Witness Name: William Wright
Statement No.: WITN2287019
Exhibits: WITN2287020 – WITN2287086
Dated: 15th April 2021

INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF WILLIAM WRIGHT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 January 2020.

I, William Wright, will say as follows: -

Section 1: Introduction

1. *Please state your name, address and date of birth*

1.1 My name is William Wright. My date of birth is GRO-C 1958 and my address is known to the Inquiry. In this statement, I will be giving further information about my involvement in campaigning and research relevant to the Inquiry's Terms of Reference in response to the questions addressed to me in the Rule 9 request.

Section 2: Organisations involved in campaigning activities

2. *Describe your involvement in setting up:*
   (a) any campaigning organisations whose aims or activities are relevant to the Inquiry's Terms of Reference; and/or

(b) any organisations offering support and assistance to people who are infected or affected

State when each organisation was set up, what prompted or led to its establishment and what its aims or objectives were or are

2.1 In 2012, I was a founding Trustee of Haemophilia Scotland. I became Chair and still hold this position. Prior to this, I was Chair of its predecessor, the Scottish committee of the Haemophilia Society. In the following paragraphs, I describe my involvement with the Haemophilia Society in Scotland and the events which led to the formation of Haemophilia Scotland.

2.2 From approximately 1998, I was an active member of what became known as the Scottish Haemophilia Groups Forum, which at that time acted as the Scottish face of the UK Haemophilia Society.

2.3 The Scottish Haemophilia Groups Forum was formed in 1997 or 1998, prior to the establishment of the Scottish Parliament. It drew its membership from representatives from the Haemophilia Society's local groups across Scotland. The Forum was very much led throughout its existence by the late Philip Dolan. The Inquiry has already drawn upon documents attributable to the Forum when Counsel made a presentation on the Skipton Fund on 22 March 2021.

2.4 I held no office within the Forum but I regularly attended meetings of its steering group and took part in lobbying activities. I sometimes drafted communications on behalf of the Forum. The governance of the Forum was informal. My recollection is that it did not have its own bank account. The Forum eventually petered out around 2010 because it was no longer recognised by its mother organisation, the Haemophilia Society. This followed a governance review by the Society which, as an individual member, I had fed into by exchanging emails with the CEO and Chair of the Society. The Society set up an

alternative Scottish Committee to act as its focal point in Scotland, as described below. Around this time, Philip Dolan established the Scottish Infected Blood Forum (SIBF).

2.5 The Forum met in different parts of Scotland, including in my own front room. Sadly, most of the other members of the Forum who were actively involved in the infected blood campaign have now passed away. The Forum's focus became the questions surrounding how we became infected with Hepatitis C but I also recall us pressing in Scotland for supplies of newly developed non plasma derived Factor 8. I exhibit some minutes of our meetings as **WITN2287020**.

2.6 In November 1999, I was part of a Scottish Groups Forum/ Haemophilia Society delegation who met with senior representatives of the Scottish National Blood Transfusion Service at the Western General Hospital in Edinburgh. The meeting, from the Society's perspective, was led by their CEO, who had travelled up from London, rather than any Scottish based member. I exhibit the minutes from this meeting as **WITN2287021**. This was a particularly significant meeting for me personally as it recorded the SNBTS thinking on two matters - firstly, the timing on when they thought HCV infection through blood and blood products had ended and secondly, the possibility of ALT tests being used as a marker of abnormal liver function in donors which they had weighed up against their apparent desperation at the time in the mid1980s to avoid taking any action that might threaten the voluntary blood supply. While not minuted, I recall the surprise expressed by SNBTS representatives that someone could be infected as late as 1986 and us responding "He is sitting here" (as I was present at the meeting and was infected in May 1986). The second point has always been of interest to me as I was diagnosed in 1986 as being infected with hepatitis C as a result of ALT testing. At the meeting, SNBTS expressed the view that ALT testing could produce false positive results. The doctors at the RIE were 100% confident from my ALT test result that I had been infected

with NANB hepatitis and so how could they say that this testing was an unreliable way of working out whether a donor might have been similarly infected?

2.7 The formation of the Scottish Parliament in May 1999 radically changed our situation. It enabled closer contact with MSPs from across Scotland than had been the case with MPs. We would meet MSPs both inside the Parliament's temporary building and stand outside the building to lobby them.

2.8 The consideration of formal petitions by the new Parliament offered an opportunity for us to submit proposals for its consideration of our campaign in a manner that had not previously existed (and still does not exist) within the UK Parliament. The Scottish Petitions Committee system was relatively accessible in that it only required evidence of trying to get answers from Government and, if they do not give an adequate response, the petition only requires one of two signatories.

2.9 One of the key actions taken by the Forum was in 1999 when we drew up and submitted formal petition PE45, which was one of the very first petitions to be submitted to the Parliament. The Petition called on the Scottish Parliament to hold an independent inquiry into hepatitis C and other infections that people with haemophilia had contracted from contaminated blood products and to consider providing financial assistance for people with haemophilia affected by hepatitis C similar to that already provided for people with haemophilia infected with HIV. I exhibit a copy of PE45 as **WITN2287022.**

2.10 There was also another petition submitted by Thomas McKissock, PE185, which raised similar issues in relation to blood transfusion infections. The two petitions were ultimately considered together by the Health Committee. I exhibit paperwork that I hold in relation to this petition as **WITN2287023.** I note that the Members' Briefing in relation to the petition incorrectly states that SNBTS introduced a test

on all blood products in 1987 which was supposed to detect Hepatitis C and HIV.

2.11 Following representations, the then Minister for Health and Community Care, Susan Deacon MSP, established an internal inquiry into the matters raised in the petitions. I exhibit some correspondence that I exchanged with Susan Deacon and officials regarding this inquiry as **WITN2287024**. I set out some concerns about the internal inquiry in this correspondence.

2.12 The Scottish Executive published their report following this internal investigation in October 2000. The report was entitled "Hepatitis C and Heat treatment of Blood Products for Haemophiliacs in the Mid 1980s" which I exhibit as **WITN2287025.** I received a letter dated 24 October 2000 from Susan Deacon summarising the findings of the report which I exhibit as **WITN2287026.** The report by the Scottish Executive concluded that there were understandable technical reasons as to why a heat treated product that eliminated hepatitis C was not available in Scotland until 18 months after this was available in England. The investigation failed to find any evidence of any policy by Haemophilia Centre Directors deliberately to mislead patients about the risks of hepatitis. Susan Deacon made a statement in Parliament on the basis of this report, stating that the infections had been "unavoidable". The report appears to have formed the basis of the Scottish Government's distinct opposition at that time to holding an independent inquiry and (until the establishment of the Ross Committee which I discuss below), their failure to acknowledge that any form of financial support should be provided to those who had contracted hepatitis C from blood/ blood products.

2.13 During this time, there was a significant amount of activity in terms of the campaign within the Scottish Parliament. Despite the opposition of Susan Deacon, support for our campaign was growing amongst MSPs. The Health Committee of the Scottish Parliament had decided to await the report of the Executive's internal investigation before

taking further action. I gave evidence, together with others, to the Health Committee on 14 March 2001. During the session, the Committee also heard evidence from representatives of the Scottish National Blood Transfusion Service. I exhibit the report of proceedings as **WITN2287027.**

2.14 In October 2001, the Health Committee issued their report. It recommended that a no fault system for the provision of practical and financial support for those infected should be introduced to resolve the issues raised in PE45 and PE185 within 12 months. The Committee's report, which I exhibit as **WITN2287028** sets out their reasoning for that conclusion and also the history of their involvement in the matter. As far as financial assistance was concerned, it was concluded that

> *"The level of financial assistance awarded to any claimant should be determined on the basis of need, having regard to the physical or psychological loss individually suffered, and should include redress for practical difficulties such as the inability to obtain an affordable mortgage or life assurance."*

2.15 As a result of this recommendation, an expert group on Financial and Other Support was established by Malcolm Chisholm MSP, who had by then taken over from Susan Deacon as Health Minister. My own impression was that Malcolm Chisholm was prepared to go further than WT. From records released by the National Records of Scotland it was clear that in 2001 Susan Deacon was opposed to our calls for financial support. Ministers feared making payouts because they thought that "it would create a precedent for compensation and lead to immense future difficulties". She said the Executive would look "unsympathetic" but her "inclination" was for court action because of the wider implications. I exhibit an article from BBC News dated 1 January 2017 which refers to the records that have been released as

WITN2287029. I would like the Inquiry to recover these records and investigate this matter further.

2.16 The Expert Group subsequently set up by Malcolm Chisholm was chaired by Lord Ross. The Ross report was published in March 2003. I exhibit a copy of the report as **WITN2287030**. The report made a number of recommendations about levels of financial support that should be made to those suffering from hepatitis C and their relatives. It also included recommendations about other mechanisms that could be put in place to support people suffering from hepatitis C (such as counselling services) as well as recommendations about legal aid and dispute resolution procedures for medical negligence cases more generally.

2.17 Following the Ross report, there was a debate at the time about whether it was within the competence of the Scottish Parliament to make these payments. I note that, within Lord Ross's report, he recommended that, if there was any question over whether the Scottish Executive could implement his proposals then the matter should be referred to the Judicial Committee of the Lord Advocate. Ultimately, the UK wide Skipton Fund was established. However, the levels of payment made under the Skipton Fund were lower than had been recommended by Lord Ross. Most of Lord Ross's recommendations were never implemented, as set out in an assessment commissioned by Haemophilia Scotland to coincide with the 10th anniversary of the Ross Report. I exhibit this as **WITN2287031**. There has been some progress recently in relation to a number of Lord Ross's recommendations with the increased payments that are now available, including payments to widows, under the Scottish Infected Blood Support scheme. However, there remains considerable work to be done to meet the recommendations in full.

2.18 The support we received in the early years from the Scottish Parliament came from across the political spectrum. However, I

distinctly remember one meeting in the Parliament building where we briefed opposition MSPs, Nicola Sturgeon and Shona Robison, who both later became Cabinet Ministers for Health. Nicola Sturgeon established the Penrose Inquiry when she was Minister for Health and Shona Robison was Cabinet Secretary for Health when the Penrose Report was published and therefore the Cabinet Minister who responded to it. Notably, when she was an opposition MSP, Shona Robison asked a parliamentary question in October 2003 about whether the First Minister would reconsider the level of support which I exhibit as **WITN2287032**. She also tabled a motion in January 2004 criticising the newly established Skipton Fund and seeking reconsideration of payments and those entitled to them. I exhibit this motion as **WITN2287033**.

2.19 Nicola Sturgeon had similarly tabled a number of parliamentary questions and motions around this time while an opposition MSP. I exhibit a news release from Nicola Sturgeon dated 23 January 2003 about questions she had regarding the announcement of ex gratia payments under the Skipton fund as **WITN2287034.** I also exhibit an e-mail that I received from Nicola Sturgeon in 2001 regarding financial support as **WITN2287035.**

2.20 Both Nicola Sturgeon and Shona Robison were consequently very familiar with the scandal when they went on to become Ministers.

2.21 Margaret Smith, who at the time was a Scottish Liberal Democrat MSP, also expressed support and expressed frustration that the Scottish Executive had not listened to the Health Committee's report about financial assistance. I exhibit an e-mail that she sent to a campaigner on 13 December 2013 regarding the issue as **WITN2287036** and I also exchanged emails with Conservative MSPs about the disparity between the payments under the Skipton fund and the Lord Ross recommendations in 2004 which I exhibit as **WITN2287037.**

2.22 One particular recollection I have from the early days in the Scottish Parliament (in around 1999 or 2000) was that, while in the public gallery watching a health debate in the main chamber, I witnessed a senior Official from the Scottish Government pass a note to the front bench to the Cabinet Minister for Health, Susan Deacon MSP. The official was Dr Aileen Keel and my understanding is that she was Deputy Chief Medical Officer at that time. It appeared to me to be a very odd action as I would not have expected such communication to be "regular". Footage of this incident may exist in the Scottish Parliament's video archives and I would like the Inquiry to try and locate this. This incident prompted me to consider that many of the officials who were employed in senior civil service positions in the new devolved Scottish Executive had been employed similarly prior to May 1999 in the Scottish Office by the UK Government. I understand that Dr Keel was Senior Medical Officer at SHHD from February 1992. Dr Keel was present at the meeting I attended with the Haemophilia Society and members of SNBTS which I referred to a paragraph 2.6. Given her involvement during such a crucial time in various meetings and her role in briefing the health minister during this period (I suspect she was key adviser to ministers at this time), it is my firm view that it absolutely essential that Aileen Keel gives oral evidence to this Inquiry about her involvement in briefing government (both pre and post devolution) about matters related to the scandal and our campaign.

2.23 A summary of the actions taken by the Scottish Haemophilia Groups Forum and other campaigners in the early days is set out in what we now call the "Accordion leaflet". It was prepared by the Haemophilia Scotland CEO, Dan Farthing-Sykes. I exhibit the leaflet as **WITN2287038.**

2.24 By 2004 or 2005, I had become increasingly disillusioned with the response of both the UK and Scottish Government to our plight and

the lack of impact that our input was having. Our dismissal by Andy Kerr MSP when he was Health Minister was a particular low point. In April 2006, the Health Committee had called for a Public Inquiry. I exhibit the official report of the proceedings where they made that recommendation as **WITN2287039**. Andy Kerr refused to act on that recommendation. I exhibit a letter to Roseanna Cunningham MSP from Andy Kerr dated 16 June 2006 where he asks the health committee to reconsider their decision to call for a public inquiry as **WITN2287040**. I also exhibit as **WITN2287041** a Scottish Executive news release (also dated 16 June 2006) which sets out their position as Mr Kerr also wrote to me regarding this matter on 23 April 2007 where he set out the Scottish Executive's position on the matter and I exhibit this as **WITN2287042.**

2.25 Similarly, Andy Kerr opposed amendments put forward by supportive MSPs to strengthen the Smoking, Health and Social Care (Scotland) Bill during its passage through the Scottish Parliament to extend the scope of Skipton Fund payments, for example to include people who had died before 29 August 2003. The Bill became the Smoking, Health and Social Care (Scotland) Act 2005 and provided for payments to be made by Scottish Ministers to certain persons infected with hepatitis C. These were administered via the Skipton Fund. I exhibit a report about the passage of the Bill and the various proposed amendments as **WITN2287043.** The report details a session on 1 March 2005 where members of the Scottish Haemophilia Forum and the late Frank Maguire of Thompsons solicitors gave oral evidence about the Bill.

2.26 The position of Andy Kerr was a significant contributing factor to my disillusionment and depression referred to in my first written statement WITN2287001 and at that point I withdrew from active involvement in campaigning as part of the Forum.

2.27 While I had some involvement in the intervening years, it was not until around 2009 or 2010 that I was fully drawn into renewed and active involvement with the Haemophilia Society.

2.28 In 2008, the Haemophilia Society had replaced the Scottish Groups Forum with a committee chaired by Ken Peacock and appointed a part time Scottish development officer, Susan Warren, who reinvigorated its activity in Scotland and provided welcome drive and expertise to energise voluntary input. She was employed on a p/t basis to lead a two year development project aimed at increasing awareness of haemophilia in Scotland and providing face-to-face outreach work for those isolated due to their condition. I exhibit a copy of the first newsletter that was produced in March 2009 by Haemophilia Scotland (which at that time operated within the Haemophilia Society framework) as **WITN2287044.**

2.29 My understanding is that several members of the committee became unwell and enthusiasm dwindled.

2.30 In 2011, I was asked to establish a new committee for Scotland by the then Chair of the Haemophilia Society Board of Trustees, Liz Rizutto. This came after my personal input to the Society's governance review referred to in paragraph 2.4. I became Chair of the Scottish Management Committee on 21 July 2011 and with the assistance of Susan Warren set about recruiting willing and able members. At that point the committee members were hand-picked and it took some time to later establish a process of elections and accountability.

2.31 Our initial task was to lend renewed purpose in Scotland to promoting wider awareness of the problems of bleeds and bleeding disorders; provide for people joining together to share experiences in dealing with bleeds and treatment; and providing supporting information and a focal point to people with bleeding disorders in Scotland. It was not, initially, to engage at that time with the by then ongoing Penrose

Inquiry, albeit I was personally and individually a very active core participant. In establishing the new Committee we were aware of the work that was separately taking place by the Haemophilia Society (as a core participant) in inputting to the Penrose Inquiry and at that point we felt it was wrong to impose a newly established committee with wider purposes into the work being coordinated by our solicitors at Thompsons. That work was drawn from a separate advisory group and included professional input from the Haemophilia Society who at that point employed a policy officer, Dan Farthing, who was based in Edinburgh, to lead the Society's input in to the Penrose Inquiry.

2.32 The Scottish committee already had considerable work to do in re-establishing understanding of bleeding disorders in Scotland and supporting those individuals and families with issues arising from repeated bleeds. In approaching a number of individuals to join that committee, I was keenly aware of the need to focus upon issues arising from bleeding rather than only on infections.

2.33 Part of that work included conducting an evening briefing session on 29 February 2012 for MSPs in the Garden lobby of the Scottish Parliament which was remarkably well attended, with 20 MSPs joining us and then the Cabinet Secretary for Health Alex Neill MSP speaking and acknowledging the impact on those infected.

2.34 At a further Parliamentary briefing we organised in April 2013 (by which time Haemophilia Scotland had become a separate Scottish charity as discussed below), the Minister spoke again about the actions that the Scottish Government intended to take when the Penrose report was published, including meeting with key stakeholders to discuss the way forward. The Minister expanded on what he had said a year before by saying that, "I intend to review the existing support provisions for people who contracted Hepatitis C from NHS contaminated blood when the final report of the Penrose

Inquiry is being considered". His remarks can be reviewed in full at https://youtu.be/Vjgmun57DtU

2.35 In my own presentation to MSPs, I referred to the need to act positively in response to the infected blood disaster but also to be forward and outward looking in providing for everyone with a bleeding disorder.

2.36 It was only later that we were gradually drawn as a body into the deliberations of the Penrose Inquiry, in response to the wishes of some Scottish members who were infected.

2.37 As Chair, I then became much more engaged in some of the wider issues the Inquiry was raising, rather than only those directly applicable to my own personal case.

2.38 The decision to form a Scottish charity, separate from the Haemophilia Society, was eventually made in 2012. At that point in time, the Society no longer funded or employed any staff based in Scotland and there was an inevitable distance between the Haemophilia Society Board which always met in London and the campaigners in Scotland who had worked together in the Penrose Inquiry (which was still ongoing but had not yet reported). There were differences of opinion about how to proceed on the issue of pushing for a UK Inquiry while still awaiting the outcome of the Penrose Inquiry.

2.39 The Scottish group felt that it was important to see the Penrose Inquiry through and that it might undermine our commitment to that aim if we were to become involved in making calls for a UK wide Inquiry at that time, which was the aim of the Haemophilia Society Board in London. It would have been impossible to engage with, follow up and contribute to two Inquiries at the same time. We did not know what the conclusions and recommendations of the Penrose Inquiry might be.

2.40 Further, by this time, if not before, it was apparent that we were much closer to the workings of the Scottish Parliament and, in particular by this time, to the key figures within the Scottish Government. We felt that the trustees and staff in London lacked that proximity to politicians whom we thought could advance the campaign's objectives in Scotland. In addition the Society's funding for the Scottish Development officer was being withdrawn, despite a case being put unsuccessfully in 2009 for extension of the aforementioned Scottish Development Project into a distinct separate 'service' for Scotland.

2.41 Forming an independent Scottish charity was an idea that had its roots in a paper written by Dr Ken Peacock which had been considered many years before by the Scottish Haemophilia Groups Forum. I exhibit the agenda for the meeting where the paper was discussed and a copy of the paper as **WITN2287045.** When the relatively new Scottish Committee of the Society resigned en masse in 2012 (only a year after formation of the Committee) to set up an independent alternative which was to be rooted in Scotland rather than London, we did so in the knowledge of the difficult task we faced.

2.42 When Haemophilia Scotland was first set up as an independent Scottish charity in 2012, we had no constitution, no members, no income, no charitable status and no staff. We built on the goodwill and support of many people in Scotland with bleeding disorders, the recognition of Haemophilia Centres and some political and government figures. Within two years we had a constitution, members, income, charitable status and staff. The most important element was the commitment and willingness of volunteers.

2.43 The purposes of Haemophilia Scotland (as set out in our constitution) are to provide support, information and advocacy for those with bleeding disorders. Our geographical frame of reference is Scotland

although we have been involved in projects in Malawi and Kenya, which required an amendment to our original constitution. I discuss the activities of Haemophilia Scotland further below.

3. *Identify any positions that you have held within the organisation, the dates that you held these positions and your role and responsibilities in that capacity.*

3.1 I have been Chair of Haemophilia Scotland since its establishment as an independent Scottish Charity in 2012.

3.2 As Chair, my key responsibilities have been to provide leadership and cohesion to the Board, members and others affected by bleeding disorders, chairing Board meetings (including preparing beforehand and following up afterwards), acting as line manager to the CEO, maintaining key relationships with Government, its agencies, haemophilia units and the Scottish Parliament, responding to or initiating press and media inquiries, meeting with individual members of Haemophilia Scotland at home or elsewhere, speaking at members meetings including the AGM and acting as host in various circumstances, actively supporting the Scottish Bleeding Disorders Network and along with other trustees, being responsible for the purposes of the charity and its legal responsibilities.

4. *Describe the main activities of the organisation, and any outcomes achieved by the organisation over the years since its establishment*

4.1 The activities that Haemophilia Scotland have been engaged in are set out on our website https://haemophilia.scot/ . We are now established as a Scottish Charitable Incorporated Organisation (SCIO). We have been registered with the Office of the Scottish Charity Regulator (OSCR) as a charity since 3 October 2013. Prior to becoming a SCIO, we were registered as an unincorporated association. Since our establishment as a SCIO, the Scottish Government have part funded our activities each year

4.2 I have throughout the period of my involvement with Haemophilia Scotland been deeply fortunate to have enjoyed working with my fellow Trustees who have taken responsibility for the governance of the charity. Thanks to their efforts, we had the necessary administrative infrastructure in place to be an effective charity within two years.

4.3 In the years following the establishment of Haemophilia Scotland as an independent charity, we became increasingly drawn into the proceedings of the Penrose Inquiry which did not report until 2015. Haemophilia Scotland became a core participant in its own right in February 2014. We were involved in instructing our solicitors and responding to media enquiries. Our growing involvement in that Inquiry culminated in the response we organised on the day that the report was published and the related work with the Scottish Government thereafter. We contributed substantially to the work of the Scottish Government's Financial Review and Clinical Review which led to the establishment and refinement respectively of the Scottish Infected Blood Support Scheme, which I discuss further below.

4.4 We seek to work closely with our sister charity, the Scottish Infected Blood Forum (SIBF), by hosting joint members meetings. Usually, when we meet Ministers, we do so jointly. It is important to note that SIBF conducted a useful scoping exercise which was funded by the Scottish Government, setting out the impacts of Hepatitis C on those who had been infected as a result of blood and blood products. The final report was published in March 2015. I exhibit a copy of the final report of the Scoping exercise as **WITN2287046.**

4.5 Another important activity undertaken by Haemophilia Scotland was when, in 2015 the Scottish Parliament's Health Committee was examining the issue of "Duty of Candour" and we were invited to meet with some of the members of the committee. This was because we

had experience of the problems faced by patients or patient groups when medical treatment had gone wrong. I exhibit a note of the meeting as **WITN2287047.** While progress was subsequently made on this issue in the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016, it did not provide for a patient's right to "receive full copies of any written reports and letters between medical professionals about them personally". This was a suggestion which we put forward in our submission dated 20 September 2015 to Committee members following the meeting. In this submission, we set out potential ways forward to strengthen the ambit of the Duty of Candour, beyond what was proposed in the Bill. The proposals are set out in Annexe A to the note of the meeting referred to above. For the reasons set out in the submission, this remains an outstanding ambition.

4.6 Recently, we have sought to draw Scottish Government attention to matters where the lessons of the Infected Blood disaster do not appear to have been immediately to mind in Government thinking. I exhibit as **WITN2287048** a letter dated 18 December 2020 from Haemophilia Scotland to the then Public Minister for Health, Joe Fitzpatrick MSP, about the appointment of a Patient Safety Commissioner and about changes to blood donation rules. Haemophilia Scotland are now engaged in deliberations with Scottish Government about the opportunity that a Patient Safety Commissioner might afford as it is of potential importance to those who have been affected by the contaminated blood disaster. Following the findings of the Cumberlege Report, Scottish Government has brought forward this proposal to address several areas for improvement in patient safety. Given our experience with infected blood products we do not see why that oversight should be restricted to medicines and medical devices but that provision should be extended to provide for the lessons learned from this Inquiry and other Inquiries investigating the infected blood disaster.

4.7 One outstanding task which we have yet to complete is the establishment of a permanent memorial/artwork to those who have passed away due to the infected blood disaster or have been affected by it. Haemophilia Scotland hosted a memorial event on 2 March 2016. Scotland's First Minister, Deputy First Minister and Health Minister attended the event. I delivered an introduction. I exhibit my introductory remarks as **WITN2287049.** The First Minister also delivered an address. She made reference in her remarks to the fact that families, as well those infected, were also in need of support. I exhibit the text of the remarks of the First Minister as **WITN2287050**. The event was the launching platform for a permanent memorial. A concerted effort has been made by a dedicated group of volunteers to raise the funds for the memorial. At the time of writing, approximately £35,500 has been raised and the fund continues to grow. The design and location within Scotland's capital city have yet to be agreed.

4.8 The support that we have offered in terms of events and via other means are set out in our newsletters and reported on our website. We provide information via our website and social media. It is sometimes very difficult to measure the support that we have afforded to particular individuals but in terms of what Haemophilia Scotland has achieved, for me personally, one of the most important elements of the work we do is often simply lending a sympathetic ear, in some cases to those who have never told anyone about their plight.

4.9 In terms of the advocacy purpose of Haemophilia Scotland, I am always wary of claiming that particular actions led to particular outcomes, when decisions rest with politicians. In effect we can only confirm that outcomes relate to those particular actions when asking the decision maker directly what swayed their decision. We have over the years been involved in considerable lobbying of politicians and

raising the profile of the issues arising out of the scandal via press and media. Further information can be found at https://haemophilia.scot/the-campaign/campaigning-in-the-media/. We have also been in receipt of a Scottish Government briefing paper which appears to indicate the influence Haemophilia Scotland had in Scottish Government's thinking on how to respond to the Penrose report. I exhibit the briefing as **WITN2287051.**

4.10 I discuss below in Section 10 the crucial role that Haemophilia Scotland played in the establishment of the Scottish Infected Blood Support Scheme (SIBSS).

4.11 To this day, funding for Haemophilia Scotland remains a formidable challenge, particularly as most charities find securing funding for advocacy so difficult. We have been involved in ongoing inquiries, working groups and seeking support for survivors of the infected blood disaster. In that respect we look to the Republic of Ireland, a country similar in size to Scotland, envious of its funding arrangements. We currently employ two full time staff members, including our CEO Dan Farthing-Sykes, who has a deep knowledge of the issues relating to infected blood products, much of it gained prior to his employment with us. The Inquiry itself places significant unfunded demands on our small staff. At the outset of the Inquiry, we were warned by the CEO of the Irish Haemophilia Society that one of the biggest challenges arising from the Lindsay Inquiry was to have a patient body left at the end of it. I have in the last few days been in discussion with office bearing colleagues about the possibility of having to wind up the charity if new funding cannot be secured. Staff time spent on this Inquiry is unlike our other areas of work as it is not funded yet it is drawing upon staff time and our focus and attention.

4.12 A very real potential outcome of this Inquiry is that, because we are not spending time on funded work or pursuing avenues where funding might be available, no new funding is coming in to maintain

the employment of two members of staff. This is particularly given that Scottish Government funding has decreased in the last four years from £100,000 per annum to £60,000 per annum, £50,000 per annum and now £25,000 per annum.

4.13 This is despite the fact that a great deal of work remains to be done. There are fundamental lessons to be learned, not only for the treatment and support for those with bleeding disorders and their families. If this Inquiry can make recommendations that improves support for those affected, addresses the failures in communication that remain to this day in health services and medicine, educates practitioners, gives an improved voice to patients and responds to their expectations then much of the efforts made and frustration campaigners have experienced may yet prove to be worth it.

4.14 At the time of writing, the impact of the coronavirus crisis on our members and others with bleeding disorders, including those affected by the infected blood disaster, is a major challenge in terms of offering support, information and advocating on the additional issues the crisis raises for them.

Section 3: Involvement in committees and/or working groups

5. *Set out your membership, past or present, of any committees or working groups relevant to the Inquiry's Terms of Reference*

5.1 I was invited to be part of the Scottish Financial Review and the Scottish Clinical Review which I will discuss below in Section 10.

5.2 I have been a member of the Steering Group of the Scottish Inherited Bleeding Disorders Network (SIBDN) since its establishment.

6 *Identify any positions that you have held within any relevant committee or working group, the dates that you held those positions and your role and responsibilities in that capacity*

6.1 As explained in paragraph 3.2, I am a member of the Steering Group of the Scottish Inherited Bleeding Disorders Network (SIBDN). I have been a member since SIBDN was established in 2016.

7 *Describe what you can recall about any matters relevant to the Inquiry's Terms of Reference that were considered by the committee or working group of which you were a member, including your recollection of the information considered by the committee or working group, the discussions held and the decision reached.*

7.1 The SIBDN is relevant to the Infected Blood Inquiry because it offers a model for how patient representatives, Haemophilia Centres, Government and its agencies can work together to improve haemophilia services and address problems jointly

7.2 On April 15th 2015, the Council of Europe Committee of Ministers recommended that *"to optimise the organisation of haemophilia care, a system should be established in each member state to allow the implementation of a multidisciplinary approach for treatment and care of patients (for example by setting up an advisory body including the representatives of the relevant clinicians, patients organisations, the health ministry, the paying authority, blood establishments and the regulatory authorities or by setting up centres of excellence)".* The present Scottish network largely fits that recommendation.

7.3 As a managed clinical network it has to meet the requirements of the National Services Division (NSD) which commissions and performance manages national specialist services on behalf of NHS Scotland. National commissioning is reserved for those specialist

services where local or regional commissioning is not appropriate. The Forum is thus not a bespoke design for haemophilia. At the time of writing, it is currently subject to a major internal performance review. Despite it fitting sometimes awkwardly into an existing administrative template it supports and/or enables close working between patient representatives, doctors, nurses and other health support staff.

7.4 For example, the expansion of the Haemophilia psychology service across Scotland beyond what was an initial pilot based in Edinburgh has probably been due in large part to the case made via SIBDN.

7.5 Similarly, most recently, the relationships established via the Network have facilitated a very rapid resolution of an incident during the current Covid 19 crisis. Complaints were received by Haemophilia Scotland about an issue arising with a home delivery company. Contact was made with network members who work in public agencies who in turn took the matter up. The company's proposed practice then rapidly reversed in favour of families receiving home deliveries.

7.6 During the recent meetings of the Network's steering group, we have raised the issue of care plans for people with bleeding disorders. I was asked at the last meeting if we still wanting to pursue this and build it in to next year's work plan. I confirmed that we did. This was prior to the oral evidence in February 2020 from the Inquiry's psychosocial Expert group confirming the need for care plans.

Section 4: Research and investigations

8 *Describe, and provide details of, any investigative or research work you have undertaken that is relevant to the Inquiry's Terms of Reference.*

8.1 In what amounts to over twenty years of asking questions about how we came to be infected, I am struggling to recall many of the matters that I have followed up upon. I also cannot claim to have devoted as much time to investigation in terms of requests to governments or its agencies as other campaigners across the UK, many of whom have passed away. I have however been furnished with materials which have prompted my questioning of politicians, officials and agencies, either directly or via various forms of media.

8.2 We must in Scotland acknowledge the research work done by Alice Mackie and Bruce Norval in particular.

8.3 I was drawn to start seriously doubting the official responses to our plight as "unavoidable". That doubt was fed when I was sent an annotated set of documents in an unmarked envelope in the late 1990s with the title "Haemophiliacs Fight for Justice". I did not know the source. I shared copies at the time with the Haemophilia Society and remember discussing them with Lucy McGrath, who was employed by the Haemophilia Society at that time. The first page of the document poses the question "*should all the plasma have been ALT tested for the Hepatitis C virus, and could lives have been saved?"* As set out in paragraph 2.6 above, I have always been interested in the topic of ALT testing and these documents therefore seemed to be particularly relevant. I have already provided a copy of these documents to the Inquiry's Investigative team but for completeness, I exhibit a further copy here as **WITN2287052.**

8.4 I became more alarmed at the actions of the British Government, the NHS and the actions or lack of them when two key further facts came to my attention.

8.5 Firstly, in 1999,Lucy McGrath had dug out and passed me some details about ALT test screening of donations in other countries. In Italy it was introduced in 1970 and in Germany in 1968. I passed the details she sent me onto a reporter.

8.6 Secondly, the attempt by the Government to apply Crown Immunity and maintain it until 1991. This is a matter that the Penrose Inquiry made only passing reference to in its Preliminary Report and in fact to my mind ignored. I did not understand why Government took the action they did in terms of the declarations they made, the personnel involved and why the production facility in Edinburgh was 'protected' by it. I have never found a full and reliable explanation of why this was the case and what it was the Government was fearful of. I believe this is a matter worthy of a much deeper investigation and public exposure. It is difficult to avoid the thought that having injured and harmed us via NHS treatment, Government felt the need to protect itself from us instead of supporting us.

9 *Outline the information or material that you found through your investigative efforts and/or research*

9.1 I have highlighted some key documents that I have discovered below. I have also acquired further documents including information from medical journals, government communications and minutes which I would wish to provide to the Inquiry.

9.2 I would like to draw attention to a minute of a meeting between Scottish Government officials and Haemophilia Consultants which took place on 10 February 2000. This document is available on Relativity as PRSE0003715. The document came to light during the Penrose Inquiry and has troubled me ever since. Both my wife Rosy and I annotated our concerns about it at the time when I printed the document. I exhibit a copy of the document with our annotations as **WITN2287053**.

9.3 As shown by our annotations to the document, I have always wondered who Mrs Towers is and what her role was in the meeting. She is not listed as being one of the attendees at the start of the minutes of the meeting that I had access to. I note that the Inquiry

has access to a set of these minutes under Inquiry Reference ARCH0003312_020. In the list of attendees in this version of the minutes, she is listed as Mrs Lynda Towers of the Scottish Executive Solicitors Office.

9.4 From my review of the document, it appears that the primary purpose of the meeting was plainly to consider statistics in terms of the numbers infected. However, what shocked me was the attitude later in the meeting of Government officials to the haematologists' request for authority to try and trace patients who had received blood product concentrates but were no longer in touch with haemophilia centres and might not be aware that they had been infected with Hepatitis C. Haemophilia Centre Directors Professor Lowe and Professor Ludlam clearly felt they had to seek authority from Scottish Government to identify former patients that they had reason to believe might be ill having contracted a potential killer virus. What was controversial for me was the fact that the response of Government officials was that, before taking any such action, the lawyers at the NHS Central Legal Office (CLO) had to approve this first. It appears from the minutes that Mrs Towers was the person who advised that CLO advice should be taken. It remains hard for me to understand why lawyers would be involved in providing advice about tracing patients. That was clearly a medical and/or public health matter and that was why the haematologists had sought authority to take it forward. I am unaware of any such efforts to trace infected haemophiliacs beyond those already known having been taken or authorised at that time.

9.5 This matter has been of profound concern because it potentially meant that the Scottish Government officials and/ or NHS lawyers made a decision in 2000 to restrict attempts to trace people who would benefit from potentially lifesaving treatment for their Hepatitis C. The consequence of this is that it could have potentially allowed the health of those people to deteriorate to the point of death. I have made various efforts to try and establish what responses or paper

trail followed on from the doctors' request for authority but none ever came to light. I remember raising my concerns in a conversation with a senior and experienced MSP in 2017 who suggested in response that "no, they wouldn't have written anything down. It would all be phone calls". The lack of any written response or subsequent record raises further questions to me over the secrecy at a time when lives were at stake. I would like the Inquiry to investigate what happened following this meeting, including establishing what advice was given by the CLO.

9.6 My concern has been compounded by the fact that, 16 years later, during the work of the Short Life Working Group that was established following the Penrose Inquiry recommendation that the Scottish Government should take steps to offer an HCV test to everyone in Scotland who had had a blood transfusion before September 1991 and had not been tested, it was found that up to 71 people could have been infected with HCV from blood concentrates administered in Scotland but that they had never been tested. I exhibit a copy of the Penrose Short Life Working Group report dated August 2016 which sets out the position as **WITN2287054.**

9.7 My conclusion is that, as a consequence of the lack of Scottish Government action in 2000, up to 71 people with bleeding disorders may have become unknowingly more ill over the intervening years. In some cases, they may have died. It appears from the minute that the Scottish Government in 2000 were more concerned about possible court action which might have resulted from the untraced haemophiliacs being found than tracing people who might need treatment and thus saving lives. Haemophilia Scotland recently submitted a Freedom of Information request to ask about the implementation of the recommendation of the Penrose Short Life Working Group that attempts should be made to trace these people. The response indicated 36 people could not be traced and that 13 people had passed away. I question whether, if action had been

taken in 2000 whether these 36 people could have been traced and whether any of the 13 deaths could have been prevented. I exhibit a copy of the response to the Freedom of Information request dated 29 March 2021 as **WITN2287055.**

9.8 I also note that Aileen Keel, who at the time was Deputy Chief Medical Officer, was also present at the meeting. Also during the Penrose Inquiry, I found a copy of minutes of another key meeting on 1 September 1999 between the Scottish Government and Haemophilia Doctors where Dr Keel was present. The minutes of this meeting have the Inquiry reference PRSE000978. Her presence at these meetings has reinforced my view that Aileen Keel was a key Government adviser during this period in relation to the Government's response to the scandal in Scotland and that she must give oral evidence before this Inquiry.

9.9 I also have a copy of a letter that was sent to doctors about the lookback exercise from the Chief Medical Officer on 3 April 1995. I note that the letter stated that further queries about the lookback exercise should be directed to Dr Keel. I exhibit this letter as **WITN2287056**. It is therefore important to me that the Inquiry also investigates her role in the lookback exercise.

9.10 One of the matters that has particularly troubled me over the years has been what appeared to be a lack of input from public health experts into what constitutes an unmitigated public health disaster. I would have expected the Penrose Inquiry to look into the response that there was from public health officials in Scotland but the matter hardly featured in its deliberations. Given that it involved human to human transmission of fatal viruses, albeit via blood borne rather than airborne routes, the apparent failure of public health officials to warn the public of the risks involved, both prior to and after use of blood and blood products remains one of the key unanswered puzzles of the story. Hepatitis was to be listed as a notifiable disease.

9.11 I recall raising the fact of my infection and interest in the scandal during a private chance discussion with a retired Director of Public Health in a large regional Health Board in around 2007/8. Her response ran along the lines that "yes, they had been involved but that was all dealt with now." This suggested to me that public health doctors/ officials were involved but that it had been covered up. It is important to me that the Inquiry investigates public health and who was involved.

10 Describe the efforts that were involved in obtaining the information or materials referred to in question 9 above.

10.1 I discovered the documents above when I was a core participant during the Penrose Inquiry during the process of documents being disclosed by that Inquiry.

11 State whether there is information or material that you were unable to obtain access to during your investigative or research work and if so provide an outline of what you were seeking but have been unable to obtain.

11.1 As outlined above, I have been unable to establish what occurred following the meeting of 10 February 2000 in terms of correspondence or the advice given regarding the tracing of haemophiliacs who had been infected. I would like the Inquiry to try and find this information.

Section 5: Individual campaigning activities

12 Outline the aims and outcomes of any campaigning activities insofar as relevant to the Inquiry's Terms of Reference that you have undertaken as an individual.

12.1 My own involvement in the campaigning effort has varied over the years depending on my personal health circumstances. Indeed, the

word "campaigner" has never sat comfortably with me as it can provoke resistance and prejudice from Government, medical associations or funding trusts as witnessed in the evidence already heard by the Inquiry. Campaigning involves asking questions where they may not wish to be asked and pressing authorities to take action they have tried to avoid. In extreme cases it can even involve surveillance by the State as reported on the front page of the Times on 30 November 2018 about Lockerbie families being 'put under observation' as they became increasingly organised. Indeed there have been discussions among 'campaigners' in Scotland where we have worried that mail was being opened or telephone calls being tapped. .

12.2 I have learned of the need to work positively with decision makers, build trust no matter what challenges they present and to try to persuade them. That involvement in seeking to persuade press, media and politicians of the need for better recognition, response and reparation was based on a number of resources that I was able to draw upon. Firstly, I had been employed professionally in media positions and my career had also involved working with politicians, government and its agencies (both before and after devolution) and had gained some insight into how Government and its agencies operate. Secondly, I have been deeply privileged to hear from many survivors of the disaster, both still alive and the bereaved. Many of those who told me their stories some time ago have now passed away. The knowledge of what befell others like me who were infected and the injustice of repeated Government responses, particularly at UK level, mean that I cannot simply walk away. Those who have been subjected to grinding financial, emotional and physical hardship deserve to be believed and deserve support. I feel duty bound to provide assistance as the State and its services has over decades let them down very badly.

12.3 As explained above, I had no formal role within the Scottish Haemophilia Forum, albeit I was sometimes a point of contact for it and undertook a number of campaigning activities as an individual as outlined below. It is difficult to recall all of the aims and outcomes as I tended to write letters to MSPs and to the media as and when particular issues that seemed to me to be important arose.

12.4 One of the main themes that comes across in my letters is my desire for a public inquiry to be held. One of the failings of Government that struck me early in my involvement was the failure of successive Governments to conduct an independent inquiry to learn lessons from a disaster of such scale and complexity, recognise the failings and rebuild trust. Repeated empty ministerial apologies have only over decades made the hurt more acute. I have exhibited at paragraph 2.24 above a copy of a letter that I received from Andy Kerr MSP, the then health minister in April 2007 on this topic. I discuss further below the correspondence that I sent to Nicola Sturgeon MSP when it was announced that a public inquiry would be held in Scotland in Section 8 below.

12.5 I also recall being concerned about the availability of and funding for hepatitis C treatment that was effective and tolerable. I contributed to the campaign for greater investment in effective treatment by agreeing to speak at an agenda setting conference in 2004. I exhibit a copy of the agenda for the conference in April 2004 as **WITN2287057** and my handwritten notes of my presentation as **WITN2287058.**

13 *Describe the various campaigning activities you have undertaken, including meetings, demonstrations, complaints and letter writing in relation to clinicians; NHS bodies; blood transfusion services; pharmaceutical companies, financial assistance schemes, government ministers, MPs, MSPs, Assembly Members or MLAs and/or government departments and civil servants.*

13.1 I first went to see my MP about my concerns in 1997 and wrote to a succession of MPs and MSPs. Due to the high number of encounters I have had with MPs and MSPs, I am unable to recall them all. I have provided throughout this statement examples of letters that I have written to MPs and MSPs. I have further correspondence with politicians within my possession that I would wish to provide to the Inquiry.

14 Describe the response (if any) that you received to the activities described in paragraphs 12 and 13, identifying who responded, when they responded and what the response was.

14.1 I have provided responses that I have received from MPs and MSPs to particular letters in the relevant sections of my statement. I have further responses in my possession which I would wish to provide to the Inquiry.

15 What involvement have you had with the media as part of your campaigning activities? Identify, if you are able, the media outlet and timeframes of the media output, and outline the nature of your involvement.

15.1 Again, due to the high number of appearances that I have made in the Scottish media and quotations that I have had in newspapers, I am unable to recall them all. I can recall having letters published in both the Herald and the Scotsman. I exhibit as some letters that I have written to these newspapers and some newspaper cuttings that I have collected over the years as **WITN2287059**. These are by no means exhaustive and I have further newspaper cuttings that I would wish to provide to the Inquiry.

15.2 I recall one exchange in the letters page of the Herald with former First Minister (and now Lord) Jack McConnell who had claimed that payments under the Skipton Fund should be conditional on no further

legal action by beneficiaries as there was no fault. I challenged him publicly and he did not pursue the point any further. This letter that was published on 30 March 2004 has already been recovered by the Inquiry. The newspaper cuttings that I hold are far from comprehensive. During the Penrose Inquiry, I provided a shirt box full of newspaper cuttings that I had gathered. I was promised by Penrose Inquiry staff that these would be returned at the end of that Inquiry but they never were. I would like this Inquiry to try and recover these cuttings from the Penrose Inquiry archive.

15.3 As explained above, I have had letters published in both the Herald and the Scotsman and other newspapers. I have also appeared frequently over the years on BBC Scotland (both television and radio) and STV, more often in my capacity as Chair of Haemophilia Scotland. I would like the Inquiry to carry out a search of the archives of the main Scottish media outlets to build as full a picture as possible of the coverage in Scotland relating to the Infected Blood disaster.

15.4 In 2004, I appeared in the BBC Frontline Scotland documentary called *Blood and Tears.* I understand that the Inquiry has a copy of this documentary and I consider it to be important evidence.

Section 6: Complaints to the police, ombudsman or regulatory bodies

16 Provide details of any complaints that you have made to:
(a) the police;
(b) an Ombudsman
(c) a regulatory body (e.g the General Medical Council)
stating when the complaint was made, whether and if so to what extent it was investigated and what the outcome of the complaint was

16.1 I personally have never lodged any complaint with any of the above organisations. As mentioned in paragraph 12 of my second written statement (Reference WITN2287002), I was interviewed in 2003 by Superintendent Stephen Heath when he was carrying out his

investigations into the circumstances of infection across Scotland. I did not hear anything further following the interview. Reference to the investigation is made in the note of the meeting of our evidence to the Scottish Parliament's health committee when they were examining the "Duty of Candour", which is exhibited at paragraph 4.5. No explanation has ever been offered as to why the report of the investigation has never been made available, even in redacted form. I would like the Inquiry to recover the report and to make it available.

Section 7: Litigation

17. Have you been involved in any litigation relevant to the Inquiry's Terms of Reference?

17.1 Yes. I was, until relatively recently, involved in an action of damages in the Court of Session in Edinburgh which related to my infection with hepatitis C as a result of receiving a Scottish factor VIII concentrate (type NY) for a thigh bleed in May 1986. This was the first and only time I received such treatment. My case centred on whether I should have received this treatment and the circumstances leading up to it. The details of the circumstances of my infection are set out in my previous statements to the Inquiry and in the oral evidence I gave to the Inquiry in the summer of 2019.

If so,

a. Who was the litigation against?

17.2 The defenders (defendants) in the action as originally raised on my behalf in 1999 against were (a) the Secretary of State for Scotland on behalf of (i) the Scottish Home and Health Department (ii) the Scottish Office Department of Health and (iii) the Scottish National Blood Transfusion Service ("SNBTS") (b) the SNBTS (c) Lothian Health Board and (d) Lothian University Hospitals NHS Trust. When

the action was raised on my behalf in 1999, we had relatively little information about the circumstances of my infection and so those representing me took the view that I required to raise the action as widely as possible in order that a relevant claim was initiated against all possible defenders before 1999, after which time the claim may have become barred by limitation. The complex issue of limitation in the action is discussed below. As I explain below, I had been kept in the dark about the circumstances of my infection and its aftermath. The action was sisted (stayed) for many years. This allowed certain information to become available to me as a result of the Penrose Inquiry, which reported in 2015, though the extent to which I was able to uncover the details of my infection within that Inquiry was limited (as explained below). At the outset of the action, the preliminary investigations were funded by me.

17.3 As the action progressed, I was able to obtain funding on a contingency basis for the action to proceed. I was also able to obtain the services of a firm of solicitors and Senior and junior Counsel on a speculative basis. This had not been available to me when the action had been raised many years before. To have progressed the case without these arrangements being in place would have put me at risk of losing the family home. Due to my financial situation as a result of my infection, I would not have been able to progress the action without these funding arrangements being available to me.

17.4 The sist (stay) was recalled at around the time of the conclusion of the Penrose Inquiry in 2015. In due course, the identity of the defenders was changed by way of amendment so that ultimately it progressed against (a) Lothian Health Board, as responsible for the acts and omissions of the hospital staff and the management of the Royal Infirmary of Edinburgh at the time of my infection there in May 1986 and (b) the Common Services Agency, a non-departmental public body, constituted under the National Health Services (Scotland) Act 1978, as responsible for the acts and omissions of the

SNBTS which produced the factor VIII concentrate given to me in May 1986 which was manufactured at the Protein Fractionation Centre in Edinburgh and which caused my infection.

b. In which jurisdiction did the litigation take place?

17.5 The litigation took place in the Court of Session in Edinburgh.

c. What is your understanding of the issues involved in the litigation?

17.6 The litigation involved a number of complex issues. In essence, I sought damages from the defenders for negligence. The issues involved in the case against the first defenders (Lothian Health Board) were as follows:

(a) Whether the care which I had received when I attended the accident and emergency department of the Royal Infirmary of Edinburgh ("RIE") on 9th May 1986 had been negligent. I had been referred to the RIE that day by my GP. My GP records indicated that I had been referred to the hospital on the basis of possible haemophilia. I was not a diagnosed haemophiliac at the time but had had investigations into my bleeding as a child. The argument for the court was that the orthopaedic doctor who saw me that day had been negligent in that he failed to take a proper history from me. We argued that had he done so, he would have elicited the investigations into my bleeding status which had been undertaken on me as a child and referred me for treatment within the haematology department, where we said that my bleed could have been treated without the use of a factor concentrate. This was a cause of action which was introduced in response to the defence advanced by the Board. They argued that as my bleed had progressed by 14th May to a re-bleed, I would in any event have required to be treated with a concentrate and would in any event have become infected. This argument about the 9th of May was introduced in the event that the Board were proven correct, which we disputed. We argued that if they were right about what would

have happened on the 14th, then there had also been negligence on the 9th, at which time the bleed had not advanced to become a re-bleed and at a time when it could have been treated more conservatively;

(b) Whether the doctor who saw me on 14th May 1986 (the day I was infected) was negligent in giving me factor VIII concentrate without obtaining a clotting screen to ascertain if I had haemophilia or another bleeding disorder, what type I had or the level of it (it was accepted that he did not do so as a matter of fact) and by not contacting a consultant before treating me (it was accepted that he did not do so as a matter of fact);

(c) Whether the junior doctor was negligent in not obtaining my informed consent for the treatment with factor VIII concentrate or advising me about reasonable alternatives, including not having any treatment, cryoprecipitate or DDAVP. The failures to warn me about the risks of the product were not accepted as a matter of fact by the Board. That the risks of the product ought to have been known by him was not accepted either, nor were the risks themselves of transmission and possible serious outcome of infection (see below);

(d) Whether the first defenders ought to have procured a supply of the then available English factor VIII concentrate (8Y) for use on previously untreated patients like me. It had become apparent to us during the course of the Penrose Inquiry that a supply of this product had been procured after my infection for use on previously untreated patients like me (the evidence of which I refer to below). I was asked questions and gave oral evidence to the present Inquiry about the letters which were revealed to me in the Penrose Inquiry about attempts made to procure such a supply in the aftermath of my infection. It has subsequently come to my attention (though this was not known to me during the course of the litigation) that I was, in fact, not the only person to have become infected with HCV as a result of a first treatment with factor VIII concentrate during the course of 1986. This fact became apparent to me on seeing a copy of the letter uncovered during the course of the current Inquiry under reference HSOC0011756. This letter shows that another patient under the care of Dr Ludlam at the RIE was infected in that way

earlier in 1986; This alarming evidence from February 1986 was not uncovered during the Penrose Inquiry; and

(e) Whether, but for the negligence, I would have been treated other than with the factor VIII concentrate which I did receive and thus would not have become infected.

17.7 The issues involved in the case against the second defenders (the CSA as responsible for the NHS) were as follows:

(a) Whether it was or should have been known that the NY concentrate was likely to transmit NANB hepatitis to me on first infusion and that the disease was possibly a serious one (also relevant to the case against the Board);
(b) Whether SNBTS were negligent in providing for the treatment of patients like me a factor VIII concentrate which was infected with HCV;
(c) Whether SNBTS were negligent in failing to procure a supply of 8Y for patients like me; and
(d) If there was an obligation to procure such a supply, whether it could have been procured, on what basis and whether I would have received it.

17.8 Further issues in the case included:

(a) Whether the action was time barred (see below) and, if so, whether the court should exercise its equitable discretion to allow the action to proceed anyway; and
(b) What loss had been caused by the infection and the value of that loss, in particular the extent of the loss caused as a result of the interruptions to my employment.

d. What is your understanding of what information was obtained during the litigation?

<u>The facts relating to my infection</u>

17.9 When I approached solicitors in connection with my case, I was able to recover my medical records. It was only then that it became apparent to me that after my infection occurred, an investigation was instigated by Dr Ludlam with the junior haematology doctors (Dr Austin and Dr Craig) who had been involved in my treatment. The relevant entries were produced with my first report. As I said, there was no reason for me to think that I could have been treated other than as I had been. Despite discussing matters with Dr Ludlam after I became infected in 1986, I was given no reason to think that anything had gone wrong. I was unaware that any such investigation had been undertaken or that there was any reason for it to be. I was shocked to learn this as it suggested that something had indeed gone wrong. It was also only when my medical records were recovered that I became aware that Dr Ludlam had described my infection to my new treating consultant when I moved to Manchester as "unfortunate" in a letter of 7th December 1987. I was also only made aware at that time that there had been further correspondence between them about me after I had moved to Manchester, as described elsewhere in my evidence to this Inquiry.

The possibility of an alternative treatment

17.10 The information which became apparent to me in the run up to and during the litigation was very interesting. As I detailed in my previous statements, I had been completely unaware of the possibility of me being treated other than with the factor concentrate treatment which I did receive. It was only as a result of the information made available to me by Dr David Evans in 1996 that the possibility of treatment with DDAVP was first revealed to me. I brought this to the attention of the Haemophilia Society at that time. Their position was that I could not have been infected in 1986 as products were not infective at that time. They were, in fact, wrong about that understanding as it was based on the lack of infectivity in the English 8Y product only. They sought an explanation from Dr Ludlam in the late 1990s as to how I

could have become infected in May 1986 (see Inquiry references HSOC0012063 and HSOC0012064). I am unaware if they ever received a written response.

17.11 I was able to obtain supportive expert reports in relation to my case. An independent expert consultant haematologist gave an opinion stating that there had been negligence in the way in which I had been treated and that I should have received DDAVP, which would have avoided my infection. Various documents pertaining to the extent of knowledge about alternative treatments, such as DDAVP or cryoprecipitate and their relative safety compared to concentrates were uncovered and were produced in the litigation, including the following:

(a) "DDAVP in Haemophilia and von Willebrand's Disease"; The Lancet, ii, pp 774 – 775, 1 October 1983;
(b) Copy of Kernoff et al, 'High risk of NANB hepatitis after a first exposure to volunteer or commercial clotting factor concentrates: effects of prophylactic immune serum globulin', *British Journal of Haematology*, 1985; 60:469 (Inquiry reference PRSE0003439); and
(c) Copy of Colvin et al, 'A prospective study of cryoprecipitate administration: absence of evidence of virus infection', *Clinical and laboratory Haematology*. 1987; 9:13-15 (Inquiry reference PRSE0003838).

17.12 Indeed, it became apparent to me and my advisors that the guidance which was in force at the time of my infection included a recommendation that mild patients like me should have been treated with DDAVP, if possible (UKHCDO guidance issued on 14th December 1984 under Inquiry reference PRSE0002282).

Knowledge of the risks of NY

17.13 During the course of the Penrose Inquiry, information became available to me which was supportive of the contention that it was known or should have been known to both those treating me and those who produced the concentrate with which I had been treated that it would be highly likely to infect me with HCV (then known as NANB hepatitis) and that NANB hepatitis could, in some patients, develop into a serious, if not life threatening condition. Academic papers to which I was given access supported these contentions, as follows:

a) Mannucci P M, Capitanio A, Del Ninno E, Colombo M, Pareti F and Ruggeri Z M (1975) Asymptomatic liver disease in haemophiliacs. Journal of Clinical Pathology, 28, 620-624 (Inquiry reference PRSE0000616);
b) Preston F E, Triger D R, Underwood JC E, Bardhan G, Mitchell VE, Stewart RM and Blackbum E K (1978) Percutaneous liver biopsy and chronic liver. disease in haemophiliacs. Lancet, ii, 592-594 (Inquiry reference PRSE0003622);
c) Spero J A, Lewis J H, Van Thiel D H, Hasiba U and Rabin B S (1978) Asymptomatic structural liver disease in hemophilia. New England Journal of Medicine, 289, 1373-1378 (Inquiry reference PRSE0002523);
d) Fletcher et al, 'NANB hepatitis after transfusion of factor VIII in infrequently treated patients', *British Medical Journal*, 1983; 287:1754 (Inquiry reference PRSE0002154);
e) Preston et al, 'Non-A, non-B hepatitis and heat treated concentrates', The Lancet, 27 July 1985:213 (Inquiry reference PRSE0004594);
f) Hay CR M, Preston FE, Triger DR and Underwood JC E (1985) Progressive liver disease in haemophilia: an understated problem? Lancet, i, 1495-1498 (Inquiry reference PRSE0004229);
g) Kernoff et al, 'High risk of NANB hepatitis after a first exposure to volunteer or commercial clotting factor concentrates: effects of prophylactic immune serum globulin', *British Journal of Haematology*, 1985; 60:469 (Inquiry reference PRSE0003439); and

h) Schimpf, 'Liver Disease In Haemophilia', The Lancet, 1986; 323 (Inquiry reference PRSE0001049).

The procurement of 8Y

17.14 As I stated above, it became apparent to me during the course of the Penrose Inquiry that a supply of a safe English product (8Y) had been procured as a result of my infection. This formed the basis of an argument that such a supply could and should have been procured for patients like me before. I address what we found out about that possibility in connection with the defenders' response below. However, it is important to realise, I think, that we had attempted to find out more about the circumstances of my infection during the course of the Penrose Inquiry. We made an application to the Chairman to be able to ask specific questions, in particular about the circumstances in which I had become infected. We wished to pose these questions to Professor Ludlam who was the consultant in charge of the department where I had come to be infected. We were not allowed to ask these questions. I understand that the reasons for that refusal were that the Inquiry was interested under its terms of reference investigating not specific cases but general systemic issues. We had argued (unsuccessfully) that the examination of the circumstances of my infection would illuminate questions relating to the existence and/ or fitness for purpose of any system designed to protect patients like me. Indeed, a topic for examination by the Inquiry had been introduced shortly before the oral hearings started to deal specifically with cases like mine, defined as follows:

"The use of blood product concentrates in Scotland in the period between the introduction of NHS heat treated products in 1984 and the supply of NHS products sufficiently treated to inactivate Hepatitis C"

I produce for the Inquiry the transcript of the day (Friday 14th October 2011) when my representatives argued for questions to be asked relating to my case. I exhibit this transcript as **WITN2287060.**

17.15 It became apparent during the course of the Penrose Inquiry that a supply of 8Y could have been made available to the SNBTS as part of the ongoing clinical trial of that product and that there was good reason for it to have been suspected that the product would be unlikely or at least less likely to transmit HCV on first infusion than the then available Scottish concentrate. Although I have given evidence about these matters to the Inquiry in my oral session, the following were the relevant pieces of correspondence:

(a) Letter from Dr Boulton to Dr Perry dated 27th June 1986 (Inquiry reference PRSE0003845);
(b) Letter from Dr Boulton to Dr Cash dated 27th June 1986 (Inquiry reference PRSE0002000)
(c) Letter from Dr Perry to Dr Boulton dated 2nd July 1986 (Inquiry reference PRSE0003030);
(d) Letter from Dr Boulton to Dr Perry dated 4th July 1986 (Inquiry reference PRSE0001784);
(e) Notes Dr Boulton dated 4th July 1986 (Inquiry reference PRSE0002783);
(f) Letter from Dr Perry to Dr Boulton dated 7th July 1986 (Inquiry reference PRSE0003814);
(g) Letter from Dr Frank Boulton to Dr Robert Perry dated 7th July 1986 (Inquiry reference PRSE0004097);
(h) Letter from Dr Robert Perry to Mr Norman Pettit dated 10th July 1986 (Inquiry reference PRSE0004383);
(i) Letter from Dr Perry to Dr Boulton dated 24th July 1986 (Inquiry reference PRSE0003143);
(j) Letter from Mr Norman Pettit to Dr Robert Perry dated 24th July 1986 (Inquiry reference PRSE0003693);
(k) Letter from Dr Robert Perry to Dr JK Smith dated 24th July 1986 (Inquiry reference PRSE0001397);

(l) Letter from Dr Perry to Mr Pettit dated 28th July 1986 (Inquiry reference PRSE0004146);

(m) Letter from Dr JK Smith to Dr Robert Perry dated 1st August 1986 (Inquiry reference PRSE0002616);

(n) Letter from Dr Perry to Dr Boulton dated 5th August 1986 (Inquiry reference PRSE0002643); and

(o) Letter from Dr Perry to Dr Boulton dated 7th August 1986 (Inquiry reference PRSE0002611).

17.16 It had also been apparent from the Penrose Inquiry that subsequent to that supply being procured, Dr Ludlam had himself been able to procure a supply of 8Y for virgin patients independently of the SNBTS procurement route (see paragraph 22.67 of the Penrose Inquiry final report). It was on the basis of that evidence that it remained unclear to us during the course of the litigation what the appropriate procurement route would have been. Thus, the case about the procurement of the 8Y was advanced against both defenders, both having apparently had the ability to procure a supply. The defenders never revealed what the appropriate procurement route was designed to be.

17.17 As I note below, the position of the defenders to the litigation was that it was not known until the 1990s that 8Y was in fact safe as regards the transmission of HCV. During the course of the Penrose Inquiry and the litigation, we were able to access certain documentation which suggested that it was in fact well known before my infection that 8Y was safe. The following documents were produced in the litigation to support that contention:

a) Letter from the Blood Products Laboratory to Haemophilia Directors in England and Wales dated 24 July 1985 (Inquiry reference CBLA0002224);

b) Copy minutes of a meeting of the Central Committee for Research and Development in Blood Transfusion dated 19th December 1985 (Inquiry reference PRSE0001229);
c) Minutes of a meeting of the Central Committee for Research and Development in Blood Transfusion dated 9th July 1985 (Inquiry reference PRSE0002420);
d) Report by Dr Robert Perry for Haemophilia Centre Directors dated 10 January 1986 (Inquiry reference PRSE0003457);
e) Note of a meeting held at the Protein Fractionation Centre, Edinburgh on 17 March 1986 (Inquiry reference PRSE0003964); and
f) Annual report of the Blood Products Laboratory to March 1986 (Inquiry reference PRSE0000793).

e. What was the response of any defendant to the litigation?

17.18 The defenders refuted at every turn almost every contention which we made in the litigation. The particular points which were taken against me were:

(a) That the action was time barred (see below). In particular, they argued that despite my contacts with Dr Ludlam in the aftermath of my infection I knew or should have known earlier than 1996 that an alternative treatment could have been used;
(b) That there had been no negligence at all, even by the doctor who gave me a concentrate without knowing my clotting status. It was formally denied that there was negligence in not contacting the consultant, despite Professor Ludlam having said at the Penrose Inquiry that he should have been contacted in a hypothetical case which I assume was based on mine (see paragraph 22.79 of the Penrose Inquiry final report);
(c) That even if a consultant had been contacted and a clotting screen done, I would have been treated with a NY anyway due to the severity of my bleed;
(d) That it was not known that 8Y was safe at the time of my infection and that was not known until 1993. In that regard, it was argued that

preliminary evidence that it might have a reduced risk of transmission of NANB hepatitis was first published on 10th October 1986 (reliance was placed on the paper by Colvin & Ors in Clin Lab Haematol 1986, 8, 85 – 92);

(e) That no supply of 8Y could have been procured for me anyway, despite a supply having been procured after my infection; and

(f) That the loss which I had suffered was not as much as I claimed it was (I address this below).

17.19 No admission of liability was made formally. The action was concluded without any apology or explanation as to why I had been misled about how I had come to be infected, why an investigation took place or what changes in practice resulted from it. The principal expert instructed on behalf of the Board was Professor Brian Colvin. Though I understand that expert witnesses are independent, I found it odd that he had been the expert instructed by the Penrose Inquiry to advise on matters surrounding infections around the time of mine and that he should be instructed to speak for the Board. Arguments were advanced about why DDAVP might not have been appropriate and why it might not have worked. Of course, I had been given DDAVP as cover for a biopsy in 1992, (with excellent results) which was part of the Board's case against me on limitation and was thus known to them. Also, it was argued that the DDAVP might not have achieved a haemostatic result for me. It appeared that no consideration had been given to the papers upon which we had relied which indicated that a satisfactory increase in my factor VIII level would easily have been expected, in particular in light of my high resting factor VIII level which Professor Colvin appeared not to have considered.

17.20 As far as the potential value of the case was concerned, I claimed that my working life had been significantly affected by my infection and the numerous treatments for it I have received over the years. Against me, it was argued in the defenders' written pleadings that the

liver biopsy which I had undergone in 1992 had indicated that *"the degree of stenosis [was] unusual and [prompted] speculation about the co-existence of alcohol abuse, diabetes or obesity".* Further, it was suggested that *"his remnant risks from cirrhosis are associated with his long history of misusing and abusing alcohol, which began in early adulthood".* These comments are clearly speculative. I was virtually abstinent from alcohol from 1989 to 1996 (as advised), I carried no excess weight and still do not have diabetes. I had had some problems with alcohol as a result of my experiences of treatment for HCV in the early 2000s, as described in my previous statements. It seemed that the defenders wished to make something of alcohol in the case against me. There were no such issues until after the treatment for my HCV. There was no basis for thinking that there had been. These problems were caused by my infection. As a result of this argument being taken against me, which seemed to based on "speculation" in a biopsy report, I required to seek the opinion of a psychiatrist as to the cause of my various troubles as being linked to the infection. I found this most invasive and very unpleasant to have to re-live. I did not think it was at all reasonable for the defenders to have taken this approach.

f. How was the litigation conducted?

17.21 I refer above to the way in which the litigation was conducted as a result of the approach taken by the defenders. Breach of duty was never accepted formally.

17.22 It was consistently argued by both defenders that my case was time barred in terms of section 17 of the Prescription and Limitation (Scotland) Act 1973. The action was not raised until 1999. This was despite the fact that I had had no basis for thinking that I could have been given any treatment other than the factor VIII concentrate which I did receive until 1996, when I spoke with Dr Evans. This had been as a result of the conversations with Dr Ludlam in which no hint of

there having been any alternative to what was given to me. I had never known about there having been an investigation into my infection until the recovery of my medical records for the purposes of the contemplating the litigation in the late 1990s.

17.23 When the proceedings were originally contemplated, my solicitors contacted Dr Ludlam for comment on my case. He took advice about the possibility of providing an expert report and was told that he should not. He asked to speak with me at that time. When my wife and I met with him, we both felt that he was trying to dissuade me from taking the case to court. He did not feel able to answer me when I asked what he would have done by way of treatment recommendation, had he been contacted by the more junior doctors. He told me that DDAVP would not have been appropriate in my case. This, of course, was contrary to the advice I ultimately received from the independent expert.

17.24 The time bar argument was also taken despite the position which had been adopted on behalf of the Board at the Penrose Inquiry. In arguing that questions about my case should not be allowed in that forum, it had been argued that the litigation (which was ongoing at that time) was a more appropriate place for questions about my case to be asked. It therefore came as a surprise that the very same Board argued in the litigation that the questions could not, in fact, be asked as the action was time barred.

17.25 To an extent, issues arose about the facts of the case. There was no direct note of my attendance at the hospital on 9th May 1986. There was indirect reference to my attendance at that time from a later date. It was unclear what type of doctor had seen me on the 9th and precisely what they had done.

17.26 Overall, the litigation was very difficult. The need to prove negligence with support from the very medical profession I sought to criticise was difficult. The fact that despite having been kept in the dark for many

years about the circumstances of my infection by the NHS, it was argued by the NHS that it was time barred was difficult to understand and to accept. When I did take the case to court, it was argued that some of the loss I had suffered was my own fault. There was no basis for doing so. I had to relive certain difficult parts of my life which resulted from the infection. I did not think that that was necessary or reasonable.

17.27 I was fortunate that by the time my action proceeded after 2015 I had had the benefit of certain information being available to as a result of the Penrose Inquiry and of funding being available to me. None of these things had been available to me years before. I am sure that they were not available to many others who otherwise may have wished to seek compensation in court, who were unable to do so.

g. What was the outcome of the litigation?

17.28 The litigation was concluded extra judicially shortly before the diet of proof (trial) many years after the action had been raised, without apology and without any admission of liability on the part of the defenders.

Section 8: Other Inquiries

18 Describe any involvement that you have had with any other inquiry (such as Archer, Penrose or Lindsay)

18.1 It is important to point out that, contrary to common understanding, there were other inquiries prior to the Archer and Penrose Inquiries. There was the internal investigation conducted by the Scottish Government which produced a report in October 2000. The Scottish Parliament subsequently launched its own inquiry and I gave evidence in person before the committee in March 2001 and they

produced their own report. There was also the Ross committee which was established in March 2003. I have provided further information about these committees and inquiries in Section 2 of my statement above.

18.2 While I was not involved in the Archer Inquiry, I did write to Andy Burnham MP, the then Health Secretary, on 18 June 2009, about the Government's response to the Archer Inquiry. I exhibit this letter as **WITN2287061.** I also exhibit the response that I received dated 22 July 2009 as **WITN2287062.**

18.3 One of the particular benefits we have had in Scotland has been the ability to influence decision makers via the devolved Parliament (as discussed above). We have also had access to the courts in Scotland. I was involved at different periods in working with two of the key figures who facilitated contact with MSPs and initiated steps that led to the establishment of the Ross Committee (as discussed above) and the Penrose Inquiry. The late Philip Dolan, vice chair of the Haemophilia Society and chair of the Scottish Haemophilia Groups Forum introduced us to the late Frank Maguire, a Solicitor Advocate who was a partner with Thompsons Solicitors and who was well connected in Scottish public life. Both Frank and Philip appeared before the Scottish Parliament's Health Committee and were appointed by the then Health Minister Malcolm Chisholm MSP to the Ross Committee. The documentation relating to the deliberation of the Ross Committee demonstrate the critical role that Frank in particular had in influencing the Committee to which reached the forward thinking conclusions which I discussed in Section 2 of my statement. Frank made himself readily available to us and one of the consequences of those discussions was that we agreed to pursue a twin track approach to securing a full statutory Inquiry which was to become the Penrose Inquiry. We reached the view that, while the Scottish Parliament allowed much greater opportunities to influence MSPs and the political process, we could not rely on that alone while

successive Health Ministers set their faces against the idea of a statutory inquiry.

18.4 In parallel to the political avenues that we were pursuing, Frank had identified that there were legal openings available to try and force a statutory Inquiry via the Scottish Courts. I much admire the families of Mrs O'Hara and Reverend Black, who died following their infection with Hepatitis C as a result of treatment with blood/blood products. GRO-A and GRO-A were the petitioners in the Judicial Review of the decision of the Lord Advocate to refuse to hold fatal accident inquiries into their relatives' deaths and the decision of the Scottish Ministers to refuse to set up public inquiries into those deaths. Lord Mackay of Drumadoon issued his judgment on 5 February 2008. His Opinion stated that the decision not to hold Fatal Accident Inquiries into the deaths of Rev David Black and Mrs Eileen O'Hara was incompatible with Article 2 of the European Convention on Human Rights. He held that public inquiries would satisfy their Convention rights. I was not involved that action personally and cannot comment beyond noting that the FAIs into those deaths and two others were part of the Penrose Inquiry's terms of reference.

18.5 Frank also attended meetings with MSPs and, in the run up to the 2007 Scottish Parliament elections, pressure was placed on political parties to commit to a statutory inquiry in their election manifestoes. The SNP included a commitment to hold a public inquiry in their manifesto for the 2007 Scottish Parliament elections. When the SNP became the largest party in the Scottish Parliament and formed a Government following the election, Nicola Sturgeon MSP was appointed as Cabinet Secretary for Health and announced that there was to be a public inquiry, I wrote to her setting out various recommendations as to how the Inquiry should be conducted from my perspective as a patient. I suggested that a helpline should be established, a website should be created with daily reporting of proceedings, proceedings of the Inquiry should be conducted by way

of away days outside of Edinburgh to take oral evidence from the sick and infirm and that there should be the option of confidentiality. A Penrose Inquiry website was established but to view the proceedings we had to travel to Edinburgh and core participants were afforded confidentiality, no helpline was established and there were no away days. I exhibit my letter dated 5 June 2007 as **WITN2287063** and the response I received dated 21 June 2007 as **WITN2287064**.

18.6 While the Scottish Government had initially intended to await the outcome of the Archer Inquiry before establishing a Scottish Inquiry, this position changed following the publication of the Opinion of Lord Mackay of Drumadoon in the Petitions by Rosaleen Kennedy and Jean Black in February 2008, mentioned above. In light of that, the Scottish Government decided that progress in establishing the Inquiry would not be delayed to await the outcome of the Archer Inquiry and decided to proceed with holding a Scottish public Inquiry under section 28 of the Inquiries Act 2005. I exhibit a copy of Nicola Sturgeon's statement to the Scottish Parliament on 23 April 2008 setting this out as **WITN2287065.**

18.7 Following this announcement, I continued to press the Scottish Government to make progress with establishing the Inquiry. There was a delay in setting up the Inquiry due to the withdrawal of Lady Cosgrove as Chair. I exhibit as **WITN2287066** a response I received from John Swinney MSP dated 4 December 2008 and as **WITN2287067** a response I received to a letter to Nicola Sturgeon MSP dated 17 December 2008.

18.8 I was appointed as an individual core participant in the Penrose Inquiry. I gave a written witness statement. In the Penrose Inquiry, the written statements were all taken by the Inquiry team and legal representatives were not involved at all in that process. I was not called to give oral evidence though my legal representatives recommended to the Inquiry that I should be invited to do so. Representations were made at an oral hearings but Lord Penrose

refused the application for me to be called as an oral witness. There were very few patient witnesses and a limited number of core participants. Patient core participants were selected on the basis of the timing and type of their infection, with each allocated to a sub-category comprising their infection type (HCV or HIV) and their presumed decade of infection. It was unclear why the patient witnesses had been selected and thus whether they were deemed to be "representative" of any particular part of the patient group. None of the oral witnesses were recognised "campaigners". It appeared that Lord Penrose did not wish to hear from any of the people who had devoted years to securing the very Inquiry that he was presiding over.

18.9 The Penrose Inquiry was often a very frustrating process. The support we were offered and the involvement we had were both very different to the present Inquiry. There was no Red Cross type support for individuals and no commemoration. Press and media were on occasion criticised for their attendance by the Chair rather than encouraged to report on it. While expenses were available to the few people who were called to give evidence, they were not made available to those who simply wished to observe the proceedings in person. Proceedings were not broadcast via the Inquiry website therefore we had to travel to Edinburgh if we wished to view the proceedings. I did so on several occasions and found myself significantly out of pocket as a result.

18.10 Lord Penrose would often set very tight deadlines for responses from our lawyers, who in turn would have to secure information and input from us. In contrast, he himself would often take long periods of time to conduct work in between announcements. We were unpaid volunteers. We felt that he had little respect for us. He did not even acknowledge us when passing us in the corridor. We had to stand when he entered the room. He was on occasion rude to our QC and would sometimes refer to us in hearings to our lawyers as "those

people sitting behind you". The Penrose Inquiry was very focused on science and it often felt as though the voices and the stories of the victims were ignored. This experience is why I have always emphasised that pace is very important in the current inquiry. Core participants must have the opportunity to digest documentation and to allow them to be able to provide instructions to their legal representatives and to have meaningful input.

18.11 I recall that on the opening day of evidence on Tuesday 8 March 2011, Lord Penrose stated that

"this Inquiry is funded from the National Health Service Scotland's budget. Every pound that is spent on the Inquiry is a pound that is not available for the care and treatment of National Health Service patients in Scotland. Every hour of clinicians' and other specialists' time that is spent at this Inquiry is an hour that is not available for scientific research or for the care and treatment of patients in the wider health service"

This has always made me question why the Scottish Government thought it was appropriate to use the health budget for the Inquiry.

18.12 At the outset of the Inquiry, I recall expressing gratitude in the press and media that someone was willing to take on such a difficult role. Why on earth would anyone want to grapple with such complex issues which had stretched back over decades? However, I came to feel a sense of resentment towards what I saw as his high handed position as discussed above.

18.13 As set out in section 7 of my statement, Lord Penrose was very much concerned with the "general" rather than the specific and while we tried to raise what we identified as potential systemic failures exemplified by individual cases that led to the infection of previously untreated patients, we were not allowed to explore them in the depth that we wanted to. By always focusing on generalities, much useful

detail went untested which could have highlighted wider systemic shortcomings.

18.14 I have always felt that Lord Penrose and his team's lack of respect for survivors and victims was demonstrated in the closing submissions that were made at the final planned day of oral hearings on 30 March 2012. Inquiry Counsel, Laura Dunlop QC, thanked all of the Inquiry staff but did not thank core participants. No acknowledgement was made of the hundreds and thousands of hours that core participants had devoted (on a voluntary basis) to trying to assist the Inquiry to get to the whole truth.

18.15 After the various closing statements of Counsel, including Counsel to the Inquiry and Counsel for the Health Boards and SNBTS, I can recall that there were visible tears of anger from some of the survivors who were present in response to what they had heard.

18.16 In the early days of the oral hearings, there were sessions devoted to statistics but it was felt by the patients that these issues had not been fully explored. Lord Penrose had stated that the subject would be returned to at a later date for further oral examination but that had not happened. Our solicitors made an application for further oral evidence to be heard on the topic of statistics and a further oral hearing was held on 29 October 2012 for parties to make submissions. Lord Penrose was clearly unhappy about being asked to conduct further oral examination. I exhibit the transcript of the hearing as **WITN2287068.** Lord Penrose issued a written decision on 9 November 2012 in which he refused the application to call or re-call the witnesses. He indicated that some further information would be sought in writing at the initiative of the Inquiry. I exhibit his written decision as **WITN2287069.** Despite the fact that we had raised the concerns which gave rise to this extra hearing, we were not involved in any further work on this matter.

18.17 Throughout the Penrose Inquiry, I was left with the impression that the Chairman's mind had already been made up, with a list of topics that had been put forward in the preliminary report which it took a Herculean effort to have altered and added to. It appeared to me that the Inquiry had already determined their conclusions by the time of the preliminary report (which had been produced without the involvement of the patient interest core participants). It appears from the preliminary report that by the point of its production, there had been significant involvement in the work of the Inquiry by key members of the medical profession who had an interest in the outcome.

18.18 I was also extremely frustrated with the "Maxwellisation" process. There was a delay between the hearings concluding in October 2012 and the report being published on 25 March 2015. During this time, warning letters were being issued to those who may have faced criticism in the final report. When reading the final report, I felt that the narrative in the report was not followed through in the conclusions. It would often appear that the narrating of what happened was leading to a point where a different conclusion could (and should) have been made, such as criticism being made of a particular action or lack of action. I have always been suspicious that the "warning letters" process led to a dilution of the conclusions in the final report.

18.19 During the Penrose Inquiry, there was a single medical assessor, Oliver James, who gave medical input to Lord Penrose behind closed doors. I was very keen that this Inquiry did not adopt this approach and Haemophilia Scotland (together with the Scottish Infected Blood Forum) made representations to the Inquiry in that regard. This is why I am so keen that this Inquiry's expert groups should play a key role.

18.20 On the day that the Penrose Inquiry report was published, Haemophilia Scotland organised two events, firstly a very public

press briefing in response to the Report and secondly a more private event with lunch for those who had been infected or affected and were likely to be very upset at what they had heard. I was also very heavily engaged in radio and TV interviews, although the UK press and media opted to cover the burning of the Penrose report in the street by others as their headline.

18.21 We conducted the press briefing in the same auditorium as the Report had been delivered by the Secretary to the Inquiry (as Lord Penrose was unable to attend the event on the publication event due to ill health). There were many others present who had been directly affected and in many cases had travelled from outwith Scotland and had not been core participants and therefore had not had prior sight of the report.

18.22 There was considerable anger expressed from the gallery immediately after the Inquiry Secretary gave her statement. It was extremely difficult to regain any order to present what we had intended to say to the press and media who had assembled.

18.23 During questions from the press afterwards, I learned from the Times newspaper that the Prime Minister David Cameron had announced in response that an extra £25 million was to be allocated to support schemes. After a broadcast interview with STV ending at 11.15pm that evening in Glasgow, I was then up for much of the night back in Edinburgh drafting a letter to David Cameron about his announcement, asking him why he had announced £25 million rather than another sum. I exhibit this letter as **WITN2287071.** Despite a reminder, he never answered my letter. Nor as I understand it was a single penny of that money allocated to any rise in payment levels or introductions of new beneficiaries. Put bluntly, to me it appeared to have been remote UK Government political spin in response to potentially damaging attention on the issue. David Cameron also apologised in the House of Commons and acknowledged that the disaster should not have happened. He did not expand on what he

was apologising for nor did he set out what action he would take based on the apology, other than to set out the announcement of the extra money for the schemes. I exhibit as **WITN2287072** a letter dated 4 September 2015 from then Cabinet Secretary for Health, Shona Robison MSP, to Jane Ellison MP, Parliamentary Under Secretary of State for Public Health which indicates that the £25 million was never planned for anything in Scotland, despite the fact that it was announced on the day of publication of the report of a Scottish Public Inquiry.

18.24 The other event that we hosted that day was a lunch and refreshments reception after the press conference. No media were present. This was an event for infected people and their families to meet away from wider public attention in a nearby church building. In attendance were the Cabinet Minister for Health, Shona Robison MSP and Public Health Minister Maureen Watt MSP. They both sat at tables and listened attentively to the stories of the grief and losses of some of those present. Shona Robison was later to state that it was those stories that confirmed for her the need to act. I set out below the events that followed the publication of the Penrose report in terms of the establishment of the Scottish Infected Blood Support scheme.

Section 9: Haemophilia Society

19 Describe any involvement that you have had (other than as a member) with the Haemophilia Society insofar as relevant to the Inquiry's Terms of Reference.

19.1 I have described my involvement with the Scottish Groups Forum and the Scottish Committee and the events that led to the establishment of Haemophilia Scotland above. Haemophilia Scotland now enjoys a very good working relationship with the Haemophilia Society on a wide variety of issues.

19.2 We both recently, along with Haemophilia Northern Ireland wrote jointly to the Chancellor of the Exchequer seeking levelling up of payments under the respective support schemes across the UK, for those who continue to face grinding hardship.

Section 10: Trusts and Schemes

20 Describe any involvement that you have had (other than as a beneficiary) with any of the trusts and schemes established to provide financial assistance.

20.1 I have always felt it important that victims of the contaminated blood disaster receive full and just financial recompense and have been engaged in correspondence with politicians on this issue since I became involved in campaigning. I exhibit a response received to a letter that my MP at the time John Swinney sent to the Department of Health on the issue dated 5 November 1997 as **WITN2287073**. I also exhibit as **WITN2287074** a letter that John Swinney received from Sam Galbraith MP dated 4 September 1998 about no fault compensation.

20.2 Having followed the progress of the Ross Committee (discussed above), I took a keen interest in the establishment of the Skipton Fund. I remain mystified about the decision making as to why the fund became UK wide on the basis of a Scottish Government established Committee report. I wrote to my MP Pete Wishart about this and he received a response from the Secretary of State for Scotland. I exhibit this correspondence as **WITN2287075**. I am also unclear as to why the figure of £20,000 was arrived at rather than the £50,000 recommended by Lord Ross. As stated above, the recommendations of Lord Ross have never been implemented in full.

20.3 I had a number of questions following the setting up of the Skipton Fund. I engaged in correspondence with my MP, Pete Wishart, about getting parliamentary questions asked about the governance of the Skipton Fund and about progress it was making in getting payments to Scottish victims. I exhibit the correspondence that I had with him and the answers received to the parliamentary questions as **WITN2287076.**

20.4 I also had two exchanges directly with the Skipton Fund that stand out in my memory. Firstly, when the Fund was initially established, I had concluded that there would be an initial rush to make claims and that the administering charity would have to be sufficiently resourced to respond to that pressure. When I enquired during a telephone call about how many staff were employed by the Fund, I was refused an answer. It was kept secret and I felt that the governance and administration of the Skipton Fund was, initially at least, far from transparent. This is reflected in the questions that I sought to have answered in Parliament as referred to in the paragraph above. I also asked my MP Pete Wishart to write to the Department of Health about my concerns. I exhibit a copy of the response that he received dated 15 September 2004 as **WITN2287077.**

20.5 Secondly, I recall a conversation some years later with the late Martin Harvie (who became the CEO of the Skipton Fund) where he explained the challenge he had faced when taking over. He had inherited a position where the Skipton Fund had been defrauded by his predecessor to the tune of a very large sum of money. I believe it was in the range of £400,000 and resulted in prison sentence for the person who was responsible. This meant that money intended for those who were in need as a consequence of their hepatitis C infection was siphoned off into the bank account of a presumably well paid executive.

20.6 Haemophilia Scotland was heavily involved in the establishment of the Scottish Infected Blood Support Scheme (SIBSS).

20.7 In my view, one of the most significant achievements of Haemophilia Scotland in relation to the infected blood products scandal was demonstrated by the response of Scotland's First Minister Nicola Sturgeon MSP to a question in the Scottish Parliament on 26 March 2015, which was the day after the Penrose report was published. She confirmed that a review of financial support would be taken forward as a matter of urgency. I exhibit the question and the response as **WITN2287078**.

20.8 The statement from the Health Minister Shona Robison MSP and the subsequent debate that afternoon set out the way forward in terms of financial support. The Minister's acceptance of the timing we proposed to conclude the work of the review group by our proposed date of World Haemophilia Day 2016 was critical to what was to follow. I exhibit the statement of Shona Robison in response to the Penrose Inquiry and the subsequent debate as **WITN2287079**.

20.9 I believe those ministerial statements laid the foundation for the significant changes and improvements (particularly for widows) that were made over the succeeding months to the ex gratia support mechanisms.

20.10 The proceedings in Parliament on 26 March 2015 set the tone for the work that took place from then on with Scottish Government. The Cabinet Secretary for Health Shona Robison immediately announced a Scottish Government sponsored review of the existing financial support schemes for those infected in Scotland.

20.11 The first step in the Financial Review was for a Chair to be appointed. Ian Welsh (Chief Executive of the Health and Social Care Alliance) was appointed as Chair. Several people from the infected and affected community were appointed to be part of the review group, together with Scottish Government officials and lawyers and Patrick McGuire from Thompsons Solicitors.

20.12 The Terms of Reference were then agreed. I exhibit the Terms of Reference as **WITN2287080.**

20.13 The Terms of Reference set out that the Group was to report to Scottish Ministers by no later than November 2015. This felt like a fairly tight deadline but was set because the Minister was keen to make progress. I recall her setting out two principles in particular that remain central to the current Scottish scheme. Firstly, the need for greater political accountability of any support structure. Secondly, the importance of focusing on need amongst those who had been infected and affected. The latter principle was to provide to be very important in resolving the adjustments to the scheme that were made at the time of the Clinical Review.

20.14 We set about the task, to my mind with a collective desire to make improvements to the support arrangements which existed at the time. All our meetings were recorded and minutes are available.

20.15 Central to the work of the Financial Review Group was examining the provisions made under similar support schemes. This included the existing Skipton, MacFarlane and Caxton Funds and their CEO, Jan Barlow, attended one of our meetings in person.

20.16 We also considered the question of benchmarking and received presentations on schemes in other countries, in particular Canada and the Republic of Ireland. We also heard from schemes operated to support injured servicemen and other medical/health injuries. While Scottish Government representatives had signalled that the existing categorisation of hepatitis C stage and HIV would remain preferable, they agreed that we needed to conduct wider consultation amongst those infected and affected.

20.17 Haemophilia Scotland was commissioned to conduct a consultation exercise with those affected with a series of roadshows that fed into the Financial Review Group's deliberations. This was in line with our

wish to ensure that those affected had a say and were able to influence how any new Scottish scheme was shaped. Budgeting by Government in Scotland could then be carried out accordingly. I exhibit a summary of the Regional meetings that was prepared for the Financial Review Group as **WITN2287081.** This is in stark contrast to the approach taken in England where headline figures have sometimes been announced by Government before any significant consultation has been conducted with those most in need.

20.18 The deliberations of the Financial Review Group culminated in the Group's report, which was published on 17 December 2015. I exhibit the report as **WITN2287082.**

20.19 The Group recommended that a new Scottish scheme should be established to include current and future Hepatitis C and HIV beneficiaries. This was a proposal that secured support at the regional meetings referred to above. There were a number of reasons why a new, separate Scottish scheme appealed to us. Firstly, the potential for political responsiveness within Scotland where we could make an impact. We were able to take advantage of devolution. Secondly, the different manner in which widows/widowers were provided for. Thirdly, the end to means testing that remains such a controversial element of some schemes in other parts of the UK. Fourthly, the provision to re-examine the clinical impact upon those listed in Stage 1 (I discuss the clinical review in more detail below).

20.20 The Group made a number of proposals in relation to increased annual payments, supporting widows and widowers, increased lump sum payments for chronic hepatitis infection, support and assistance grants and areas where further work was required. An argument was presented that everyone should be paid the same but this was not a position that was supported by Haemophilia Scotland.

20.21 The Report had our support and remains (in the absence of an individually focused, damages equivalent type scheme similar to that in the Republic of Ireland, which we continue to advocate) a well-founded basis for ongoing support. It led to the establishment of a Scottish based scheme that is administered in Scotland and is intended to be able to respond more effectively and efficiently to beneficiaries than its predecessors. We continue to seek greater and more realistic financial support for those infected and affected but the foundation and the structuring of the Scottish based scheme has been the best available option for us in Scotland, when we entered into review of the Alliance House based schemes.

20.22 Looking back, I feel that we failed in three particular aspects during the course of the Financial Review Group.

20.23 Firstly, a misunderstanding arose over the provision for Stage 1 widows and they were initially left out of any financial support arrangements. Stage 1 widows whose husbands died prior to the establishment of the Scottish scheme were not initially entitled to the additional £30,000 lump sum payment. While this issue was eventually resolved, we should have been clearer during the Financial Review that we wanted them included. I exhibit a joint letter that SIBF and Haemophilia Scotland wrote to the Cabinet Secretary for Health, Shona Robison MSP, on this issue in January 2018 as **WITN2287070** and her response as **WITN2287083.**

20.24 Secondly, no provision was made (and has not been made to this day) for non-dependent carers such as parents, adult sons and daughters or others.

20.25 Thirdly, we did not manage to persuade the Government to amend the necessary provisions for making financial support under the Smoking, Health and Social Care (Scotland) Act 2005. When we raised the idea of payments under the Scottish scheme being

guaranteed under law, Scottish Government representatives replied that laws could be changed just as policy could.

20.26 However, we were keen not to delay the additional support that was on offer for those who were in need and we pursued the Government's acceptance and implementation of our recommendations. I appeared before the Scottish Parliament's Health Committee on 9 February 2016 and strongly urged them to support the recommendations so that the new payments could start as soon as possible. Prior to my appearance, Haemophilia Scotland submitted to the Committee a 16 page analysis of progress in responding to the Penrose Report and the subsequent Financial Review. I have been unable to locate a copy online but I have a hard copy of this document which I can provide to the Inquiry. . I exhibit the report of the Committee's proceedings 9 February as **WITN2287084.** While we realised that there was work remaining to be done, we realised that the promised Clinical Review (discussed below) would allow some of that to be addressed.

20.27 The Scottish Infected Blood Support Scheme was launched in April 2017.

20.28 In the middle of 2017, the Scottish Government invited Professor David Goldberg to carry out an independent clinical review to assess the impact of chronic hepatitis C (Skipton stage one) on the health and wellbeing of individuals. I was one of three patient representatives invited by the Scottish Government to join the clinical review working group. This group was set up by Government but without its representatives taking part in its main deliberations. The meetings were recorded and minutes are available.

20.29 After an initial meeting where we agreed the Terms of Reference with officials, we met on three occasions. The bulk of the work was carried out by Professor Goldberg himself, including 16 interviews with randomly selected patients. The other key element that informed the

working group's deliberations was the literature review on the impacts of hepatitis C. It identified from two papers in particular that the significant psychological impact of infection with hepatitis C was "incontrovertible". These papers were Extrahepatic Manifestations of Hepatitis C: A Meta-analysis of Prevalence, Quality of Life and Economic Burden. Younossi Z et al. Gastroenterology, 2016; and "Living with Hepatitis C Virus: A Systematic Review and Narrative Synthesis of Qualitative Literature. Dowsett L et al. Canadian Journal of Gastroenterology and Hepatology 2017. The papers by Yannousi et al and Dowsett et al were not identified in the Inquiry's own Psychology Expert Group's initial report. The papers nevertheless reported findings largely in line with the evidence that the expert group has given.

20.30 The most difficult matter that we had to address from among the Terms of Reference for the Clinical Review Group was that of assessment. It was an issue that survivors had constantly mentioned as being particularly frustrating that they repeatedly had to justify at length claims for modest sums of money. This had been regarded as one of the worst elements of the previous schemes. There was a sense amongst beneficiaries that they were not trusted by Government or by the administrators of the schemes. Those of us (and our families) who felt so grievously harmed and let down by the Government in the form of NHS treatment had been treated by Government in a way which suggested that it was us who were not to be trusted.

20.31 Before reaching that solution on how we might get beyond that damaging feeling of being mis-trusted, I had put forward for consideration the question that the support schemes had never addressed of not seeing beneficiaries as individuals in their own right experiencing their own unique impacts. Instead, they are all lumped into categories. I pointed out how the Republic of Ireland takes a different approach and made contact with the Irish Haemophilia

Society. They pointed to the success of their scheme but suggested we would be better contacting the scheme administrators and others involved when their scheme was originally set up. Sensing a reluctance among clinicians to pursue it, we went no further.

20.32 The Group overall swung against it as, in particular under the established SIBSS framework, it might involve clinicians and/or other related professionals having to be involved in assessment. For Stage one recipients, clinicians would be facing a potentially insurmountable dilemma between strict objectivity on the one hand and acting in the best interests of the patient on the other, with potential significant financial implications for the latter and potentially undermining the doctor/patient relationship. In the absence of a "damages equivalent" assessment based on loss of income, it was difficult to see how a physical/mental health impact assessment could be effectively and efficiently deployed without professional input.

20.33 We therefore instead focused on the lack of trust felt by survivors under existing schemes and a rather novel solution was proposed. On the basis that the mental health impacts were "incontrovertible", provision should be made for those under the scheme as "Stage one" recipients to self-assess as minimally affected, moderately affected or severely affected.

20.34 We felt that this might restore a sense that the mental stresses were being recognised by those in authority. When it was later presented to a joint meeting of SIBF and Haemophilia Scotland members, there was an understandable scepticism about whether Government would accept and act on such a recommendation. After all, those who previously had struggled to have a voice over many years and felt undervalued and mistrusted were now to be able to make their own decisions on the impact they had experienced and receive financial support based on their own assessment. At the meeting, Professor David Goldberg, Chair of the Clinical Review Group, was able to help to persuade a packed gathering that it could be possible to persuade

the Government to adopt the recommended new approach. This was also the first public meeting where Inquiry representatives were in attendance to observe the proceedings.

20.35 I exhibit a copy of the Clinical Review Group's report which was published in May 2018 as **WITN2287085.**

20.36 The recommendations of the Clinical Review were accepted by the Scottish Government.

20.37 One issue which we had not determined during the work of the clinical review was the respective amounts that would be paid out annually to the recipients in each of the self-assessment categories (minimally affected, moderately affected or severely affected). This was not within the Terms of Reference and was ultimately a political decision. Indeed, it was to become, as we anticipated, a tricky issue as the differential between moderately affected and severely affected in particular would prove to be significant. Claimants were being asked, in the absence of detailed guidance, to place themselves in a category that would effectively determine unspecified levels of financial support. With limited guidance on what the different categories meant and without knowledge of the different payment levels, claimants had to categorise themselves.

20.38 A further issue was to arise with respect of an audit of the claims. A limited sample of claimants (about 16) were asked to justify why they had placed themselves in a particular category. Understandable angst arose because they had been led to believe their self-assessed claims were being trusted only to find that they were being questioned. No advance notice had been given to claimants that this would take place and it gave rise to some tense phone calls and correspondence. Government however acknowledged the issue and clarified that it would not be a regular exercise. They said that they were simply applying sampling to check the veracity of the system

rather than the veracity of individuals (although I know that one applicant was downgraded).

20.39 Notwithstanding the issue of payment levels, self-assessment has been an efficient and effective way of processing Stage One claims in Scotland and has been one of the important factors in re-establishing some trust between survivors and Government in Scotland.

20.40 A further contribution to that trust in Scottish (rather than UK) Government was the decision at the same time as the clinical review response was announced to "put right" the shortcomings of the original financial review for Stage One widows that I referred to above. After that misunderstanding arose, we worked hard in advocating to reverse the Scottish Government's thinking on Stage one widows. I recall in particular one radio interview with BBC Radio Scotland over the Christmas period where I was publicly critical of Scottish Government for not even discussing the issue with us at Ministerial level. Immediately following the radio interview, there was communication with the Minister, we rapidly met face to face and the matter was duly addressed.

20.41 Widows of those who were in Stage 1 also now receive 75% of the annual payment that their loved one received, resulting in them receiving payments that amount in some cases to £14,416 per year.(which has now increased as a result of the recent Government announcement in March 2021)

20.42 Rightly or wrongly, I feel a deep sense of gratitude that I was able to play a part in the deliberations in the financial review group and the clinical review group, which led, ahead of the rest of the UK, to greater payments for stage 1 survivors and stage 1 widows. There was criticism at the time that we had somehow sold out but my own feeling was that many people would have more financial support than

previously. I felt that the voices of the infected and affected had, for once, been listened to.

20.43 The amounts awarded under the schemes do not reflect everything that the infected and affected have experienced or anything approaching their losses. However, given my own knowledge of the significant difference these amounts make to some households in Scotland, until compensation is available, these amounts were for some years in favourable comparison to the less logical and less compassionate treatment of widows within the schemes in other parts of the UK. It is significant that there is no means testing in Scotland but I am continually reminded that means testing applies elsewhere. It was important to address the grinding hardship that was being experienced in Scotland and the Financial and Clinical Reviews were a step in the direction of doing so. It is however also important to remember that, while levels of support in Scotland were initially more generous than the schemes in the rest of the UK, it became no longer the case in all of the "categories".

20.44 As expressed above, work remains to be done in terms of provision for families (including carers) who were not classed as dependents. They remain a particular group whose lack of recognition I hope the Inquiry will examine.

20.45 I maintain the position that the accountability of the scheme (and therefore its responsiveness) is of overall advantage to its beneficiaries. Recently, there was a review into the operation of the scheme, as recommended in the Financial Review report. I exhibit the results of the 2020 Customer Satisfaction Survey and Review as **WITN2287086.** On 19th November 2019, I wrote to the Chair of the Inquiry setting out my understanding of why separate support schemes were established across the UK and the context for establishing UK parity or otherwise. I believe that the Customer satisfaction Survey and the reasons set out in my letter are important evidence of the benefits of having a scheme based in Scotland.

20.46 I took part in the well documented meetings with the Minister for the Cabinet Office in January 2019 and January 2020, intended to address the hardship some scheme beneficiaries in parts of the UK continue to face, as identified in testimonies to the Inquiry. Three months after the first of those meetings, an increase was made to payment levels for some beneficiaries of the English support scheme and in March 2021 further increases have been announced. I hope the latter announcement means, that however late, the time devoted in autumn 2018 and early 2019 to securing such increases was time that was of benefit to those infected and affected across the UK.

Statement of Truth

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

Signed GRO-C

Dated Apr 16, 2021