have to think about that. She could not answer it on the spur of the moment.

With respect to referring her husband to a psychiatric examination, Mr McGovern said Prof. Temperley will give evidence that he did so because he felt it would be helpful to her husband, because of his emotional state at the time. Deirdre said that her husband went into hospital at this time with raised liver enzymes, a physical condition, not a psychological one. A psychiatric evaluation simply added insult to injury, she said.

Deirdre's evidence completed the testimony of this group of personal testimony witnesses.

**PROCEEDINGS: THURSDAY 7<sup>th</sup> DECEMBER, 2000 – DAY 80**

Dr Vincent Barry, formerly chief medical consultant of the B T S B, was examined by Mr Gerry Durcan on the subject of look-back.

Mr Durcan asked Dr Barry, did he remember the circumstances of getting the look-back document of July 1987? Dr Barry said Mr Keyes requested the look-back document and Dr Walsh put it together at the behest of Mr Keyes. Mr Durcan asked Dr Barry, was the subject of look-back under discussion in the month of July 1987? Dr Barry agreed that this was the case. Dr Barry said he was aware that look-back was also being discussed in the UK. He was asked to contribute to the discussion by contacting his former UK colleagues, and in this respect he wrote a document forwarded to Mr Keyes on 13<sup>th</sup> July 1987 concerning look-back. Dr Barry said he did not request the information contained in the look-back document of 15<sup>th</sup> July 1987. Dr Barry said Dr Walsh supplied this memorandum to Mr Keyes. He could not remember if Mr Keyes had forwarded the document to him.

Mr Durcan referred Dr Barry to a hand written version of the document, which indicates that it was directed to him, [Dr Barry]. Dr Barry said it may have been directed to him amongst others. Dr Barry said as far as he was concerned, Mr Keyes wanted the information as to how to conduct a look-back. Dr Barry said he did not do anything to initiate a look-back, apart from write up the document dated 13<sup>th</sup> July 1987.

Dr Barry said he was about to retire and was told, in a telephone call, that it had been decided that a look-back would not take place, and matters would be left as they stood. Dr Barry said he agreed with the idea that it was medically necessary to conduct a look-back in 1987, but, he said, it should only be conducted when everyone was ready to do so. Dr Barry said as far as he was concerned in Cork, there were no Cork donors HIV positive, and there was no urgency on him to conduct a look-back. But having read the A A B B, a look-back should have been carried out. Dr Barry said he did not do anything with respect to look-back as he was leaving the service, and when he was asked to wait he did not see the point in initiating a look-back himself. Dr Barry agreed that he could have brought the issue to the board of the B T S B, but he thought it had been picked up by the board at this time.

Dr Barry said he was in Cork on his own, his registrar was on maternity leave. He left Cork once a month and, while he attended the board meetings, he did not suggest a look-back.

Dr Barry said he was invited to come to Dublin pending the appointment of the chief medical consultant. He was so invited by Dr Barry in 1995. Mr Durcan asked Dr Barry, did he realise the danger of onward infection with respect to look-back? Dr Barry said he was not aware of this. Dr Barry said the telephone call he received telling him that a look-back would not be necessary, was narrowed down to two people; either Mr Keyes or Mr Walsh. Dr Barry said he could swear there was a call, and the effect of the call was that he didn't need to do anything concerning a look-back. He was simply unsure which of the two the call was from.

With respect to Donor C and the issue of infected platelets, Dr Barry said the letter he issued was a standard letter sent out in respect of any infected blood donation. He said the same procedure would have applied as for syphilis. Dr Barry said he did not have the file of Donor C when he sent the letter. He said the letter was the same letter as was sent with respect to any infected donor. The same procedure was used. With respect to who would inform the hospital that infected platelets had been issued when the platelets were tested for HIV, Dr Barry said he didn't know whose responsibility this was. However, he said platelets always had to be issued urgently.

Dr Barry was cross-examined by Mr Charles Meenan on behalf of Dr Terry Walsh. Dr Barry told Mr Meenan he did not know how the document prepared by Dr Walsh ended up in his file. Dr Barry agreed that he received a phone call while he was in Cork, to the effect that he was to leave matters lie. Dr Barry says he accepts that Dr Walsh didn't make that call, but he said he was based in Cork and Dr Walsh was based in Dublin.

Dr Walsh then took the stand to say he didn't make the phone call.

The Tribunal then called Dr James Kirrane. Dr Kirrane, having been examined previously by Mr Gerry Durcan, was then cross-examined by Mr Raymond Bradley for the Irish Haemophilia Society.

Mr Bradley referred Dr Kirrane to his previous testimony, where he said to Mr Durcan that he had no involvement with the B'TSB's factor IX production. Mr Bradley referred Dr Kirrane to the transcript of a previous tribunal in which he was involved, ie. the Finlay Tribunal. At that Tribunal Dr Kirrane appeared to indicate that he was involved in attending B'TSB Scientific meetings in relation to factor IX and in keeping up to up to date with what was happening. Dr Kirrane said when he made these remarks to the Finlay Tribunal, he had entered into areas in which he had no expertise. He also said he was denied legal representation within the Finlay Tribunal at the same time, and had become quite disoriented as to what was being asked of him, and why it was being asked. Dr Kirrane said his evidence now was that he had no involvement with the production of B'TSB factor IX, and his advice in fractionation matters was confined to Sephadex chromatography as opposed to Cellulose chromatography, through which factor IX was produced. Dr Kirrane said a Dr Chung was in charge of the cellulose chromatography.

Dr Kirrane said he would accept there was a conflict between his evidence to the Finlay Tribunal and his evidence to the Lindsay Tribunal. But, his position now was that he had nothing to do with the production of factor IX and offered no advice on the production of factor IX as an external consultant.

Mr Bradley then referred Dr Kirrane to a document dated 1973, where it appears that Dr Kirrane was involved in the analysis of factor IX. Dr Kirrane said this material was sent to the diagnostic laboratories in UCD from Pelican House, to be measured. He could not say whether he had signed the document, while his name did appear on it.

Mr Bradley then referred Dr Kirrane to an inter-departmental memo of the B'TSB. In this memo the chief technical officer forwarded a technical memorandum to a group of people, amongst whom was Dr Kirrane. The information was sent to Dr Kirrane for information. The technical memorandum in question was the B'TSB technical memorandum No. 31 relating to the preparation of human factor IX concentrate.

Mr Bradley asked Dr Kirrane, why would the chief technical officer of the B'TSB be sending such a document to him? Dr Kirrane said Mr Bradley would have to ask the chief technical officer why he sent it to him. He said perhaps the chief technical officer wasn't aware that he wasn't the person responsible for the production of factor IX in the fractionation unit.

Mr Bradley then referred Dr Kirrane to a selection of scientific meetings of the B'TSB. Mr Bradley referred Dr Kirrane to the meeting of 14<sup>th</sup> December 1983, at which it is stated that satisfactory results were obtained in clinical trials of factor VIII concentrate prepared by the B'TSB. Dr Kirrane said he could remember nothing about this particular item.

Mr Bradley referred Dr Kirrane to various other scientific meetings at which he was in attendance during 1983, and at which factor IX and factor VIII were discussed. Dr Kirrane said he could remember nothing about these particular events.

Mr Bradley then referred Dr Kirrane to a scientific meeting where the topic of AIDS was discussed. Dr Kirrane said he was aware that AIDS was an infectious disease and was of world-wide interest at that time, but he was not an infectious diseases expert and would not have taken a great interest in infectious diseases. Dr Kirrane said he did not know what was meant by appreciating the possibility that AIDS could be blood-borne.

Mr Bradley referred Dr Kirrane to a letter from Dr Ottridge to the Department of Health. Dr Kirrane said he had never seen the letter until it appeared here. The letter concerned the treatment of two AIDS patients in the Mater Hospital in the department where Dr Kirrane was working in May 1983. Dr Kirrane said this patient was under the care of Dr Ottridge, who was treating him in his capacity as a clinician and not as a haematologist. Dr Kirrane said he would not necessarily know that there was an AIDS patient in the Mater Hospital in May of 1983.

Mr Bradley put it to Dr Kirrane that, given that these were the first two AIDS patients to be treated in Ireland, would it not be a matter of interest to him, and to his colleagues within the Department of Pathology in the Mater Hospital that such patients were being treated at the hospital? Dr Kirrane said he was not aware that these patients were being treated at the hospital in May 1983.

Mr Bradley asked Dr Kirrane was he saying he sat on the scientific committee meeting from 1970 until 1985 and offered no other contribution other than with regard to Anti-D. Dr Kirrane said that is what he was saying, except to maybe offer general information which he would have had in the context of being a pathologist at UCD. Dr Kirrane said as far as he knew, there was no outside consultant with respect to the production of factor IX, during the years he attended the Scientific Meeting of the BTSB.

**PROCEEDINGS: TUESDAY 12<sup>th</sup> DECEMBER 2000 – Day 81**

Counsel for the Tribunal, Mr John Finlay SC, addressed the Chairperson. He said it had been intended to start the third phase of the Tribunal's investigation today with the evidence of Professor Temperley. But, said Mr Finlay, a considerable volume of additional documentation had been adduced by various parties. Mr Finlay said it would not be possible for the witness to familiarise himself with the documents in the time available, and in these circumstances he was applying for an adjournment of the Tribunal until Thursday, January 11<sup>th</sup> 2001. The Chairperson then adjourned until this date.