Witness Name: Brian O'Mahony
Statement No.: WITN7418001
Exhibits: WITN7418002-WITN7418015
Date: 18 October 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

BRIAN O'MAHONY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 April 2022

I, Brian O'Mahony, will say as follows: -

Section 1: Introduction

1. Please set out your name, address, date of birth and any professional qualifications relevant to the duties you discharged as President of the Irish Haemophilia Society.

1. My name is Brian O Mahony, my address is number GRO-C GRO-C Ireland and my date of birth is GRO-C 1958. I qualified as a medical laboratory scientist in 1978 and in 1982 became a fellow of the Institute of Biomedical Sciences in the UK and a fellow of the Academy of Clinical Science and Laboratory Medicine in Ireland.

2. Please outline your employment history including the various roles and responsibilities that you have held throughout your career, as well as the dates of these positions.

2. I was employed as a medical laboratory scientist in the Children's Hospital, Crumlin, Dublin in Ireland from 1978 to 1982 and as a senior medical laboratory scientist from 1982 to 1994. In 1994 I took secondment from this post to take up the post of President of the World Federation of Haemophilia [hereinafter referred to as the WFH]. I was President of the WFH. from 1994 to 2004 and subsequently President of the European Haemophilia Consortium [hereinafter referred to as the EHC] from 2011 to 2019. I have severe haemophilia B and an extensive family history of haemophilia B. I was co-opted to the Board of the Irish Haemophilia Society in 1982 and have been on the Board since that time with the exception of the period 2003 to 2004. I was elected as Chairman of the Society in 1987 and re-elected annually until 2003. I stepped down from the Board in 2003. I was appointed as Chief Executive and ex-officio board member in 2006 and hold that position to date.

3. Please set out your membership (past and present) of, or your involvement (past or present) with, any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership, the nature of your involvement and any responsibilities you had.

3. I was Vice President of the WFH from 1992 to 1994 and President from 1994 to 2004. I am a member of the World Federation of Haemophilia Coagulation Product Safety Supply and Availability Committee from 2002 to the present day. I was a member of the European Haemophilia Consortium Steering Committee from 2006 to 2019 and President of the EHC from 2011 to 2019. I have been a member of the EHC Medical and Scientific Advisory Group from 2019 to present. In Ireland I have been a member of the statutory National Haemophilia Council from 2004 to date and a member and vice-Chairman of the Haemophilia Product Selection and Monitoring Advisory Board from 2002 to date. I have been a member of the Board of the Irish Blood Transfusion Service from 2014 to date

and an observer at their Medical and Scientific advisory group since 2014. I am Chairman of their Research Committee since 2021. I have been a member of the statutory Hepatitis C Consultative Council since 2012. I was a member of the Hepatitis C Department of Health Review Group in 2014 and involved in the procurement committee for Hepatitis C medications in 2016.

4. Please provide details of any business or private interests you have or have had which are relevant to the Inquiry's Terms of Reference.

4. I have been a consultant or speaker for Biomarin, Freeline and Uniqure who are developing haemophilia Gene Therapies.

5. Please confirm whether you have provided evidence to, or have been involved in, any other inquiries 1 ; investigations; or criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C.

5. At the Institute of Medicine Inquiry in the United states in 1994, I gave evidence on the response of various Governments to the infection of people with haemophilia with HIV. This primarily related to their response on HIV compensation. In 1995, while in Canada on WFH business, I met with some investigators from the Royal Canadian Mounted Police to give them some information that they requested for their forthcoming Inquiry. I was not asked to give evidence at the Krever Inquiry in Canada. In 1997 I was involved in the negotiation on the Terms of Reference for the Finlay Tribunal of Inquiry in Ireland. From 1997 to 1999 I was involved in the negotiation of the Terms of Reference for the Lindsey Tribunal of Inquiry into the infection of people with haemophilia, with HIV and /or Hepatitis C and related matters. I was involved with our legal team on a constant basis during the Inquiry and in preparing and reviewing documentation prior to and during the Inquiry. I also gave evidence to the Lindsey Inquiry on two separate occasions; with one statement relating to self-sufficiency [WITN7418002] and my second statement relating to the response of the Society [WITN7418003]. In 2007 I gave evidence to the non-statutory Archer Inquiry in the United Kingdom. From 1989 to 1991, I was involved in assisting our

members in relation to potential litigation against the State in relation to HIV and Hepatitis C infection. The Irish Haemophilia Society put in place a legal team for our members to progress their compensation claims and we had also undertaken the possibility to fund a test case. In 1989 we retained lawyers in the USA to assist members in achieving a settlement against some of the United States pharmaceutical companies in relation to their infection with HIV. Members who participated received a settlement in 2001.

Section 2: The work of the Irish Haemophilia Society

6. What support and assistance has the Irish Haemophilia Society provided to those infected with HIV and hepatitis over the years.

6. AIDS first became an issue for the Irish Haemophilia Society in 1983. I raised this at a meeting of the board of the Irish Haemophilia Society as a potential concern in March 1983, having read an article in a laboratory magazine. In May of 1983 there were articles in the UK media about hospitals using "killer blood". I organised a meeting that month with Sean Hanratty, the chief scientist in the Irish Blood Transfusion Service Board and expressed to him my concern about the use of imported blood products and the potential risk of AIDS and Hepatitis from this importation. He saw no reason why the needs of people with haemophilia in Ireland could not be met totally by products manufactured from Irish plasma, and he stated this should decrease the risk of AIDS, Hepatitis and other blood borne viruses which may surface. He recommended we discuss this with the treating consultant. This push towards self-sufficiency was an ongoing topic for the next three-years. In May 1983, we were also in communication with the U.K. Haemophilia Society in relation to our concerns about AIDS and we arranged for the treating consultant in Dublin to write an article on AIDS for our newsletter. We also wrote to the treating consultant expressing our concerns about AIDS and the lack of self-sufficiency for haemophilia products in Ireland. Throughout the rest of 1983 we sought further information from our treating consultant and published this in our newsletters. That year we funded to the tune of £8,000.00 research into the immune system of people with haemophilia due to our concern about AIDS. This was at a time when our annual expenditure was around £6,000

7. In his replies to us, the treating consultant pointed out that all blood products could potentially cause AIDS or non A non B Hepatitis and that the risk of bleeding was much greater than the risk from any viral infection. We had also sought details of the products being used and the costs of these products from the Blood Transfusion Service Board but they refused to give us this information and suggested that they would discuss this with the treating consultant and we could discuss this subsequently with him. During 1983 we were becoming increasingly concerned about the risk of AIDS. We wanted Irish plasma based products as soon as possible but this was moving very slowly. We were concerned that we needed to get information out to our members and therefore we had the treating consultant write an article for our newsletter in September. It is worth bearing in mind that, at that time, the Irish Haemophilia Society was a very small voluntary organisation with very limited resources. The Organisation had no office or permanent address until 1987; and no staff member until we had a part-time secretary in 1987. There were no full-time staff until 1989. The Committee consisted of parents and people with haemophilia who were not professionals and their activity for the Society was undertaken in their free time from work, family and other commitments. There was no funding available from the Department of Health or the Health Service and the funding being used had to be raised through fundraising.

8. The Society typically produced one or two newsletters each year. There was also a significant amount of contact between Board members and members by phone. There was a strong culture of members attending conferences such as our Annual General Meeting, so we would try to find good speakers on topics such as AIDS who could give useful information. HIV and AIDS were covered as topics at our Annual General Conference from 1984 onwards. In 1984 there was a talk on the immune system and AIDS at the Annual General Meeting. In 1985 there was a lecture on AIDS and haemophilia and also a separate workshop on AIDS. This included a workshop on the impact of AIDS on the family and sexual transmission of AIDS. In 1986 there was a talk at the Annual General Meeting about the production of Factor VIII concentrates and self-sufficiency. In 1986 we also had a special one-day seminar on AIDS and counselling. In 1987 there was

a talk on treatment of HIV infection and in 1988 talks on living with haemophilia and HIV and sexual transmission of HIV. From 1984 to 1986, we continued to lobby for the production of Factor concentrates from Irish plasma and an increased level of self-sufficiency.

9. In December 1984 we had the first diagnosis of AIDS in an Irish person with haemophilia. The indication from the treating consultant at that time was that this may be the only case of AIDS we would see in a person with haemophilia and that perhaps only 1% of those who were HIV positive would go on to develop AIDS. Following this first case of AIDS in a person with haemophilia, the Society produced a special booklet on haemophilia because of the lack of public knowledge on haemophilia. In the first week of January 1985 the Society also produced a special update for members following this case and we also had the treating consultant send a letter to patients at the same time. The treatment centres also started the use of imported heat-treated factor VIII and Factor IX concentrates from January 1985. In March 1985 the then Chairman of the Society attended a lecture by Dr. Peter Jones, Director of the Newcastle Haemophilia Reference Center, organized by the U.K. Haemophilia Society. He returned with a copy of a book published by Dr. Jones called "AIDS and the blood" which mentioned the potential risk of sexual transmission of the AIDS virus and the consequent danger of partners being infected, which could also lead to the infection of future children born to the couple. There was also an article in June 1985 in the UK Haemophilia Society bulletin authored by Dr. Charles Forbes that further highlighted the risk of sexual transmission with the potential for HTLV III infection in 1% to 2% of wives. Dr. Forbes recommended the use of barrier protection in the form of condoms. Just after that time our chief consultant took a six-month sabbatical and was replaced by a series of locums. I had contacted the locum Consultant to ensure that members were given their HTLV III antibody results without delay and offered condoms to protect against HIV transmission to their wives or partners. The hospital could not provide condoms so the Society agreed to provide these. I purchased the condoms and attended outside the weekly clinic for a couple of months in 1985 and distributed condoms to members as they were leaving. We continued supplying condoms until the centre provided them from 1987. When partners of members were

tested for HIV in 1991, following the initial HIV settlement, none were HIV positive.

10. During the course of 1986 we had a seminar and workshop on AIDS, we increased our counselling and support to members including the organization of peer support meetings at one of the hospitals. We met with groups representing gay people to encourage them not to donate blood and we encouraged plasmapheresis donations from the public. We also produced an information booklet - Haemophilia The Basic Facts - to counter a lot of public misconception about the condition. In early 1987 I produced a fact sheet for the Society, which was distributed to members in relation to AIDS. The clinical impact of AIDS on our population was starting to become apparent and members were being encouraged to take a high protein diet and to visit the hospital more frequently. The Society was very concerned about the financial burden on members and also their lack of access to life or mortgage insurance. At this time, there was a lot of fear, anxiety and ignorance about AIDS in the public domain. Board members or members infected with HIV did not wish to speak publicly about HIV or AIDS and there was a reluctance to associate haemophilia with AIDS. This was also the policy at that time of the WFH. It fell to me to speak publicly on this issue when required on behalf of the Society and I became de-facto spokesman on these issues. I was fortunate to escape HIV infection but many of my friends and colleagues with haemophilia were not and I felt a responsibility to put their case in public if required.

11. We met with a junior Minister and corresponded with the Minister for Health in relation to the provision of insurance for people with haemophilia. In May of 1987, together with Dr. Barry Harrington who was a dentist involved in the haemophilia service, I carried out a survey of members who had been infected with HIV. This survey was sent out by the National Treatment Centre, as we did not have access to the list of people who had been infected. We received 58 responses to the survey which highlighted the burden on our members.

12. In October 1987 I became Chairman of the Irish Haemophilia Society and I made helping our members with HIV and AIDS our top priority. In April 1988, using the results of the survey, we put together a submission to the Minister for Health called “AIDS, Haemophilia and the Government” [WITN7418004]. At that time 106 people with haemophilia had been infected with HIV, 9 had developed AIDS and 4 had died. The submission talked about the financial burden in relation to the inability to obtain life insurance or mortgage insurance, dealing with the financial costs of HIV infection, the social burden and the personal burden. It outlined the need for Government action. We proposed ways in which the Government could deal with all of these issues. We realised that it could be difficult for the Government at that time to put in place life insurance and mortgage insurance and to deal with some of the provisions due to lack of mechanisms to do so. As an alternative, we suggested that a trust fund could be set up which could deal with these issues. The Department of Health did not respond in any substantive way to this survey and set of proposals and therefore in late 1988 we decided to launch a public recompense campaign using the media and working with politicians to try to achieve recompense and assistance for our members. The UK Haemophilia Society were undertaking a similar campaign at the time and we shared information and campaign materials on some occasions. This led to the establishment of the Haemophilia HIV Trust in 1989 which I will describe in a later section.

13. In terms of staffing, we were then able to employ a part-time secretary, two days per week, from 1987. In 1988 we applied to the Health Service for funding for an AIDS coordinator and funding was granted in 1989 after our successful recompense campaign. During the campaign in early 1989 we were offered funding from the Government for counselling which we did not take at the time because it was offered as a way of ending the campaign. However, when the campaign was subsequently successful in achieving recompense, we then went back to the health service and successfully sought this funding and therefore we were able to employ a full-time nurse counsellor from 1989. The recompense campaign consumed most of our time and resources for the first half of 1989. During the course of 1989 and 1990 we also worked with members and with the legal team whom we had put together to assist members in taking litigation

against the State. We also met with lawyers with a view to assisting our members to potentially take legal action against pharmaceutical companies in the United States.

14. By 1990 therefore, we had successfully achieved recompense for our members via the Haemophilia HIV Trust, we were helping coordinate possible legal actions for our members in both Ireland and against US Pharmaceutical companies and the Society had our first full- time staff. The dedication of our full-time staff became crucial in the coming years as more and more members became ill from HIV or AIDS. From 1990 to 1999 the Society provided a critical illness service whereby our staff led by the nurse counsellor and the AIDS coordinator would visit people with haemophilia who had HIV at home, put in place services for them at home and if necessary nurse them at home. This enabled several members to die at home with dignity. We also put in place special arrangements with an empathetic firm of funeral directors who dealt with our members very sensitively in this situation especially in the context of the requirement for body bags.

15. Hepatitis C became an issue from 1989 at the same time as we were starting to see very serious clinical consequences from the HIV infection. We organised a lecture on replacement therapy at our annual conference in 1989 which included a discussion on non-A, non-B Hepatitis and in 1990 the guest speaker at our annual conference was Professor Preston from the U.K. who spoke on Hepatitis C. In 1990 and 1991 we worked with the centres to ensure that members got their Hepatitis C blood test results as expeditiously as possible and in 1992 Hepatitis C was once again one of the main topics at our annual conference. In 1993 we met with the hepatologist in the main adult hospital to discuss the first Hepatitis C treatments which were available. We were concerned at that time because there was a charge for these treatments and we believed they should be free of charge for our members and we advocated on this to the Department of Health. This advocacy was successful. At a meeting in September 1993 with the Department of Health we also raised the issue of Hepatitis C compensation for the first time. In 1994 we published a special booklet on Hepatitis C and we organised specific conferences on Hepatitis C for our members in both Dublin

and Cork. Also, in 1992 we published our first Blood Product Policy. We were acutely aware of the devastation that blood borne viruses had caused in our community and we wanted to be proactive in setting out our aims for the future for achieving safe and efficacious treatment for all with bleeding disorders. The Policy was our method of setting out our objectives and goals in this regard with a view to advocating for them. The Policy aims were broadly achieved and by 1996 we published a further updated Blood Product Policy which included discussion of areas such as provision of prophylaxis and provision of recombinant synthetic products for all with haemophilia. The Policies were also meant to assist with the fact that we did not want decisions made in the future about access to replacement therapy without input from the Society.

16. From 1990 onwards we organized annual conferences and events for members with HIV and or Hepatitis C. In the early years, when there were no successful therapies available for HIV, these were often holistic weekends where members would be offered a range of alternative therapies to help them cope with the psychological impact. In later years they became focused on treatment options, on education, on peer support and on information. The annual conferences for members with HIV or Hepatitis C continued until 2017 and following the successful treatment of our community for Hepatitis C, they have now been superseded by conferences on ageing and haemophilia, which deal with the same cohort of members and some additional members.

17. During the course of the 1990s our work and support for members with HIV and Hepatitis C continued. In almost all cases, those with HIV were also infected with Hepatitis C. We had a separate cohort of people infected with Hepatitis C who were not infected with HIV. This included a significant number of people with mild haemophilia who had little contact with the Society prior to their infection. The work included advocating for the availability of treatment right from the first treatments for Hepatitis C in 1994 to the later generations of treatment involving Interferon and Ribavirin; then the triple therapies adding in Boceprevir or Telaprevir and finally the direct acting antivirals. In the case of access to the triple therapies and the direct acting antivirals we advocated successfully with Health Ministers, James Reilly and Leo Varadkar respectively, for prioritised

access for people with haemophilia. This advocacy included provision of information and data, meetings with officials and several meetings with the Ministers involved. We organised education sessions on HIV and Hepatitis C at our major conferences and also separate conferences for members with HIV and Hepatitis C. We published a specific newsletter called Positive News, we organized group meetings and peer support networks. We liaised with the hepatology centres to ensure that people with haemophilia were contacted in relation to treatments.

18. When members were going through Hepatitis C treatments we would meet them at the hospital on a weekly basis. Typically, members going through these harsh often yearlong treatment regimes would be seen once a week in the Hepatology Centre. We would meet them adjacent to the Centre to give them support and information and to help them support each other. This peer support was vital. We also worked closely with the infectious disease consultants who were treating our members for HIV and Hepatitis C co-infection. We advocated successfully for specific co-infection clinics for people with haemophilia to be held at the Haemophilia Centre. We liaised with the liver transplant team in Dublin and also accompanied members to London, if requested, for liver transplant assessment for co-infection. We worked with the clinical team at the National Adult Centre on the funding and design of a purpose-built haemophilia and hepatology inpatient, 14-bed unit, which opened in 2013. We worked with the Hepatitis C Consultative Council on a series of annual information days on Hepatitis C and the Society also organised separate information days on Hepatitis C treatments on several occasions. Several of the Hepatitis C treatment regimes required a year of therapy with very significant and debilitating side-effects.

19. We provided a lot of individual and group support to members and their partners. During this time, my colleague and I were in direct contact with the vast majority of people with Hepatitis C on an ongoing basis. We internally monitored the number of people with haemophilia who were availing of treatment and the number who still required treatment, and we encouraged them to seek information and to consider treatment at the earliest opportunity. We produced several specific newsletters dedicated to Hepatitis C therapies and managing

Hepatitis C, including how to cope with treatment. In 2016, following several meetings with the then Health Minister Varadkar, we received assurance that all of our members would be offered the latest treatment by 2017. This target was exceeded and we were able to announce the effective eradication of Hepatitis C in our members by the end of 2016. Following completion of a course of treatment for Hepatitis C we convened a facilitated full day discussion with a group of people with haemophilia and their partners and sought feedback on our services and support to identify what strategies had worked best. We then commissioned a team at Dublin City University to look at our communication strategy to see what elements had been successful and therefore would be most useful to use with future therapies or situations.

20. In addition, we advocated for and worked with our legal team and other advisors on implementing legislation for the establishment of the Hepatitis C compensation tribunal, the provisions of the Health Amendment Act [WITN7418005] and the amendments to the compensation tribunal granting additional HIV compensation. This was in addition to very lengthy negotiations lasting in excess of two years on the Terms of Reference for the Lindsay Tribunal. Following the report of the Lindsay Tribunal, we worked on the life, mortgage and travel insurance proposals and legislation, the establishment of the National Haemophilia Council, the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) and the taxation concessions for members. Some of these are detailed in later sections of the statement.

21. The National Haemophilia Council [WITN7418006] is a statutory body, which was established following the Lindsay Tribunal report. It brings together the Irish Haemophilia Society, the Directors of the four Haemophilia treatment centres, the Department of Health, the Health Service Executive and some additional experts. The Council recommends Policy to the Minister of Health and the Health Service Executive on Haemophilia and bleeding disorders. The Council reports annually to the Minister and organises peer reviewed external audits of the treatment centres on a regular basis. The Council has been an excellent vehicle for reaching consensus on priorities nationally and for improvement in access to treatment and care for people with Haemophilia and bleeding disorders.

22. The HPSMAB. was established on a non-statutory basis in 2002. It includes the Irish Haemophilia Society who have two representatives and one external advisor as required, the Directors of the three comprehensive treatment centres, the Department of Health, an expert nurse, and the Contract holder. The HPSMAB. have presided over the procurement process for Haemophilia and bleeding disorders since 2002. In that time, a total of 27 tenders have been carried out. The safest and most efficacious treatments have always been purchased and this is also being done on a very cost-effective basis. As the process became more competitive potential savings were channelled into buying better products and more products. Some savings were also re-invested in comprehensive care infrastructure including a new National Coagulation Centre, a new treatment centre in Cork and additional equipment such as specific dental suites. The per capita use of Factor VIII in Ireland increased from 3.7 IU per capita in 2002 to the equivalent of 14 IU per capita today. Ireland was the first country in the world to treat all people with severe Haemophilia A and B with extended half-life factor concentrates from 2017 and 2018. In 2019 the first licenced subcutaneous treatment for Haemophilia A was introduced as a treatment option for every individual with severe Haemophilia A. The Irish Haemophilia Society carried out a retrospective analysis of the work of the HPSMAB. from 2002 to 2018 and found that this process had resulted in significant savings to the country, compared to the previous procurement method, despite the very significant increase in quality and quantity of medications procured due to the efficiency and effectiveness of the process and the knowledge of the Board on the Haemophilia pipeline allowing for optimal timing of procurement cycles to optimize innovation and competition. The continuing role of the Irish Haemophilia Society on the HPSMAB. is one of our most important contributions to continuing improvement in Haemophilia care.

Section 3: Relationship with the UK Haemophilia Society ("UKHSOC")

7. What was the relationship between the Irish Haemophilia Society and the UKHSOC? How frequently did the two societies meet?

23. The Irish Haemophilia Society and the UK Haemophilia Society had a friendly relationship going back to the 1970s and early 1980s. Several members of the Irish Haemophilia Society would also have been members of the UK Haemophilia Society at that time. The UK Society at that time had an office and a full-time staff and were much better resourced than the Irish Haemophilia Society. We were close enough in geographical terms and identity to develop an information affiliation with the UK Society. There were no formal relationships but contacts certainly started in 1983. In May of 1983 the then Honorary Secretary of the Irish Society wrote to David Watters, General Secretary of the UK Haemophilia Society, expressing our concern in relation to AIDS and asking him what their current advice was. Mr. Watters replied with a copy of the advice which they had received from the Chairman of their own medical advisory panel setting out their view at that time. There would have been sporadic contact between the organisations in the following years.

24. On several occasions we invited representatives from the UK Society to our annual conference and the Irish society usually received an invitation to the UK Haemophilia Society residential weekends in the late 1980s and early 1990s. At those times both organisations were dealing with AIDS and the impact of AIDS and HIV on our members. It was also common practice for the Irish Society to invite doctors from the UK to present at some of our conferences as they had a greater number of experienced centre directors. The UK Haemophilia Center Directors Organisation (UKHCDO.) also held their annual meeting in Dublin in 1988 and the Irish Center Directors were affiliated with the UKHCDO. During the 1980s the Irish Society also met on an annual basis for an afternoon with the Northern Ireland group of the UK Haemophilia Society. These meetings discussed our general activities and there was also a social element. In 1988 and 1989, as the Irish Society sought recompense, which led to the establishment of the H.H.T. in Ireland, the UK Society were involved in a similar campaign which led to the establishment of the Macfarlane Trust. We shared information and materials and I recall discussing our "AIDS, Haemophilia and the Government" submission with David Watters.

25. During our subsequent advocacy campaign for recompense David Watters and a person with HIV from the UK attended one of our public meetings and spoke. This was in the period just after the Macfarlane Trust had been established in the UK. This was very helpful at the time. In 1991 when we were pursuing compensation, again this coincided with the UK compensation campaign which ultimately led to payments from the John Major led government. During the course of our advocacy campaign we again invited David Watters to attend one of our meetings and outline the response of the UK Government to their request for compensation. In the course of the late 1980s and early 1990s, individual people with haemophilia from the Board of the UK Society attended some of our conferences and we would also meet them when we attended their UK Chairman's weekend conferences. When I was elected as Vice-President of the World Federation of Haemophilia in 1992, I got to know Reverend Alan Tanner who was then the Chairperson of the WFH. We worked together on occasion until he retired from the Board in 1996. He was a very empathetic and caring person. I had a great deal of appreciation for the people I knew from the UK Haemophilia Society at that time. They were helpful to us at a time when we were under-resourced and starting to advocate seriously. We would also meet with representatives from the UK Society at meetings of the EHC or the WFH. We have always had friendly relations with the UK Society but there was never a formal working relationship. Haemophilia is a very strong global community and many of the organizations learn from each other to collaborate on and share publications and ideas. This is not a competitive business.

8. What assistance did you give the UKHSOC firstly in preparing for the Archer Inquiry and secondly on their work campaigning for compensation for those infected with HCV via infected blood?

26. I provided assistance and support whenever possible to the UK Society during their preparation for the Archer Inquiry. I would have provided details of the Irish Inquiry procedures and recommendations, how the Inquiry heard evidence from witnesses and members of our community including the importance of personal testimony. We would have discussed the Irish compensation scheme for Hepatitis C and the subsequent improved compensation for people with HIV, our work on

life, mortgage and travel insurance, the funding for the Society from our Government, the provisions of free healthcare in Ireland through the Health Amendment Act of 1996. I attended more than one meeting in the UK with the Society and other campaigners. I assisted by chairing one meeting, which brought together the Society and several of the campaign groups in an effort to seek consensus on what recommendations they wanted for the future. The issues had been ignored or unaddressed for so long by the UK Government that it was difficult for the community to agree on an appropriate response.

27. The second submission of the UK Society to the Archer Inquiry outlining their recommendations for the future include six areas where I would have discussed with the Society and the other campaign groups what we have been able to achieve, how we achieved this and my views on what they should be seeking. These areas included the establishment of a National Haemophilia Committee on a statutory basis to include key doctors and the Haemophilia Society, formal participation of the Haemophilia Society in the tender or procurement process for factor concentrates, access to free and comprehensive healthcare, access to life insurance, mortgage insurance and travel insurance, government funding for the Haemophilia Society and proper compensation. In the course of their subsequent campaign work seeking Hepatitis C compensation, I had no formal involvement but had some discussions with Society representatives on a few occasions, usually on the margins of EHC meetings.

Section 4: The Haemophilia HIV Trust

9. Please describe your understanding of the circumstances which led to the establishment of The Haemophilia HIV Trust ('the HHT'), and your involvement in the same.

28. In 1987 I was elected as Chairman of the Irish Haemophilia Society and helping our members with HIV was my top priority. In order to identify the real requirements of our members with HIV, together with Dr.Barry Harrington who was the dentist treating our members at the National Haemophilia Adult Centre

and a long-time Board member of the Society later from the 1990s, we compiled a detailed survey asking questions about their financial, healthcare and personal needs.

29. At that time we had just over 100 people with Haemophilia who had been infected with HIV. It was not possible for the Society to send out this survey due to confidentiality and as we did not have the identity of all those who have been infected with HIV the survey was sent out through the National Haemophilia Treatment Centre to people with HIV at the beginning of 1988. Of the 70 surveys sent out, 58 were returned. The survey covered areas including marital status, number of dependants, employment status, income levels, availability of life and mortgage insurance and social welfare benefits. When we analysed the results of the surveys received it was clear that members had concerns in relation to provision of life insurance and mortgage protection insurance, additional costs relating to HIV infection, including laundry costs, dietary costs, heating costs, telephone costs and travelling costs to hospitals. In addition, we had obtained a greater appreciation of the social family and personal burdens experienced by our members. Dr. Harrington and I, based on these results, formulated the submission for the Government entitled "AIDS, Haemophilia and the Government" [WITN7418004]. We believed that as our members had become infected through treatment provided by the State, the Government had a moral obligation to assist our members in these very difficult circumstances. We set out detailed proposals in relation to life insurance, mortgage protection insurance and amendments to benefits available under the social welfare system, to take account of their specific needs. The submission set out the need for a high protein diet, food supplements, electricity allowances and hospital visit costs.

30. People with Haemophilia with HIV were being told to stay healthy and eat a high protein diet while regularly attending hospital. This cost money. Many were living on Disabled Persons Maintenance Allowance, which was about £48.00 per week. It was obvious that our members could not maintain their health, a good diet or provide for their families on such an amount of income. We realised that in terms of providing some of these benefits it would be difficult for the Government to do so as they could claim that there were no precedents or

mechanisms available. In this case, as an alternative, we recommended the establishment of a trust fund in the amount of £400,000.00 per year for three years. If such a trust fund was established, we recommended the trustees be appointed by the Department of Health, the Health Boards and the Irish Haemophilia Society. The submission was sent to the Minister for Health in May 1988 and we received an acknowledgment of receipt. A meeting took place with officials of the Department of Health in July 1988 to discuss the submission and it was indicated to us that the validity of the submission was recognised; and proposals would be put in place to alleviate the difficulties identified. In November 1988 we received further signals from the Department of Health that due to budgetary constraints the situation had changed, and we were unlikely to receive a positive response to our submission.

31. We then decided that we had no alternative but to go public and mount a political and media campaign, so that the general public would appreciate our concerns and issues, in an attempt to get the Government to take this issue seriously. We had no experience of advocacy or lobbying. On December 15th we launched our campaign with a press conference. The campaign which lasted until July 1989 included speaking to the media, lobbying politicians at both parliament and local council levels, keeping our members apprised of developments so they could understand the rationale behind our efforts and join in lobbying local politicians. We had a small number of very brave members who had HIV who agreed to speak publicly in order to put a human face on the campaign. At that time we had one part-time secretary who worked two days per week. The campaign was run entirely by the Board as volunteers and we were fortunate that we had several Board members and volunteers who took a very active part in the campaign. We asked all of our members to contact their local members of Parliament and seek their support for the campaign. We sent summary data to all members to support them in this endeavour. We used the opportunity of meetings abroad including in the European Parliament and at the inaugural meeting of the European Haemophilia Consortium to promote our case and get access to the media in Ireland. In February 1989 the Society met with the health spokespeople from all of the opposition parties and sought their support for the campaign. We were getting increasing media coverage.

32. Following a meeting with a number of members of Parliament, including a former Taoiseach, a delegation of those members of Parliament, led by the former Taoiseach, went to the Minister for Health and urged him to support our proposals. On the following day we had a meeting with the Minister for Health to discuss their proposals. At that meeting the Minister did not offer recompense. He offered the Society a place on the committee to review services available to all people with AIDS and also offered the Society £50,000 for counselling services. We accepted the place on the Committee but we did not accept the funding for counselling at that time, despite the fact that we had no funding, as we felt this could have been used to finish the campaign. In March 1989 we secured the agreement of the two main opposition parties to support a Private Members Bill in the Parliament asking for the Government to set up this Trust Fund. This vote was scheduled for April 26th, 1989. The motion stated "*Dáil Éireann recognises the particular position of Haemophilia sufferers who are HIV positive and who have contracted AIDS. Dáil Éireann considers that the State has a particular responsibility to all AIDS sufferers and the State must take into account that many Haemophiliacs were infected with the HIV virus through blood products supplied, albeit unwittingly, by State agencies. Dáil Éireann therefore calls on the Government to establish a trust fund of £400,000 per annum for HIV infected Haemophiliacs. Dáil Éireann also calls on the Government and particularly the Minister for Health to ensure that every public health facility is made available to all AIDS sufferers*".

33. At that time we had a minority Government. In the week leading up to the vote we lobbied all of the opposition parties and all of the independent members of Parliament to seek their support for the motion. In that week I spent a lot of time in the Parliament meeting with members of Parliament and calling members of Parliament on the telephone. We also had many members contacting their local members of Parliament. The Government party during the week made no move to discuss the issue or seek a compromise. On the day of the vote the then Taoiseach, Charles Haughey, arrived back in Ireland from a trip to Japan and threatened an election on this issue if the Government was defeated as this was a financial issue. At the debate that evening in the Parliament the Taoiseach and

his full front bench attended the debate and sat in the front row which was extremely unusual for a private members motion. The Government was defeated by 72 votes to 69 despite having put forward their own last minute amendment promising £250,000 to the AIDS fund, which was a separate organisation catering for the needs of all people with AIDS.

34. Following their defeat in the Parliament, the Government called an election for June 15th. We maintained our campaign at that time, urged members to lobby their candidates in their constituencies. Crucially we also wrote to the leaders of all the opposition parties and sought their written commitment that they would implement the trust fund if in Government. We received this commitment from all the parties with the exception of the Government party. The election produced a result where the Government lost some seats and had to enter a coalition with one of the parties who had indicated their support for the trust fund. We then had meetings with the leader of that party and following this the programme for Government included a one-off sum of £1 million to be made available to people with Haemophilia who were infected with HIV, through the establishment of the separate trust fund called the Haemophilia HIV trust. Even at this last minute the Government attempted to have the money paid through the AIDS fund but we insisted on the establishment of a separate trust fund called the Haemophilia HIV Trust.

35. Agreement was reached on the establishment of a separate trust board with seven trustees. Two trustees were nominated from the Irish Haemophilia Society, two trustees from the AIDS fund and three trustees nominated by the Minister for Health. The trustees nominated by the Minister for Health included a doctor, a health administrator and an independent chairperson. The first chair of the HHT was High Court Judge Mella Carroll.

10. Please outline your understanding of the eligibility criteria.

36. The establishment of the Trust was followed by an intense period of work including the drafting of the Deed of Trust [WITN7418007], deciding an

allocations policy, drafting forms for registering individuals and setting up mechanisms to ensure that every person with Haemophilia who had HIV could register with the trust in a confidential manner. The trustees also organised a meeting with the people with Haemophilia with HIV. This gave the trustees a chance to talk to the affected individuals and gain some measure of understanding of the problems they were facing. It also gave the eligible people an opportunity to meet the trustees. The HHT were able to confirm a list of eligible individuals through the National Haemophilia Treatment Centre. This was not a complex process.

11. Please outline your understanding of the evidence that a person who is eligible to receive payments, must provide in order to make good their application.

37. In the initial period from 1989 to 1991, when compensation was paid to people with HIV, regular payments were made to some people who were assessed as being in particular need. One off payments were made for funerals, some healthcare costs not covered by the healthcare system, equipment such as special beds, mattresses or chairs or any other equipment which was linked to the person having Haemophilia and HIV. The evidence required was generally a letter or a communication from the individual either to the HHT directly or via the Society. The procedures adopted were not overly complex and they were deliberately designed to ensure that members were given assistance as expeditiously as possible without placing an undue burden on individuals to provide evidence.

12. Please outline your understanding of the kind of assistance that is available to an applicant to the HHT.

38. Initially, regular payments were made to a small number of eligible individuals and one-off payments were made to many individuals. After 1991 regular payments ceased and one-off payments were made. After further HIV compensation was paid in 2002, a meeting of claimants was convened and they

were asked if they wanted the trust wound up and have the remaining funds distributed equally among those surviving or if they wanted the fund to continue as an emergency fund. The vast majority voted to have the fund continue as an emergency fund as they appreciated the emergency assistance which the fund was able to provide in particular circumstances.

13. Please provide details of your understanding of the kinds of payments the HHT makes.

39. Since 2002 payments have mainly been for funeral grants or one-off payments for equipment such as stair lifts or special beds. The HHT also gives Christmas payments to some of those with HIV or their surviving families if in need. This is assessed by the Society. In some situations where a person with Haemophilia has an urgent requirement for a hospital bed, a wheelchair or other equipment, the Society will pay this without delay and reclaim the cost from the HHT to ensure that there is no delay in receiving the help required. An example would be a member who was discharged from hospital to home palliative care and needed a special bed and wheelchair. We were able to fund and provide these on the same day and then claim the cost back from HHT. The fund was topped up in 2006 with a sum of €300,000. The fund continues to work presently and is currently chaired by now retired High Court Judge Roderick Murphy. Both Judge Murphy and the late Judge Carroll regularly attended our annual conferences and have got to know the members, the community and the Society. They have developed a real appreciation of the needs of our members with HIV.

14. What is your view on the success of the HTT? Do you consider it to have met its objectives?

40. The HHT has been very successful. The objectives have been met, the trustees have acted with empathy and understanding. The ability to respond rapidly and the relatively informal structure have worked very well.

41. The HHT provided regular payments to some individuals in the period from 1989 to 1991. During that time, the Society were regularly meeting with a legal team we had engaged to assist members in taking legal action against the state. At that time, the number of people with haemophilia dying from AIDS related illness was increasing significantly. In December 1990, the Society decided to start a campaign to get the Government to agree to compensate our members with HIV without them being forced to take legal action. Our concern was that with the increasing mortality, many members would be deceased before any legal case was completed. By December 1990, 35 members had developed AIDS and 16 members had died from AIDS related illness. We were also influenced by the announcement by the UK Government of compensation to people with haemophilia infected with HIV in the UK.

42. The society met the Minister for Health in January 1991 and he requested a submission from the Society. At that time 70 of the 103 HIV positive people with Haemophilia had initiated legal proceedings. Our submission that month sought a settlement of this legal proceedings and compensation for the 103 people infected and at a suggested settlement figure of £15,450,000. We received no substantive response to the submission. In the following months we met with members of parliament, sent letters to all members of parliament, sent motions to all county councils, contacted local media to follow up with the council motions and sent update letters to members. We also ran four candidates for the local elections to gain media attention for the campaign and to highlight the issue. In May we had a public meeting to introduce an all party ad hoc committee on this issue. David Watters, general secretary of the UK Society attended that meeting. On June the 10th, on the same evening that the Minister for Health was due to debate this issue on national television with myself as Chairman of the Society, the Minister announced a settlement offer of £7,000,000. This however included a claw back of the £1,000,000 paid to establish the HHT in 1989 and a payment schedule over 2 years. The legal team were in favour of accepting this offer. On our recommendation, this offer was rejected by members and we entered a period of intense negotiations to secure an improved offer.

43. We secured an improved offer of £8 million, to be paid quickly and with no £1 million claw back. On July 6th, this offer was unanimously accepted at a meeting of the people with haemophilia. Payments were tiered in a similar manner to the payment made by the UK Government and in accordance with the Society proposals agreed by our members. A married man with children received £101,000. A Widow of a deceased member received £93,000. A married man with no children received £89,000. A single adult or child received £76,000. An infected spouse received £25,000 (although there were no infected spouses when all were tested at that time) and the non- dependant relatives of a deceased man received £21,000.

15. Have there been any problems with either the terms of the HTT or its operation that you are aware of? If so, please give details

44. There have been no problems with the operation of the HHT trust.

Section 5: The Hepatitis C and HIV Compensation Tribunal ("the Compensation Tribunal")

16. Please describe your understanding of the circumstances which led to the establishment of the Compensation Tribunal in 1995 and any involvement you may have had in this.

45. In June 1993 my colleague and I met with the Hepatology Registrar at St. James hospital to discuss the use of Interferon as treatment for people with Haemophilia with Hepatitis C. We were concerned to hear that there was a charge being made for the Interferon therapy and we contacted the Department of Health with regard to this. In September 1993 we had special information meetings for our members in Dublin and Cork, and also in that month the Board of the Irish Haemophilia Society first discussed the issue of Hepatitis C compensation. We were having ongoing discussions with Department of Health officials in relation to the provision of Interferon free of charge and at a September meeting with the Department of Health officials we raised the issue of Hepatitis C compensation.

In February of 1994 it emerged that more than 1000 women had been infected with Hepatitis C via injections with anti-D, which they received following pregnancy. In March 1994 we had a meeting with the Minister for Health, Brendan Howlin, on Hepatitis C issues including treatment and compensation. At that time our thoughts on compensation were focused on *ex-gratia* payments similar to the HIV compensation, which had been paid in 1991.

46. Following many discussions, it became clear that the Department of Health were willing to concede in principle on the issue of compensation. Their preferred mechanism was to establish a Hepatitis C Compensation Tribunal, which would hear the claims of our members and also those infected via blood transfusion, renal dialysis and anti-D. Discussions continued with the Department officials in the following months. At that time the Society were also paying the expenses of some of our members with Hepatitis C when travelling to hospital for treatment for their Hepatitis C. This included, in some cases, payment for travel costs, subsistence and overnight costs in special circumstances. Hepatitis C compensation was now one of our top priorities. In April 1995 we met the Minister for Health, Michael Noonan, and his officials with regard to Hepatitis C compensation. The options discussed were *ex-gratia* payments from a trust fund or a compensation tribunal. From August to December my colleague Rosemary Daly and I had multiple meetings with Department officials. In the same timeframe, we were briefing the Board and holding briefing meetings with our members who were impacted by Hepatitis C. On December 11th, 1995 we met with Department of Health officials with regard to the setting up of a compensation tribunal and on the 16th of December we had a further meeting for our members with Hepatitis C; and put the option of a compensation tribunal to them. They unanimously agreed with this option. They also agreed that the Society should employ a legal firm whom they would all use for the compensation tribunal; and they agreed to use common expert witnesses and a common legal team where possible. We interviewed various firms of solicitors and decided to hire Lanigan Malcolmson Law from Carlow. At that time, they had offices in Carlow. We agreed that they would rent offices in the same building where we had our office so we could work very closely on these vital issues, on a daily basis.

47. We informed the Department officials of our members' decision on December 20th and we then went to the UK with our legal advisor, Raymond Bradley, to meet Professor Preston with the view of recruiting him as an expert medical witness for Society members in relation to the compensation tribunal. By the beginning of 1996, our legal team was working on the issues and on all future work from that point to the implementation of the insurance scheme in 2007, we worked very closely with our legal team. We were also working with our legal team on engaging experts including a hepatologist, actuary and psychologist who could work with our legal team to advance the individual tribunal cases of members. The first application to the compensation tribunal was heard in January 1996 and by July 1996, nine of our members had had their cases heard including several emergency applications. It is worth noting that the compensation tribunal was established and Hepatitis C compensation was paid a year prior to the initial discussions on terms of reference for the Lindsay Inquiry, four years prior to the commencement of oral hearings and six years before the inquiry report was published.

17. In 2002, the remit of the Compensation Tribunal was extended to include those who had contracted HIV, by way of the Hepatitis C Compensation Tribunal Amendment Act 2002. Why do you understand this amendment to have been made?

48. Following the initiation of the Hepatitis C Compensation Scheme in 1996, a Tribunal of Inquiry - The Finlay Tribunal - was established. Hearings were held between October and December of 1996 and the Tribunal reported in March of 1997. The Irish Haemophilia Society withdrew from the Finlay Tribunal in December 2006 as it was clear that the Terms of Reference were being interpreted in such a way as to exclude any investigation of the infection of people with Haemophilia. The Finlay Tribunal investigated primarily the infection of persons through Anti-D and through blood transfusion to a lesser extent. The Irish Haemophilia Society then entered into negotiations with the Department of Health in relation to setting up a separate Tribunal of Inquiry to examine all

aspects of the infection of persons with Haemophilia with HIV and Hepatitis C. Discussions on the Terms of Reference for this Inquiry took place at multiple meetings between 1997 and 1999. This Tribunal of Inquiry - the Lindsay Tribunal - was established by the Dáil (parliament) on 8th September 1999. The Tribunal sat for 196 days between September 1999 and November 2001. The Tribunal report was issued on the 4th September 2002. The Tribunal hearings included harrowing personal testimony from many people with Haemophilia and family members.

49. Prior to the publication of the Lindsay Report, but following the public testimony from people with Haemophilia and their families at the Tribunal, the Society and our legal team made detailed submissions to Government for further compensation and specific criteria where additional compensation could and should be granted [WITN7418008]. In particular, we were of the view that the 1991 HIV *ex-gratia* payments, while very welcome at that horrendous point in time, were totally inadequate as compensation. The Irish Government accepted that the HIV compensation awarded in 1991 was neither fair nor equitable, and consequently further legislation was passed [Hepatitis C Compensation Tribunal (Amendment) Act 2002 No. 25 of 2002]. This was the final piece of legislation passed prior to the dissolution of the Parliament and the subsequent General Election. This Act allowed for further compensation for persons with Haemophilia who had been infected with HIV or Hepatitis C in addition to extending the number of parameters under which compensation could be paid.

18. Please outline your understanding of the eligibility criteria.

50. The Hepatitis C Tribunal was established in 1995 on a non- statutory basis.

51. This was changed to a statutory Tribunal by the provisions of The Hepatitis C Compensation Tribunal Act of 1997 [Number 34 of 1997]. This was done following the report of the Finlay Tribunal of Inquiry under the 1997 Act, the following could submit claims:

a. A person who was infected with Hepatitis C by administration of anti-D, blood transfusion or blood product supplied within the State;
b. Children or spouse of the above who were infected;
c. Dependants of the above who had died;
d. Carers who had suffered significant financial loss.

52. Claimants could decide before their hearing if they wished to also pursue a claim for aggravated or exemplary damages or take an additional 20% on top of their settlement from a Reparation fund.

53. Claimants could decide to opt for a single lump sum payment or a provisional award, which allowed them to return later and seek further compensation if specified clinical events (for example the need for a liver transplant) occurred.

54. They had to show that their Hepatitis C was caused by anti-D or blood products on the balance of probabilities. In the case of people with Haemophilia, this involved searching their medical records to ascertain when they had been treated with plasma derived factor concentrates or cryoprecipitate.

55. Reasonable costs and witness costs and expenses were also paid.

56. The Applicant waived no legal rights to make a claim but waived the right to take legal action against the State if they accepted the award.

57. Awards or any decision of the Tribunal could be appealed to the High Court.

58. In 2002, the Parliament passed the Hepatitis C Compensation Tribunal (Amendment) Bill, 2002 [WITN7418009]. This Act was to amend and extend the Hepatitis C Compensation Tribunal Act, 1997 [WITN7418010] to enable the Tribunal to award compensation to certain persons who contracted HIV within the State from certain blood products and to provide for related matters. The relevant blood products specified under the Act were blood products and blood

components used to treat persons with Haemophilia or other blood clotting disorders in respect of those conditions. The Act also made reference to the previous 1991 HIV settlement.

59. Following the 2002 Act, those who could apply for compensation included:
    a. People with Haemophilia who had been infected with HIV and/or Hepatitis C;
    b. Children or spouse of the above who were infected;
    c. Dependents of the above who had died;
    d. Carers who had suffered significant financial loss;
    e. Widows or Dependents of those who had died. They were entitled to claim for pain and suffering, general damages, loss or diminution of expectation of life or happiness, which the deceased suffered during his or her lifetime and to which the deceased would have been entitled if he or she had survived and brought a claim for compensation to the Tribunal. (The widow was therefore not disadvantaged financially by the fact that her spouse had died prior to this. This overturned the inherent unfairness of the 1991 awards).

60. New areas of claim were introduced under the Act:
    a. Children, spouse, father or mother of those who had died could claim under loss of society or psychiatric injury including post-traumatic stress disorder;
    b. Partners or spouses of those infected could claim under loss of consortium;
    c. Children or spouses of those who had died could claim for loss of society (loss of their partners or parents care, companionship or affection);
    d. Dependents could also claim for aggravated or exemplary damages where the dependents established that the deceased would have had a legal entitlement to such damages;
    e. The additional provisions of this Act were also applied to people with Haemophilia who had not been infected with HIV but were infected with Hepatitis C.

61. This amended Compensation Tribunal Act effectively provided a pathway to fair and equitable compensation for people with Haemophilia with HIV and their families and removed the disadvantage they had suffered if the person with Haemophilia was deceased prior to the Act being passed.

19. Please outline your understanding of the evidence that a person, who is eligible to receive compensation, must provide in order to make good their application.

62. A narrative of their treatment and probable date of infection with Hepatitis C (assumed to be the first date they received plasma derived factor concentrate) or HIV from their medical records.

63. Personal evidence of pain and suffering.

64. Evidence of impact on education and employment including on potential loss of earnings.

65. Evidence of impact on their personal relationships.

66. The legal team for the individual would have scrutinised their medical records, interviewed the individual with regard to their experience and engaged expert witnesses such as haematologists, hepatologists, infectious disease consultants, psychologists and actuaries in preparing the case for hearing.

20. Please outline your understanding of the kind of assistance that is available to an applicant to the Compensation Tribunal.

67. Legal representation including solicitor and barrister.

68. Tribunal will usually pay reasonable costs for expert witnesses who can give evidence on the Claimants' clinical history and/ or prognosis, financial losses, psychological impact

21. Please provide details of your understanding of the kinds of payments the Compensation Tribunal makes.

69. The Tribunal makes payments in relation to the individual affected for general damages, damages for pain and suffering or personal injury, loss of earnings or potential earnings. Payments can be made to partners or spouses for loss of consortium including the impairment of sexual relationships with the claimant.

70. In the case of individuals with HIV or Hepatitis C who were deceased prior to the claim being made, payments can be made to dependants equal to the amount of the general damages including damages for pain and suffering, personal injury, loss or diminution of expectation of life or happiness which the deceased suffered during his or her lifetime and would be entitled if he or she had survived and brought a claim for compensation to the Tribunal. Payments can be made to children, spouse or partner or father or mother of the deceased for loss of society including the loss of the care, compassion and affection of the deceased as a result of their death. Payments can be made to the children, spouse or partner, father or mother of the deceased for post-traumatic stress disorder. The Tribunal may also make a payment in respect of aggravated or exemplary damages where the dependant establishes that the deceased would have had legal entitlement to such damages.

71. Awards are also topped up with an additional 20% reparation payment in lieu of the applicant taking legal action against the State or claiming for aggravated or exemplary damages.

72. Awards can be appealed to the High Court if the applicant is dissatisfied with the award offered. The confidentiality of applicants is maintained in this process.

Cases have also been further appealed to the Supreme Court as part of a regulated appeal process.

22. What is your view on the success of the Compensation tribunal? Do you consider it to have met its objectives?

73. It has broadly been very successful. From the earliest cases heard, it was non-adversarial and members felt that they had generally been given a fair hearing. Our members had excellent legal representation and support and very capable expert witnesses. The awards were often, in the view of claimants or the legal team, too low and a significant proportion were successfully appealed to the High Court. The vast majority of Appeals resulted in an increased award.

23. Have there been any problems with either the terms of the Compensation tribunal or its operation that you are aware of? If so, please give details.

74. The process has been very long and drawn out for some Claimants. The individual assessment of each person was a fair way to proceed and did allow each individual to set out their particular circumstances and story, be individually assessed and receive fair compensation. The ability to appeal awards to the high court was very important. However, in the case of children or younger adults, the probable impact on their education or future employment could not, in some cases, be ascertained for several years. Preparing evidence for their case at the Tribunal and having to remember and revisit all the trauma suffered as a result of their infection and subsequent medical and personal history was quite difficult for many people. The Society and the legal team provided support to members during this difficult process. On many occasions, the Claimant wanted a member of the Society team with them at the meetings and hours leading up to their hearing and also to be on hand to offer support after the process.

75. The vast majority of primary Claimants have had their cases heard. There are some secondary cases involving spouses, children or carers still going through the Tribunal. In more recent years, especially with remote hearings during the

pandemic, the Tribunal has become somewhat more adversarial and has been limiting the amount of expert testimony they will hear in some cases.

Section 6: The Health Amendment Act Card:

24. Please explain what the Health Amendment Act Card is, and how it works. In particular: (i) Please explain how the priority system works both for services and hospital beds.

76. The Health Amendment Act [WITN7418005] was introduced by legislation - the Health Amendment Act 1996 [Number 15 of 1996]. The Act provides for a card, called the Health Amendment Act or HAA card to be issued to men, women and children who contracted Hepatitis C from the administration within the State of contaminated blood, or blood products. The card gives entitlements to additional services on more flexible terms and conditions than a medical card. The card and its entitlements are for the lifetime of the card holder. The card is personal to the individual card holder and does not cover family members except in the case of access to counselling services. Eligibility is determined on an individual basis and applications for a card are made on the standard form available from the Hepatitis C liaison officer in each Health Service Executive area or via the National Hepatitis C office. The application must be accompanied by a copy of a positive test result confirming Hepatitis C infection and evidence that the infection was as a result of having received contaminated blood or blood products [WITN7418011].

77. The card provides a wide range of services and supports free of charge to people who were infected with Hepatitis C by blood or blood products in the State. HAA cardholders are entitled to the following services:

a. Open Access to public hospital facilities for Hepatitis C or any related condition. The cardholder should not have to wait more than two weeks for an appointment with their liver specialist and also for their first referral to another specialty. This is generally referred to as the two-week rule.

Once the cardholder is referred by the liver consultant to another consultant in a public hospital for the testing investigation or treatment of any known or suspected condition related to Hepatitis C (or any condition which, while not related to Hepatitis C, requires special treatment or care as a result of the patient's infection with Hepatitis C), they will be given priority appointment within two weeks for the first consultation. The decision on whether a condition falls into this category will be a matter for the liver consultant. Subsequent appointments with a specialty outside hepatology would be arranged on the basis of medical need and will not fall within the two-week rule. In practice this two-week rule has not worked in many instances due to pressure on hospital services and consultant time. The card also provides an exemption from having to pay the statutory inpatient hospital charge in a public hospital or accident & emergency department. In the event of requirement for liver transplant, if the procedure cannot be performed in Ireland, arrangements would be made and paid for, on the recommendation of the treating clinician, for the procedure to be performed abroad. If the HAA card holder is referred to a hospital as an outpatient or day patient by a General Practitioner or consultant whom they are seeing as a public patient, they are entitled to any hospital tests free of charge including tests using specialised diagnostic equipment.

b. Access free of charge to a registered General Practitioner of your choice and to all GP medical and surgical services for all medical conditions. The card holder also has access to all prescribed medications for all conditions free of charge on production of the HAA card. In practice, most members with HAA cards would use the same GP or pharmacist routinely so the GP or pharmacist keeps a record of their HAA card number on file and it need not be produced on each occasion. If the individual requires an out of hours General Practitioner service, this is also provided free of charge under the card. If an individual has to pay for the service at the time they will be reimbursed by the liaison officer. The HAA cardholder is also entitled to travel vaccinations and vaccinations for Hepatitis A and B free of charge.

c. Cardholders are entitled to all necessary routine and emergency dental treatment including full dental treatment and appliances. Dental services covered under the scheme include oral examination, scaling, treatment of gum conditions, routine fillings, extractions, root canal treatment, amputation of roots, x-rays and dentures. Other dental procedures not on this list require prior approval from a liaison officer.

d. Cardholders are entitled to free hearing tests and hearing aids with prior approval from their liaison officer. Cardholders are also entitled to an eye examination, spectacles and a grant towards the cost of frames. Cost of contact lenses is also covered.

e. Certain aids and appliances can also be provided free of charge under the card which are required for Hepatitis C or another condition. These items must be prescribed by a GP, consultant occupational therapist or public health nurse. This includes items such as walking sticks, frames, wheelchairs, grab rails, shower seats, bath and bed hoists.

f. Access to physiotherapy when prescribed by their GP or consultant.

g. A home nursing service is available in respect of all conditions affecting the health of eligible people. Referrals for home nursing have to be facilitated through the office of the clinical nurse coordinator for Hepatitis C, public health nurse or the liaison officers. Referrals can come from the liver consultant, the GP, the family or the support groups such as the Irish Haemophilia Society. Following referral, the clinical nurse co-ordinator or designated other will carry out a health and social care needs assessment to determine the most appropriate care plan. The home nursing time would be individualised and client focused. It has been our experience on several occasions that the circumstances of referral do not give ample time for a full plan to be put in place immediately in clinically urgent cases. In this situation, services are put in place very quickly in consultation with the liaison officers to ensure that the individual gets the home nursing they require without delay.

h. Access to chiropody and podiatry services including provision of customised orthotics if required. This was a particular benefit to some of our members who had ankle arthropathy.

i. Access to complementary therapies. The list of complementary therapies which is covered includes massage, reflexology, acupuncture, aromatherapy and hydrotherapy.

j. Access to counselling services for the affected individual. Access to counselling services free of charge is also provided to relatives or carers who are living with you or are in close contact with you, subject to prior approval by the liaison officer. In practice a number of spouses, partners, children or parents of affected individuals have been able to avail of counselling under the Scheme

24. (ii) Please explain how the card gives access to support for the infected person in their own home.

78. If as a result of their condition the individual is having difficulty carrying out normal household tasks, they are entitled to avail of home support services. This is available to both male and female HAA cardholders. The individual can also apply for the services of a home worker who can do household tasks such as cleaning, cooking, ironing or other work such as gardening. Application is made to one of a number of liaison officers and there is a home assessment nurse who will discuss the individual's requirements with them and the person will then be approved for a specific number of hours per week. The home care worker can be employed directly and paid by the Health Service or the individual can employ them and be reimbursed by their liaison officer.

24. (iii) Please explain the role of the specific liaison officers.

79. There are 10 liaison officers each of whom is responsible for a particular geographic area and for ensuring that HAA cardholders receive the services they are entitled to under the terms of the Act. Liaison officers are responsible for coordinating and assisting cardholders in accessing primary care services only - these are the services provided outside of a hospital setting. The national Hepatitis C office can also assist in accessing services through the hospital system and they have an oversight role nationally in relation to the work of the liaison officers and all aspects of the delivery of Hepatitis C services. Liaison officers assist Applicants with provision of services, deal with applications and liaise with pharmacists, GPs or other HCPs if the Applicant has trouble accessing their entitlements. Generally, their role works very well and they provide a very valuable service and support. The chief liaison officer or representatives from the National Hepatitis C office are invited on occasion to our conferences to give an update on services and support and answer questions from HAA cardholders.

25. Is the card a success in your view?

80. Unequivocally, yes. It has been of great benefit, especially for those who have had the most difficulty clinically. The free access to GPs and prescriptions is very valuable. The Organisations whose members benefit from the card oversee the implementation of the scheme via a Hepatitis C Consultative Council. This was established by legislation in 1996 – [S.I No. 339 of 1996] – Consultative Council on Hepatitis C (Establishment) Order 1996. The functions of the Council are as follows:

    a. To advise and make recommendations to the Minister for Health on all aspects of Hepatitis C on its own initiative or at the request of the Minister and in particular on:

        i. The health and counselling services for persons with Hepatitis C, including the funding of such services as set out in the book of estimate each year to ensure that such funding is sufficient to provide the range of services set out in the healthcare service document published by the Minister in December 1995;

ii. The organisation delivery and confidentiality of services for persons infected with Hepatitis C;

iii. The changing needs of persons infected with Hepatitis C in order to ensure that the health services respond effectively to such changing needs;

iv. Developments arising from research into Hepatitis C under the aegis of the Health Research Board;

v. The publication of information on Hepatitis C. In practice this has meant the production of a series of national Hepatitis C database reports which have tracked the clinical progression of Hepatitis C in those who received blood and blood products.

26. Please set out any of the positive or negative feedback on the Card that you are aware of, from either users or providers of services pursuant to the card.

81. Feedback on the use of the card has generally been very positive. Positive feedback on features which have been of a great benefit to our members include:
    a. The access to free General Practitioner services and prescription drugs;
    b. Access to counselling, physiotherapy and alternative therapies; and
    c. Access to home care workers and home nursing as required.

82. The card has been particularly valuable in situations where members are gravely or seriously ill. In these situations, the liaison officers, working with the Society, are happy to assist members in areas such as travelling abroad for liver transplants if required, provision of 24-hour home nursing or home care, liaison

with palliative care, and provision of the required equipment to allow people with Haemophilia to recover at home or in the case of those who are terminally ill, to die at home with dignity.

27. Many of the Inquiry's Core Participants have asked the Inquiry to make a recommendation for a similar scheme in the UK. Are there any aspects of the scheme that you would recommend are not implemented? If so, what are they and why? Are there any changes to the scheme that you would recommend? If so, what are they? Please set out the rationale for your view.

83. I would not make any changes. I would like to see the two-week rule for access to new specialities enforced but this is difficult in a post pandemic environment. The role of the liaison officers has been crucial in helping members to avoid unnecessary bureaucracy or delay.

Section 7: Steps taken in Ireland to assist individuals with obtaining mortgages and/ or insurance

28. Please describe when, and in what circumstances, you first became aware of the difficulties that people with Haemophilia faced in obtaining products such as mortgages and insurance.

84. Because of their pre-existing medical condition, people with severe Haemophilia for many years have had difficulty in obtaining life or mortgage insurance. In many cases these could only be made available with an increased loading or financial cost. When the Society prepared our submission to the Government on "AIDS, Haemophilia and the Government" in April of 1988 [WITN7418004], we proposed that the Government should make available life insurance and mortgage protection insurance for people with Haemophilia who had been infected with HIV. They were finding it very difficult, if not impossible, to obtain life insurance and mortgage insurance. This was not achieved at the time and instead following an advocacy campaign the Government established the Haemophilia HIV Trust in 1989. After 1995 when our legal team started to assist

people with Haemophilia in preparing their cases for the Hepatitis C Compensation Tribunal, it also became apparent that people had difficulty obtaining life insurance or mortgage insurance. They also had difficulty in obtaining travel insurance.

29. In 2006, the Hepatitis C Insurance Scheme ("the scheme") was set up under the Hepatitis C Compensation Tribunal (Amendment) Act 2006. Were you personally, or the Society as a whole, consulted or involved in any discussions about the needs of people with Haemophilia relating to mortgages and insurance prior to the scheme's announcement? Please describe the nature of any such discussions.

85. Following the amendment of the Hepatitis C Compensation Tribunal Act in 2002 [WITN7418010] and the publication of the Lindsey Inquiry report that year, an outstanding item of work was the provision of life insurance, mortgage insurance and travel insurance. These issues had been discussed with the Government at the time of the extension of the Hepatitis C Compensation Tribunal. The Society and especially our legal team, Malcolmson Law, were very much involved. We were involved in every stage of the discussions for the four-year period leading up to the legislation. The Department of Health established an Insurance Steering Group to look at the needs of the four groups of people who had been infected by HIV and/or Hepatitis C via blood or blood products in the State. Each of the four organisations - the Irish Haemophilia Society, Positive Action (representing women infected via anti-D), Transfusion Positive and the Irish Kidney Association - had representatives on this steering group and we also each had our legal teams attend. I represented the Society together with our then Chairman, Michael Davenport. A specific firm of actuaries were also engaged to work with the group. Our legal team, in particular, were very involved in drafting the legislation and produced the first draft of the legislation. This was a very long and complex process. We had approximately thirty five steering group meetings of long duration. During the process, we organised regular meetings with our members to update them on progress and get their feedback to help ensure we were pursuing their goals and that they understood what the

scheme would entail. Each proposed detail and provision of the draft scheme was discussed and debated in great detail.

86. The Scheme was legislated for in the Hepatitis C Compensation Tribunal (Amendment) Bill, 2006 [WITN7418012] and implemented by the Hepatitis C Compensation Tribunal (Insurance Scheme for Relevant Claimants) Regulations, 2007 [WITN7418013 and WITN7418014] .

87. We were very involved at all stages during the passing of the legislation including lobbying members of the Dáil (Parliament) and Seanad (second legislative House) to ensure that the provisions of the Bill survived the legislative process.

30. Please explain your understanding of how the scheme works.

88. An eligible person (person who is infected) applies for an eligibility certificate from the scheme administrator. They receive an eligibility number.

89. There were a number of approved insurance companies for the scheme who were approved by the Steering Group. They would provide a life insurance quote for the person. The quote would be based on a perfectly healthy person of the same age who was a non–smoker. (If the applicant smoked, this did increase their premium). The applicant would pay the normal premium and the scheme would pay the loading. The Society worked with an insurance broker following the implementation of the scheme to assist our members who wish to avail of insurance.

90. The spouse or partner of the claimant could also take out insurance but they would pay any loading applicable to their own health.

91. If the individual was deemed uninsurable (as were those with co-infection with HIV and Hepatitis C), the insurance would still be provided at the perfectly healthy person rate and the Scheme would underwrite the policy.

92. Individuals were allowed to take out life insurance up to a maximum of €420,000 or 7 times their annual income or combined annual income with their partner to a maximum of €575,000 Insurance ran to age 65 but if a policy was taken out in the first year of the scheme, a policy could run to 75.

93. For all participants, full cover applied if they took out insurance in Year 1 of the scheme.

94. After year 1: For people who were deemed uninsurable, full cover was in place if they were under 30 years of age but if more than age 30, full cover came in following 2-3 years of insurance For those over 50, similar provisions applied.

95. These provisions combined with the ability to be insured to age 75 in Year 1 led us to proactively encourage as many members as possible to avail of life insurance in year 1. A greater proportion of eligible PWH took up insurance in Year 1 than of any of the other eligible groups.

96. Mortgage insurance could be taken out to a maximum of €394,000 or the average house price in Dublin. These amounts were index linked going forward.

97. In the first year of the scheme, in recognition that many applicants had mortgages with no existing insurance, they could take out re-mortgage insurance up to a maximum of €100,000

98. The individual and their immediate family could also take out annual travel insurance with no loading. This has been very popular.

31. Is the scheme adequate in your view? Has it been a success?

99. Yes- it has worked. There was significant uptake among our members for life insurance in Year 1. We ensured that all eligible members were fully aware of the scheme and we strongly encouraged them to avail of the insurance. There was

little uptake on the mortgage or remortgage insurance. The travel insurance was widely used and remains widely used on an annual basis.

32. Please provide details of any problems with this scheme that you may be aware of.

100. No specific problems.

33. Many of the Inquiry's Core Participants have asked the Inquiry to make a recommendation for a similar scheme in the UK. Are there any aspects of the scheme that you would recommend are not implemented? If so, what are these, and why? Are there any changes to the scheme that you would recommend? If so, what are they? Please set out the rationale for your view.

101. I am not convinced that the mortgage insurance is worth all the work- there was a very low uptake. The life insurance and travel insurance have been very welcomed by our members and very beneficial to those who availed of this insurance.

Section 8: Tax Concessions for those infected with Hepatitis C and HIV via blood and blood products

34. Please explain the tax concessions in place for the income and gains from the investment of monies received from the Compensation Tribunal or the HHT.

102. Payments to eligible individuals from the Haemophilia HIV Trust (HHT) were generally one-off payments in emergency situations. There were no tax implications. People with Haemophilia with HIV received ex-gratia payments from the Government in 1991. These payments were also not liable for tax. Payments from the Hepatitis C Compensation Tribunal started in early 1996. Payments from the tribunal were tax free. Under section 191 of the Taxes Consolidation Act

of 1997 payments arising from the Hepatitis C Tribunal Act of 1997 were exempt from income tax and capital gains tax. All awards made under the Hepatitis C Act of 1997 were tax exempt including payments for loss of consortium and payments to individuals who suffered financial losses resulted from becoming a carer for a person infected with Hepatitis C or HIV [WITN7418015].

103. The Society together with our legal team and a senior accountant from the accounting firm KPMG had a series of meetings with senior officials in the Revenue Service to ensure that the tax code and tax provisions would not disadvantage our members or others who had received awards from the Tribunal. Section 189 of the Taxes Consolidation Act of 1997 deals with investment income and gains arising from compensation awards. It states that "*an individual who is permanently and totally incapacitated by reason of a mental or physical infirmity from maintaining himself or herself is exempt from tax on the income or gains from a compensation award*". Following our discussions, revenue confirmed that section 189 applied to all persons with Haemophilia or von Willebrand's disease who were infected with Hepatitis C or HIV through blood or blood products. The section applied to all those who were infected with hepatitis C through blood and blood products, including those who were positive for antibodies to Hepatitis C but negative for the virus. The exemption from income tax and capital gains tax is not always straightforward and each tax year has to be considered separately as an individual may qualify for tax exemption on their income and gains from compensation proceeds in one year but may not in another depending on their overall income and gains in each year. The income and gains are subject to what is called a 50% test. If the relevant income or relevant gains from the compensation award in a particular year constitute more than 50% of the individual's total income for that year then, the relevant income and relevant gains are tax free. If any tax has already been paid on this income, that tax would be refunded.

104. Relevant income means income arising from the investment from all or part of the compensation proceeds which can consist of dividends, interest, rental income or income from certain unit trusts or collective investment funds. Relevant gains means chargeable gains (gains which would usually be liable to

capital gains tax) accruing from a disposal of assets acquired using the compensation proceeds. It also covers gains arising from assets acquired using income arising from your compensation proceeds or reinvestment of compensation proceeds where earlier assets had been sold. If these relevant income and gains constitute more than 50% of the individual's total income for the year, they are tax exempt. Income and gains which are not tax exempt which go on the other side of the 50% calculation include salaries or directors' fees, consultancy income or self-employment income from a trade or profession. Social welfare payments such as disability allowance or invalidity pension are not counted as income on this side of the 50% calculation.

105. Members who received significant awards from the compensation Tribunal and who are not in full-time employment or who ceased full time employment will generally have tax exemption for their income and gains. Some members who are in full-time employment, receiving very significant salaries or fees will generally not be tax exempt on their income or gains. The calculation becomes more difficult for individuals who have some nonexempt income and also significant income or gains from their compensation award.

106. Individuals typically will have to do a 50/50 test calculation each year and ascertain if their relevant income and gains are liable for tax in that year. Of course this calculation can be done before the year end and with proper financial planning an individual can increase his or her chance of being tax exempt for the year.

35. Please explain any special procedures in place as to how the tax affairs of this cohort can be dealt with by tax inspectors.

107. Members who received compensation awards were also concerned about confidentiality if their tax affairs were being dealt with by the local taxation officers. The Society negotiated with the Revenue Commissioners an agreement that people with Haemophilia with HIV or Hepatitis C could, if they wish, register to have their tax affairs entirely dealt with by a senior Revenue official in the

Revenue confidential service. This service ensures increased confidentiality for persons with Haemophilia. The Revenue confidential service unit has also developed a level of expertise in relation to the relevant tax issues arising in respect of income and gains from compensation proceeds. This has resulted in an efficient and personal service for members when dealing with the Revenue. In 2011 the Irish Government introduced a Universal Social Charge on all gross income where income exceeded €10,036 annually. The Society again made representations to Revenue for an exemption from the USC for HAA cardholders. The Revenue did not grant an exemption but they did grant a concession. The USC charge is generally applied at the rate of 2% of income for the first €10,000, a rate of 4% of income for the next €5,980 and 7% of income for the remainder of annual income. Revenue agreed to cap the rate of USC for HAA cardholders at 4% providing their non-exempt income for the year was less than €60,000. If an individual passes the 50% test in a given year that exempt income will not be liable to the U.S.C. charge.

36. Please set out what tax advice services are available (to your knowledge) for this cohort of people.

108. The Society continues to maintain a relationship with the accountant who worked with us on making representations to the Revenue service. We provide periodic written updates and organise periodic meetings for members in relation to these taxation and financial issues. We also provide an annual consultation with this accountant for any of our members free of charge. The Society pays the cost of the consultation.

<u>Section 9: Please provide any other information and/or views you may have that are relevant to our Terms of Reference.</u>

109. Nothing further to add.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed: **GRO-C**

Dated:_____October 18, 2022__________________

Table of exhibits:

Date	Description	Exhibit number
2001	Brian O'Mahony Statement to Lindsay Tribunal re: self-sufficiency.	WITN7418002
2001	Brian O’Mahony Statement to Lindsay Tribunal re: Response.	WITN7418003
1988	‘AIDS, Haemophilia and the Government’ submission from April 1988.	WITN7418004
1996	Health Amendment Act.	WITN7418005
2004	National Haemophilia Council (Establishment) Order.	WITN7418006
1989	The Haemophilia HIV Trust Deed.	WITN7418007
2001	Irish Haemophilia Society submission to Lindsay Tribunal on recommendations for the future.	WITN7418008
2002	Hepatitis C Compensation tribunal (Amendment) Bill.	WITN7418009
1997	Hepatitis C Compensation Tribunal Act.	WITN7418010
2000	Guide to Health Amendment Card.	WITN7418011
2006	Hepatitis C Compensation Tribunal (Amendment) Bill.	WITN7418012
2007	Hepatitis C Compensation tribunal (Insurance scheme for relevant claimants) Regulations.	WITN7418013
2008	Hepatitis C Compensation tribunal (Insurance scheme for relevant claimants) (Amendment).	WITN7418014
2010	Irish Haemophilia Society - Tax Booklet.	WITN7418015