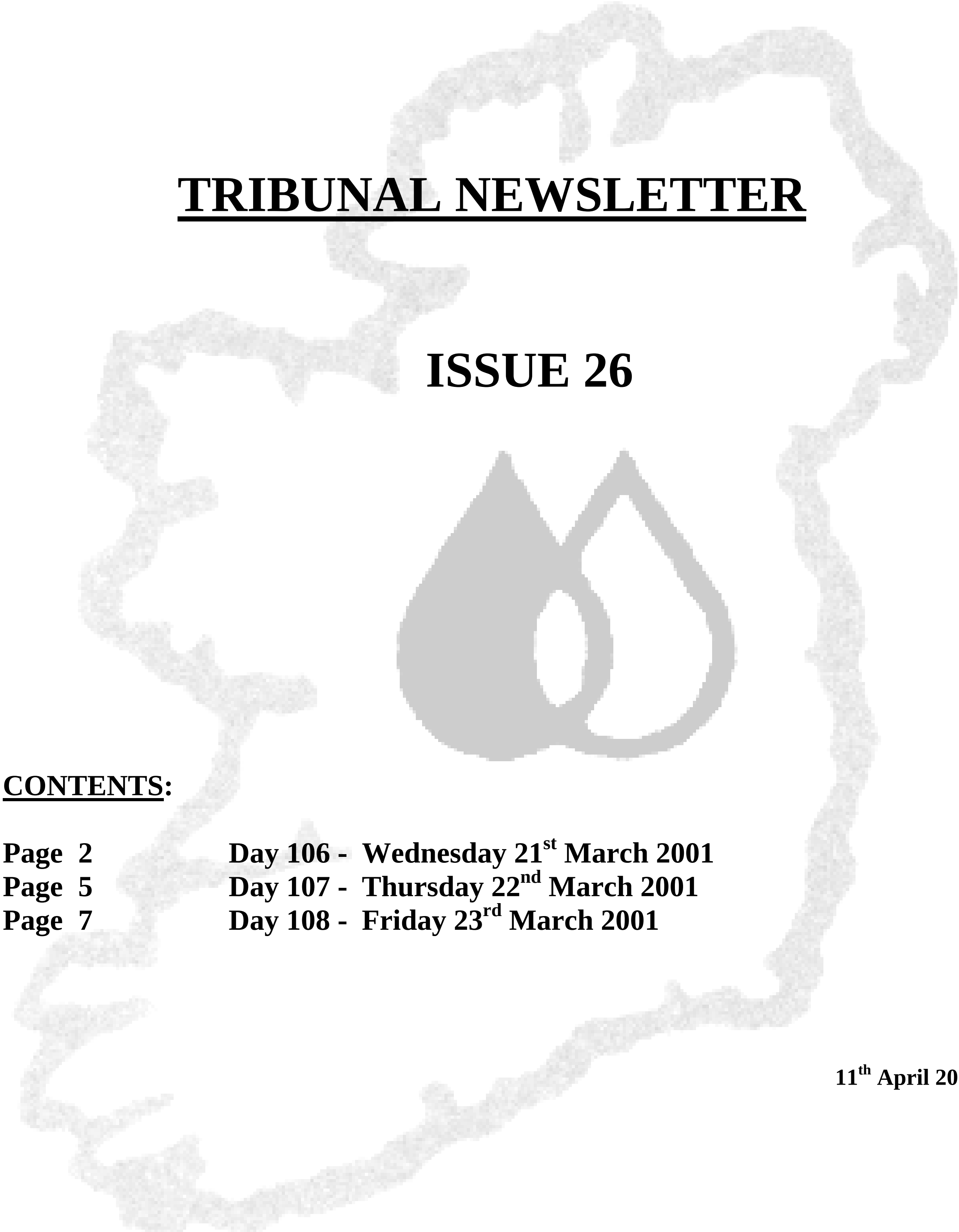
# IRISH HAEMOPHILIA SOCIETY

# TRIBUNAL NEWSLETTER

## ISSUE 26



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**11th April 2001**

# TRIBUNAL OF INQUIRY

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

## PROCEEDINGS: Wednesday 21st March 2001 - Day 106

Mr Patrick McCann for the Tribunal continued his examination of Ms Maeve Foreman, Social Worker at St. James' Hospital.

Ms Foreman outlined the work undertaken on behalf of the I.H.S. by Mr Owen Hegarty, Clinical Psychologist, and Ms Margaret King, counsellor for the Society. Ms Foreman said she was in regular contact with Ms King and organised joint visits with her in respect of families outside of Dublin. Ms Foreman said she was also in contact with the AIDS Fund Housing Project, which was a resource open to all those with HIV. She also was in liaison with the infection control nurse at St. James' and liaised with the Clanwilliam Institute. Ms Foreman said she enjoyed a good working relationship with the I.H.S. in respect of the welfare of its members and her patients to this day. Ms Foreman said she attended support weekends at the request of the Society during the 1990/1991 period.

With respect to hepatitis C, Ms Foreman agreed that she was open to providing support for those who received positive HCV results. Ms Foreman said that in June 1991 the results coming from the VRL were more reliable. However, those informed about hepatitis C were not automatically referred to her at this time. Ms Foreman said that, while some were very upset upon receiving news that they were positive for hepatitis C, it did not cause overt alarm for many as they were already aware that they had NANB hepatitis. Also, hepatitis C was not perceived as being as dangerous as HIV at this time, nor did the same stigma attach to hepatitis C as was attached to HIV.

Ms Foreman agreed that the Health Amendment Act of 1996 allowed those infected with HCV to pick a counsellor of their choice, to be paid for by the Health Board. Ms Foreman said she sourced local counsellors in some instances. However, the take-up of these services was low overall.

On the issue of respite care, Ms Foreman said that Cherry Orchard Hospital made this available from 1989 onwards. A small number of patients did access this service, but culturally Cherry Orchard was seen as a facility for drug abusers and was therefore not popular with haemophilia HIV infected people.

Ms Foreman agreed that overall a three year delay, from 1985 until 1988, occurred in appointing a social worker at St. James' Hospital. She said that the main voluntary group at this time was the Irish Haemophilia Society. Ms Foreman said some people with haemophilia opted for the services of Cairde.

The emotional impact of HIV infection was a sense of anger and loss, said Ms Foreman. She agreed that the onus was on the patient to access psychological support services in respect of these emotions, and this did not help matters. With regards to bereavement counselling Ms Foreman said the people with haemophilia, and their survivors, needed such a service. Death from HIV made this service all the more necessary. Ms Foreman said that a common experience was that the whole story of HIV could not be shared, and relatives of those who died could not be open about their loss. She said that weekends, where those who had lost relatives to HIV gathered, were good for sharing the common loss. Ms Foreman said that the I.H.S. provided a lot of support for those who were bereaved by HIV. She did not think that a person with HIV could die without the hospital knowing about it.

Ms Foreman said that since the advent of triple therapy a huge difference had occurred in the prospects of those infected with HIV. She said those so infected were now able to contemplate marriage and children, and the possibility of a normal life span presented itself. Ms Foreman said she was aware of the fears and angers aroused by HIV deaths. She said the special procedures employed with respect to the remains of those with HIV caused distress. Ms Foreman said that ways were developed of allowing relatives to bid farewell to their family members.

Mr McCann then referred Ms Foreman to the evidence of people with haemophilia concerning social work issues. Mr McCann put it to Ms Foreman that relatives may not have been aware of contact between deceased family members and social workers and that the processing and absorbing of information may not have taken place. Ms Foreman said that the social work department gave assistance to many of those who gave evidence. Ms Foreman said that she had looked at 35 statements. Of those 35 statements, up to 25 had been referred to social work services at some time.

With regards to the evidence of the witness Mary in connection with her husband Norma*n*, Ms Foreman said there was no routine referral for counselling with regards to patients infected with hepatitis C. In response to the evidence of the witness Cheryl who gave evidence on behalf of her father, Ms Foreman said that while there may have been no formal referral to social work services, she did recall a lot of informal social contact with Cheryl's father. Ms Foreman said it was quite possible that Cheryl would have been unaware of this type of contact.

With regards to the evidence of the witness Dominic, Ms Foreman said she would agree that there was no concrete offer of follow-up with respect to his HIV infection, of which he became aware in 1985.

With regard to the evidence of Karen Stephens Ms Foreman said she visited Karen's father Jerome on many occasions and conducted a lot of home visits with Margaret King in a combined effort with the Irish Haemophilia Society. Ms Foreman said Karen may not have remembered these visits.

Mr McCann also referred Ms Foreman to the evidence of Arthur with respect to his son Bill; Isabel; Vincent; Charles and Brendan. With respect to Brendan, Ms Foreman said that Brendan obtained cognitive therapy at the suggestion of the social workers.

Ms Foreman was referred to the evidence of Peter, father of Dermot. She said she knew this family well and at the time did not always think it was helpful to dwell on the difficulties. She also said that Peter would have had an independent relationship with his family.

With regard to the evidence of Siobhan, the wife of Donal, Ms Foreman said that with the support of the Irish Haemophilia Society, Sister O'Shea and Donal's sister provided support.

In conclusion, Ms Foreman said that no amount of counselling was going to take away the fact that people were infected and died from HIV.

Ms Foreman was then cross-examined by Mr Raymond Bradley on behalf of the Irish Haemophilia Society. Referring to the period 1985/1986, Mr Bradley referred Ms Foreman to a letter from Ms Kennedy, head of social work services at St. James's Hospital. It was noted in the letter that adequate counselling of the haemophilia population would require one thousand hours of social work over a 10 month period. The social work services available at the time offered a maximum of 24 hours per month for the entire haemophilia population. Ms Foreman agreed that this would amount to 24 per cent of the estimated requirement being delivered from the social work department at this time. Ms Foreman said that she was aware that the social work services available at the time were not capable of covering these requirements. She said the whole department was stretched at this time.

With regard to a letter written by Dr Daly, Ms Foreman agreed that it covered counselling from the medical perspective. Ms Foreman said there was a lack of written information at the time. She said that denial was a normal reaction to any bad news, and this reaction may have prevented people with haemophilia taking on board the practical implications of their infection. They may not have informed their partners. Ms Foreman said that all those concerned were on a learning curve at the time. Ms Foreman said that her role as a HIV counsellor was to support those infected. This support took the form of learning to live with the virus.

Mr Bradley put it to Ms Foreman that early intervention by the social work department would have made coping with the problem a lot easier. Ms Foreman said that by the time adequate social work services were put in place after 1988, much of the damage had already been done. Ms Foreman said that those concerned had had to deal with an acute anxiety state which involved the fear of death. She said some people died before adequate services were made available, however once on the unit they were seen by counsellors and social workers.

Ms Foreman said that many coped with the threat of HIV by simply not thinking about it. However, the slowly growing fear of HIV as more people succumbed to AIDS ruled out this option. Ms Foreman said at this time in the late 1980’s, it was still hoped that many would not go on to develop AIDS. Ms Foreman agreed that the effects of denial and anger became more entrenched as time went on, and it was therefore more difficult for those infected to access help. This was particularly difficult when they were expected to access help from the source of their infection. Ms Foreman agreed that there was no after hours service supplied; even when counselling was put in place there was a low take-up. Ms Foreman said it was difficult for young people to enter formal social work contract arrangements.

With respect to an observation made by Prof. Temperley that it was necessary to abandon counselling for wives and girlfriends of haemophilia HIV infections due to lack of staff, Ms Foreman said that the service was inadequate and Prof. Temperley may have been exaggerating to make the point. She said that if people asked for counselling they were counselled. She agreed that the corollary of this was that if they did not seek counselling they were not counselled.

With regards to the £15,000 made available in July 1988 from the National Lottery, Mr Bradley asked Ms Foreman if, in light of what was around the corner, was this an adequate sum. Ms Foreman said it was a starting point. From that point forward measures were put in place to deal with the crisis. She also said that the social work service linked in to community based relief services from this point.

In March 1987 Ms Foreman agreed that the I.H.S. was still providing a lot of support and was still supplying items such as condoms, even though the law had changed with respect to the provision of these goods.

**PROCEEDINGS: Thursday 22nd March 2001 - Day 107**

Mr Bradley continued his cross-examination of Ms Maeve Forman, Social Worker at St. James's Hospital.

Ms Foreman said that the social work service on offer at St. James's Hospital was not a drop-in service. The business of the social worker was conducted usually on site and tended to prioritise people who were in distress.

Ms Foreman said that home visits would be carried out usually by Margaret King on behalf of the Irish Haemophilia Society. Ms Foreman said that some home visits were carried out by the hospital social workers, but mostly these activities were dealt with by the I.H.S. through the offices of Ms King. Ms Foreman said that the home visit activity was tied to the community based services. No after hours service was provided by social work services, either in 1990 or even in 2001, said Ms Foreman. She said it was normal practice to admit those in distress to hospital. Access to social worker services would be gained the following day.

With respect to the issue of respite beds, Ms Foreman said that there was always competition for beds between those suffering from cancer and those who were terminally ill from AIDS. Where an acute medical situation arose, Ms Foreman said that an admission was always facilitated somewhere in the hospital.

With regards to the issue of a lack of privacy on the haemophilia unit, Mr Bradley put it to Ms Foreman that the space was by no means adequate, and for counselling to be successful one needed a degree of confidentiality. Ms Foreman said this was true, but counselling did not always take a formal course. Like everyone else, she said she had to make the best of the available facilities, and while there would be times when a room was needed and would not be available, this was still the case today.

In the late 1980s and in 1989, those who had contracted HIV were becoming ill and dying from AIDS defining illnesses. Ms Foreman said that there was only one full-time person engaged in HIV counselling. She agreed that HIV was more difficult to deal with than other terminal illnesses, in that a social stigma attached to HIV. Ms Foreman said that a comprehensive service required a full time social worker. She said that testing of partners, whilst important, did not take place solely in conjunction with the compensation scheme in 1991. Ms Foreman said that wives and partners had been encouraged from the start to avail of testing, however she said the pros and cons of testing were still being debated at this time.

With respect to informing people of their HIV status, Ms Foreman said that there was a strong reluctance on the part of the centre to append the words "HIV" to anyone's record. There was a fear of loss from such disclosure. Ms Foreman said this fear was palpable. She said that information on AIDS was available, including information on safer sex, but there was great reluctance on the part of those infected to bring this literature home with them. Ms Foreman said that part of her role as social worker was to intervene on behalf of patients, and this sometimes involved bypassing local services in order to maintain confidentiality and allow people to avail of their social welfare entitlements.

With respect to the issue of body bags, Ms Foreman said this was a critical issue for people. The disruption of traditional grieving and mourning procedures caused great anxiety for the families of the deceased. As a result of this, a practice developed whereby the remains of those who had died would be kept on the ward so the families could bid farewell to their loved ones. Ms Foreman said that the national guidelines still provide for the use of body bags, and this continues to cause psychological distress for those affected.

With respect to hepatitis C, Ms Foreman said that this was not regarded as highly significant in the late 1980's. Furthermore, she said the stigma was not as great with hepatitis C as with HIV. Nevertheless, hepatitis C positive status was kept confidential. There was a general perception that hepatitis C was not serious, and it was only with the Anti-D revelations and the attendant publicity on how the virus might manifest itself, that fear increased. Ms Foreman said this had a big impact on some. It was poignant that just as HIV treatment became available, hepatitis C came into the picture. Ms Foreman said there was a low risk of sexual transmission of hepatitis C, but it was possible.

Ms Foreman said that the social work department was not routinely involved in hepatitis C test results. Ms Foreman said there was no consensus in the hospital on the issue of whether or not those with hepatitis C should be routinely referred to social workers for counselling. Ms Foreman agreed that a number of patients with hepatitis C will become seriously ill.

Ms Foreman agreed that no routine system of referral with respect of hepatitis C infections, was in place for social work services. With respect to the evidence of Vincent, Ms Foreman agreed that she knew Vincent well. She agreed that patients did not feel supported at the time. Ms Foreman said, "We were social workers, not HIV counsellors. In this respect, patient's may not have felt counselled". After having talked to the social worker, Ms Foreman said that many of those with HIV may not have remembered being counselled, however statistics showed that they were counselled, but because of the informal nature of the counselling they did not feel counselled.

Ms Foreman was then cross-examined by Mr Ian Brennan on behalf of the Department of Health. Mr Brennan referred Ms Foreman to the series of correspondence for Mr Dunbar seeking the support of the Department of Health for the provision of social work services.

Ms Foreman was also cross-examined on behalf of St. James's Hospital by her own Counsel, Ms Deirdre Murphy S.C. Ms Murphy put it to Ms Foreman that the type of counselling available now was not available in the 1980's, and that the counselling available in the 1980's would have to be judged in the context in which it was delivered. Ms Murphy put it to Ms Foreman that there was no demand for counselling per se from either haemophilia patients or the I.H.S. in the mid 1980's, in particular from 1984 until 1987. Ms Foreman agreed with this suggestion but said that people obviously wanted support and information.

Ms Murphy put it to Ms Foreman that the cultural attitude abroad in Ireland at the time, would have looked upon attending counselling as being somehow "wimpish". Ms Foreman said this may be true, but people still needed support in whatever form that was going to be most helpful.

Mr McCann, for the Tribunal, then examined Sister Eadaoin O'Shea, Haemophilia Sister at the National Haemophilia Treatment Centre in St. James' Hospital. Sister O'Shea took over as haemophilia sister on 17th October 1988. She succeeded Sister Margaret King, who left the position in May 1988, therefore from May to October 1988 there was no sister in charge at the National Haemophilia Treatment Centre.

Sister O'Shea outlined the situation which pertained upon her taking up her position at St. James's Hospital. She said there had been four deaths from haemophilia HIV related illness prior to her arrival. She said that those with severe haemophilia were reviewed twice a year. People with mild haemophilia were reviewed once a year. Sister O'Shea said that the National Haemophilia Centre, upon her arrival, consisted of one room. The haemophilia sister attended to secretarial and administrative duties in addition to her nursing duties.  She said in 1992 an upgrade occurred, with three rooms being put at the disposal of the National Haemophilia Treatment Centre.

Sister O'Shea said that those with haemophilia wanted to be treated in the haemophilia unit.  She said a happy relationship existed between the nurses and the patients on the unit.  Sister O'Shea said her duties included caring for people with haemophilia, assessing those in need of social work, dealing with oncology duties and coping the package of emotions which existed on top of the illnesses.  Patients would be referred to psychological and psychiatric services as required.  A reluctance to avail of these services existed, however, as they involved an invasion of privacy.

Sister O'Shea said a fair degree of her time was taken up with crisis management and advocating the needs of people with haemophilia within the hospital.  She said that the facilities on Top Floor Hospital 1 were not suitable for long term illness patients.  Sister O'Shea said she related to the Irish Haemophilia Society, both formally and informally.  There was a constant contact and sharing of knowledge with the Society.

In her first year at the National Haemophilia Treatment Centre, Sister O'Shea said that she and the patients were on a learning curve with each other.  She said it was not particularly busy with respect to HIV infections, with 1989 to 1993 being the peak years for this epidemic.

Sister O'Shea said that, with the death of a particular patient in 1989, the threat of HIV came home to many of the younger people who had been infected with the virus.  She said this young man had been particularly popular and many attended his funeral, and with his death the reality of HIV came home to many.  This was heightened in 1991 when the compensation scheme came into being.  Sister O'Shea said from 1989 onwards, fear was the predominant emotion.

Sister O'Shea said that the staffing at the NHTC compared poorly with that available at the Royal Free Hospital in London.

Mr McCann directed Sr O'Shea to her Statement where she noted that a negative attitude prevailed towards counselling. She also addressed the issue of denial concerning HIV infection. She said some people with Haemophilia or their parents and families showed a preference for avoiding the emotional impact of being HIV positive. Sr O'Shea agreed that a negative attitude prevailed. She said "as Deirdre Murphy pointed out, because Haemophilia was a male disorder, counselling was actually sneered at".

Sr O'Shea said she had a clear recollection of an incident which occurred when she was dealing with the mother of a HIV positive teenager. Sr O'Shea said she sat down with this lady in order to encourage her to avail of the social work services available at the clinic. At the same time across the corridor, within earshot, there were two very well known members of the Society making loud jokes about counselling. They were saying "are you going to counselling today".

Sr O'Shea said that despite the awful conditions they were working in, the personnel were there and the expertise was there but, things were militating against us.

Mr McCann asked Sr O'Shea would this attitude have been the product of a young male culture, and was it something which changed with the realisation of the dangers of HIV? Sr O'Shea said it did not change over time, what did change was the desire for information and practical help and support. Sr O'Shea said she was engaged at this time both formally and informally with the I.H.S. and was in close contact with them throughout. Sr O'Shea said over time the resourcefulness and skill of the Society improved, enabling it to assist many of its Members.

Sr O'Shea said that many of the patients who died did so at St. James's Hospital. Sr O'Shea said that in the terminal phase of their illness, the acute matters had passed. Her responsibility was to make sure that the patient was given his treatment and she would keep in contact with the families of those infected and with the I.H.S.

Sr O'Shea described the infection control procedures with respect to body bags as intrusive on the family grief, but she said the NHTC did its best to minimise the effects of these necessary precautions.

With respect to testing partners Sr O'Shea said she treated up to 84 patients with HIV and tested 10 partners. She said many did not want to be tested. Testing would sometimes be requested in the event of pregnancy or where a partner was very ill and sought the solace of knowing that his wife or partner was not infected. In such circumstances a test may take place.

With regards to infection with Hepatitis C Sr O'Shea said testing became generally available in 1991. She said that NANB hepatitis was always known to be a risk in using blood products. This information was contained on the product insert which accompanied each treatment. She said NANB was known to be in the liver of those with Haemophilia. She said that preliminary testing was affected by false negatives and false positives. She said that prior to testing, NANB was regarded as a benign condition and a curiosity, rather than a life threatening disease.

Sr O'Shea described the arrival of Dr Anne Tobin. She said Dr Tobin first came to the out-patients in 1992 and went through the charts of patients at the clinics. She pulled out those she wanted and they were requested to attend for testing. Sr O'Shea said Hepatitis C did not have the same import as HIV. She said it was not as traumatic as being told of HIV positivity and patients were told of the long-term health prospects. Sr O'Shea said she would assess the Hepatitis C positive patients and it was not apparent to her that they were psychologically devastated. Sr O'Shea said the impact of Hepatitis C was not a priority, the priority was dealing with HIV which was causing deaths at the time. She said that information was very quickly available with respect to Hepatitis C and was available from the centre. Sr O'Shea said that the perception of Hepatitis C changed in 1994 with the publicity surrounding the Anti-D infections.

Mr McCann referred Sr O'Shea to the case of "Albert" who gave evidence that he was not aware of his Hepatitis C positive status until 1999. Sr O'Shea said she was familiar with this case. The medical records note that in March 1993 Sr O'Shea informed "Albert" that he was Hepatitis C positive. Sr O'Shea said it was not normal practice for her to inform patients of their Hepatitis C status. She said the Doctor would usually inform patients. Sr O'Shea said she would have noted informing Albert of his HCV status on the medical chart and followed up with an appointment with a Doctor. Sr O'Shea said that although the man was told on the day, he may not have understood it. She said she was vaccinating him for Hepatitis A on that day and he may have become confused as to the vaccination for Hepatitis A and the information that he was Hepatitis C positive.

Sr O'Shea was cross-examined by Mr Martin Giblin S.C., for the Irish Haemophilia Society. Sr O'Shea told Mr Giblin that she would administer Factor VIII and Factor IX as instructed by the medical doctors. She agreed that such doctors would be on rotation as part of their training and would come and go every six months. Meanwhile she would continue to nurse patients on a continuous basis. Sr O'Shea agreed that apart from her it was not within the remit of the Nurses to administer blood products. She said that Nurses would have a broad knowledge of Haemophilia and would be aware of the risk of inhibitors.

Sr O'Shea told Mr Giblin S.C., that in November 1989 she got assistance in the shape of haemophilia night cover. With regards to assessing patients for social work needs. Sr O'Shea said that such assessments were not always conducted on a formal basis. Sr O'Shea said that while the facilities at St. James's may have been inadequate, the counselling on offer was not inadequate and she said no amount of counselling would bridge the pain and suffering encountered by those who were infected with HIV.

Mr Giblin asked Sr O'Shea would patients sometimes cope with bad news by employing black humour. She agreed that this may be the case. With reference to her evidence that two members of the Society joked while she was dealing with a patient, Mr Giblin put it to Sr O'Shea that this may have been an example of black humour. St O'Shea said at the time she was dealing with a woman who was in her perception traumatised and in need of help. She felt at the time it was an insensitive remark because it was said out loud, it was audible and it actually portrayed the attitude towards counselling at the time. Sr O'Shea said her idea of mentioning this incident, which was not included in her Statement to the Tribunal, was not to be provocative, it was to explain how the healthcare professionals and members of the Haemophilia Society knew that counselling would in theory help but, actually having the courage to take it up and deal with these issues was a very different matter. Sr O'Shea said she was upset by the incident at the time.

With respect to dealing with Hepatitis C Sr O'Shea said Hepatitis C was not considered to be as traumatic as HIV. She said pre and post-test counselling was not mandatory for Hepatitis C, as is the case today. She said knowledge about Hepatitis C was evolving. Mr Giblin asked Sr O'Shea when did she become aware of the seriousness of Hepatitis C? She said she was caring for AIDS patients and she became aware of the dangers of Hepatitis C when the first patient died from the effects of HCV in 1993. Sr O'Shea said that she was not as alarmed then as she was now about Hepatitis C.

In 1992 the information at her disposal was that a small percentage of those infected with Hepatitis C would get liver disease. Sr O'Shea said that the management of Hepatitis C had been taken over by the Gastroentrology Unit and those testing positive for Hepatitis C were now referred to the Hepatology Centre in St. James's Hospital.

With respect to the treatment of the patient “Luke” in February 1990, Sr O’Shea said that the intricacies of product availability were not high on the education input of nurses at that time. However, she agreed that even the most junior nurse would know the difference between Factor VIII and Factor IX.

Sr O’Shea was then examined by Ms Deirdre Murphy, counsel for St. James’s Hospital.

Ms Murphy asked Sr O’Shea to characterise the response of the hospital and its various units and personnel to the HIV crisis. Sr O’Shea said that the staff at St. James’s Hospital were overwhelmed with sympathy for what had happened to the people with Haemophilia. She said the introduction of concentrates had revolutionised the lives of people with Haemophilia but tragically the events turned. Sr O’Shea said that everyone from domestics right up to the consultants gave of their professionalism and their humanity in responding to the whole tragedy which had affected people with haemophilia. This was manifest in the development of multi-disciplinary teams. With respect to attending funerals Sr O’Shea said that she could not get to all of the funerals of all those who unfortunately died but, she would try to maintain contact with families. Sr O’Shea said she did not get to all the funerals because she had lost too many.

Mr Paul Lynam, Blood Transfusion Unit in St. James’s Hospital was then examined by Mr John Finlay S.C., for the Tribunal.