Witness Name: Glenn Wilkinson
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GLENN WILKINSON

Section 1. Introduction

1. My name is Glenn Wilkinson and my date of birth is GRO-C 1964.

2. I am writing this witness statement on my own behalf and as a member of the Contaminated Blood Campaign ("**CBC**"). This statement describes my campaigning activities both as an individual and as a Founder and Director of CBC, and also provides information to the Inquiry about the activities of CBC as an organisation.

Section 2: Organisations involved in campaigning activities

3. I have mild haemophilia A. In 1995, I was diagnosed with hepatitis C (HCV) following a routine blood test performed after a tooth extraction. I was told that I had most likely been infected from a Factor VIII injection I had received in 1983. One of the key features in my case was that I did not need to have any Factor VIII on this occasion and I was never told that I would be given Factor VIII before the procedure, nor was I told I had been given Factor VIII following the procedure. I was given no informed choice whatsoever.

4. I first became aware that I had been given Factor VIII when I was informed of my HCV status in 1995. I thus had my life changed irreversibly as a result of taking a risk which was not explained to me. Part of my drive to become involved in campaigns over the years has been driven by my feeling that I was infected in circumstances where the blood products I received was, in fact, wholly unnecessary. I am not only one of the victims of this scandal but am also one of those people who had no need to become a victim.

5. Following my diagnosis, I began researching the issue of infected blood, and campaigned as an individual by writing letters and visiting my MP at the time, David Davis, to try to get him to understand the depth of the disaster that had been inflicted by a Government body on its citizens. Connecting with other infected people was difficult at the time because I did not have a computer and I wasn't in contact with any haemophilia based groups, so my knowledge on infected blood and blood products during this time period was limited. Eventually, I purchased a computer, got online and started networking with others interested in the issue and began researching the subject in more detail.

6. I kept up to date with the developments and progress of the Archer Inquiry while it was ongoing through the Haemophilia Society and I believe it must have been through the Haemophilia Society website and bulletins that I first became aware of other individuals and campaign groups such as the Manor House Group and Tainted Blood. Tainted Blood had a website and forum, a place where I could converse with other members in a similar position to myself. I was asked to join the Tainted Blood committee in October 2010 which I did.

7. In response to the release of the Archer Inquiry, the Government undertook a review in 2010 and released their report entitled "*Review Of The Support Available To Individuals Infected With Hepatitis C And/Or HIV By NHS Supplied Blood Transfusions Or Blood Products And Their Dependants*" in January 2011. I became concerned with the totally inadequate level of support given by the Government to victims, and in particular the total failure of the Government

to equalise the financial assistance schemes to bring all those with HCV in-line with those with HIV. I never received a proper explanation as to why Ministers set up the Skipton Fund in a way that separated people with HCV into two stages and only provided regular non-discretionary payments to those in stage two, when this two stage distinction was rightly never applied to people with HIV. I also did not understand why financial assistance was not made available for the bereaved spouses/partners and dependant children of people with HCV to the same extent as those with HIV.

8. I have never argued that payments to those with HIV, or to their bereaved spouses/partners or dependant children, should be reduced. Indeed I believe that none of the payment schemes developed by the Government is in any way adequate to reflect the harm that was inflicted upon victims by Government bodies. However, I have always taken the position that there was absolutely no justification for discriminating against HCV victims in comparison to HIV victims. Throughout the time I have been involved with the campaign, I believe that medical science shows that these are both viruses that inflict lifelong devastating effects on those unfortunate enough to carry the virus. I simply do not believe there has ever been any proper justification for treating HCV victims as "second-class victims" in comparison to those unfortunate enough to have contracted HIV.

9. I became concerned at this stage that the Government was not prepared to take any steps to make publicly funded ex gratia support available to infected people in a way that would ensure all groups were treated equally, and that as a result, the majority of HCV beneficiaries would continue to receive nothing. I felt that the Government was reticent to commit to providing equal ex gratia support to those infected with HCV because of the larger numbers of people who were infected, many of whom were probably not even aware they were infected.

10. I began to express my concerns about the discrepancy in available funding for people with HCV when compared to those with HIV to other committee

members at Tainted Blood. Initially, I thought the group would share my concerns. However, it soon became clear that the majority of committee members did not think it was a priority to highlight the stage one and broader HCV issues. They wanted to focus their efforts on the next phase of their campaigning, which was to focus on the haemophilia community as they felt this would stand a greater chance of success. However, I felt the stage one and related HCV issues needed to be addressed as a matter of urgency, and certainly before any further changes in support and/or any settlement in order to make sure we weren't going to be left behind yet again. I felt strongly about the differences between how HCV Stage One infected individuals, and HCV bereaved spouses/partners and dependant children were being left behind when compared to those infected with HIV and their bereaved spouses/partners and dependant children.

11. As I continued to express my views on the unequal treatment of people with HCV to Tainted Blood committee members, my relationship with the committee became strained, and eventually, in April 2011, I was told that I was to be removed from the Tainted Blood committee.

12. As a haemophiliac myself, I understand first-hand the issues and damage that has been caused to the haemophilia community. However, I have also seen the damage caused to the non-bleeding disorder community, and as such, have always felt we should all be fighting together and treated equally when it comes to any financial and other support.

13. After being removed from the Tainted Blood committee in April 2011, I began speaking with and emailing fellow campaigners who also felt they had been let down by the recent review and did not feel that their issues were being addressed adequately by other campaign groups. A meeting was arranged through my MP, Diana Johnson, with the then Health Minister Anne Milton, together with the 'stage one' campaigners who I was in contact with on a regular basis. The meeting took place in October 2011 at Richmond House, Whitehall, London. We explained to the Minister that we felt that the present

schemes were failing and explained why HCV victims felt badly let down by the review. After this meeting, we continued talking and emailing and we decided that we needed a campaign group to address our unmet needs and issues and to concentrate on advocating for equal treatment for all. We thought it would be necessary to form our own campaign group in order to create a centralised voice for all those discriminated against by the ex gratia schemes, including non-haemophiliacs, people classified as 'stage one' by the Skipton Fund, and bereaved spouses/partners and dependant children of those victims with HCV. There followed a period of discussion to develop a plan for the new group, including deciding on the group's name, logo, aims and objectives, and how we were going to promote our group within the community and within Government.

14. CBC group was officially launched on 8 February 2012. We contacted all MPs, relevant Ministers (including the Prime Minister), the Department of Health, the Haemophilia Society, The Hepatitis C Trust and the CEO of Alliance House. We also issued a press release. When we officially launched, the team members included myself, Lesley Brownless, GRO-A Ollie Carruthers, Ros Cooper, GRO-A and Nicholas Sainsbury **(WITN2050002).**

15. Sadly, after launching CBC, we faced a significant and unwarranted backlash from some members within our community. As one example of this, myself and another CBC team member Nicholas Sainsbury received some abusive and intimidating emails from one individual using a false name, which led to a police investigation under the Malicious Communications Act 1988.

16. In 2014, the CBC team welcomed Russell (a pseudonym, as he wishes to remain anonymous) as a member. He had been contacting various campaigning groups by email and social media throughout the course of 2012 and asking questions about their objectives to see which one he might want to align himself with. I could tell he was very intelligent and an excellent researcher - he knew the right questions to ask. I first met him in person when

he attended a CBC demonstration in 2014 in Witney, and shortly afterward I asked him to join the CBC team.

17. Over the years, there has been an inevitable turnover of CBC team members, and on 28 August 2012 the CBC team were deeply shocked and saddened at the death of Ollie Carruthers, who was a founder member of CBC. Today, the CBC team consists of myself, Lesley and Russell, and we are supported substantially by my wife Alison, Lesley's husband GRO-A and Russell's wife Beatrice (also a pseudonym).

18. The purpose of CBC since its inception has been to conduct research about and spread awareness of issues pertaining to infected and affected people, to provide a support space for infected and affected people to meet, in an inclusive and non-discriminatory environment, and to fight for their rights using campaigning work and litigation where necessary if possible. We promoted our Campaign Aims and a list of Frequently Asked Questions on our website and social media platforms **(WITN2050003).** CBC have always and continue to work on a voluntary basis without asking for donations or funding from our community.

19. In February 2012, we set up a private Facebook group for infected and affected people to join, and a Facebook reference page which linked to our website, which also included a private forum. In 2015, the website and private forum was discontinued; however, we kept the private Facebook group named CBC Private Chat, which provided and continues to provide an important sounding board for people to discuss issues they feel uncomfortable and/or unwilling to talk about in other groups.

20. One key aspect of our Facebook presence is that we now have both a public page which anyone can view for news and information we share, which can also be shared to others, and a private group for people to share stories confidentially. Our CBC Private Chat Facebook group membership includes people from both the bleeding and non-bleeding disorder community. This

currently makes CBC the largest fully inclusive group campaigning around issues of infected blood in the United Kingdom.

21. In 2018, we set up a private limited company called Contaminated Blood Campaign Limited, of which the directors are myself and Lesley Brownless. This was done in order for the organisation to become a core participant in the Public Inquiry.

22. The main outcomes that CBC has achieved or contributed to achieving thus far are, I believe, as follows:

    a. Conducted research to identify key questions affecting infected people and put pressure on MPs and Government agencies to answer these questions.

    b. Provided a support network, information resource and centralised voice for the bleeding disorder and non-bleeding disorder community alike, who felt their experiences and interests were not adequately addressed by other campaigning organisations;

    c. Assisted in the pursuit of litigation to demonstrate unlawful discrimination against infected and affected people;

    d. Successfully manoeuvred the Government, in part as a response to a judicial review which we developed and supported, to make non-discretionary annual payments for all HCV Stage One beneficiaries, and to also equalise payments for all HCV bereaved spouses/partners and dependant children of HCV beneficiaries in-line with HIV beneficiaries.

Section 3: Involvement in committees and/or working groups

23. I was a committee member of Tainted Blood from October 2010 to April 2011. My responsibilities during that time were to take part in internal meetings and help organise campaigning activities.

24. I helped found the Contaminated Blood Campaign in 2012, and have been a committee/team member since its inception. I am also a Director of Contaminated Blood Campaign Limited.

25. In November 2012, CBC, along with other campaign group representatives, met with the then Health Minister Anna Soubry and some of the experts who advised the Government in Autumn 2010 for their review report released in January 2011. This meeting included discussing the evidence reviewed by the expert group and allowed campaigners to raise their issues, provide feedback on the review and provide evidence which they felt should have been included.

26. In 2013, CBC began working with the Caxton Foundation Partnership Group, attending five meetings over an approximate three year period. CBC attended these meetings in order to highlight our community's issues to the Caxton Foundation and to feedback information to the HCV community.

27. In March 2014, CBC met with a lady called Ginny Brunton who was conducting research into the extra hepatic manifestations and quality of life issues in relation to HCV and how this impacts on the lives of infected individuals. This involved research and was designed to provide a report back to the Department of Health.

28. In October 2015, CBC, along with other groups, took part in a meeting organised by the Department of Health with an independent facilitator called Gerrard Hennessey. The meeting took place in London and was designed to provide a platform for consultation and feedback to the Department of Health regarding any new financial assistance scheme moving forward **(WITN2050004).**

29. In October 2017, CBC were part of the DWP Working Group, initiated by my MP Diana Johnson. The working group was set up to work with individuals affected by contaminated blood and blood products together with officials from the DWP to hear about our experiences of the application and assessment

procedures for disability benefits. After attending several meetings over an approximate two year period, the only change applied by the DWP was to review the issue of haemarthropathy cases for those with a bleeding disorder.

30. In 2019, CBC were part of a working group initiated by the Infected Blood Inquiry. This working group included twelve individuals representing various campaign groups from around the United Kingdom. The aim of this working group was to improve the level of support payments around the UK. The initial meeting included a workshop in London to develop ideas and proposals for the way forward. Further discussions took place via email and teleconference, with a face to face meeting prior to the official meeting with Cabinet Office Minister David Liddington and Health Minister Jackie Doyle Price at the Cabinet Office in January 2019.

Section 4: Research and investigations

31. Research is some of the most important work conducted by CBC. We conduct research by reading and critiquing Government reports/reviews, submitting FOIs, PMQs and writing independently to various Government bodies and other organisations, collating the documents received and identifying key information including any anomalies that could be helpful in understanding the underlying facts of the infected blood scandal. It is my hope that some of our research may be helpful to the Inquiry's investigations, so I have summarised our key findings in this section.

32. The documents we have reviewed in our research are extensive and cannot easily be summarised in a witness statement. However, I will endeavour to provide a brief summary of the topics we have researched and exhibit key documents identified. Further information about any of these topics is available upon request to my solicitors at Leigh Day.

33. Our research has thus far identified documents from the following sources:

- Blood Product Laboratories
- Blood Transfusion Service
- Haemophilia Centres
- UK and US Media
- Medical research journals
- Pharmaceutical companies
- UK and US Government bodies
- Various committees, advisory groups and working groups
- World Health Organization

34. These documents broadly cover the following themes:

a. Risk of Infection – Hepatitis
b. Risk of Infection – HIV/AIDS
c. UK Self-Sufficiency in Blood Products
d. Heat Treatment, Screening and Lookback Exercises
e. Financial Assistance, Litigation and Inquiries
f. Destruction of Documents

A. Risk of Infection – Hepatitis

35. The earliest documentation we were able to obtain about the risk of transmission of hepatitis from blood or blood products is from the late 1960s. Several American newspapers from that time contained articles about prison plasmapheresis programmes which involved the purchase of blood from incarcerated men to facilitate the production of large pooled concentrates of Factor VIII (FVIII) and Factor IX (FIX) for the treatment of haemophiliacs. Prisons in several US states had been participating in such programmes since at least the early 1960s and there had been various documented outbreaks of hepatitis since then. In 1968 the British Medical Journal (BMJ) published an article which provided the above statistics and referred to the "outstanding

hazard of commercially supplied blood – namely, the risk of post transfusion hepatitis" **(WITN2050005).**

36. A British study was then conducted which followed 943 patients with haemophilia and 123 with Christmas disease treated with various clotting agents from 1968 to 1969, 29 of which developed "clinical jaundice". The study concluded as follows **(WITN2050006)**:

> *The clinical value of free and early treatment of haemophilic patients in the saving of life and prevention of crippling is now well established. This treatment is known to carry two main hazards:*
>
> *i. The transmission of infective hepatitis*
> *ii. The development of specific antibodies against coagulation factors*
>
> *The data on hepatitis suggest that patients with coagulation defects are very resistant to clinical hepatitis. Hepatitis transmission must be related to the number of 'donor exposures' of the patients. This number will increase with the use of dried concentrates made from large pools of donors. These concentrates have advantages in treatment in that the potency is known and they are convenient to make up and administer. The problem in recommending an increased manufacture of these lies in the possible increase in hepatitis and antibodies. From the point of view of clinical hepatitis this danger seems to be small though the high incidence of Australian antigen and antibody in haemophiliacs suggests that they do become infected. We feel that the increased risk of clinical illness is not so great as to overbalance the advantages of the use of concentrates.*

37. In 1972 a study was conducted in America which concluded that older children and mild haemophiliac adults with little exposure to blood products were at a higher risk of developing hepatitis, and suggested the use of "single donor products" in these patients to mitigate that risk **(WITN2050007).** In 1973, the Department of Health and Social Security (DH)'s Expert Group on the Treatment of Haemophilia stated that the risk of transmitting hepatitis is greater with large pooled concentrates but that this "should not be a deterrent to using" these products and this "complication will decrease with universal screening of donors for hepatitis (B) antigen" **(WITN2050008)**.

38. Once the hepatitis risk from imported products had been recognised, the discussion soon turned to the need for the UK to become self-sufficient in producing blood products. The drive for self-sufficiency will be explored further in subsection C.

39. In December 1975, the TV series "World in Action" released an episode called "Blood Money" which investigated the transmission of hepatitis from blood products produced using paid donors. The programme claimed that Dr Garrott Allen of Stanford University had "warned against importing blood form the US in 1973 due to the hepatitis risk", but that British blood donors still carry a risk, just not as high a risk as paid donors in the US. Health Minister David Owen was quoted in the programme as saying "*I think there is a strong moral case and a strong commercial one for self-sufficiency*" **(WITN2050009)**.

40. In 1977, the WHO produced a report which outlined the costs of hepatitis to societies in great detail, including both direct costs, such as diagnosis and screening, healthcare and training of clinicians, and indirect costs, such as infected people taking absences from work, becoming disabled and dying prematurely. **(WITN2050010).** The report, which also confirmed that plasma products derived from large pools of plasma "*carry a high risk of contamination with the hepatitis B virus*", seemed to encourage countries to invest in the short term costs of education and prevention in order to avoid the much larger costs of treating a large number of hepatitis patients and losing their economic contributions in the long term.

41. In 1978, an annual research report to the DH by the University of London (which was also the WHO collaborating centre for reference and research of viral hepatitis) identified the existence of non-A non-B (NANB) hepatitis in haemophiliac patients receiving factor products, and concluded that "*until blood donors can be specifically screened for the virus of non-A non-B hepatitis, it would seem wise to restrict the use of blood concentrates to life threatening situations*" **(WITN2050011).**

42. In 1979, the Advisory Group on Virial Hepatitis was formed, with the mission to advise the Chief Medical Officer on the prevention and control of hepatitis. A member of the group (whose name is redacted on the copy we received) contacted the DH to advise that if haemophiliacs were contracting hepatitis, people receiving transfusions might be at risk as well **(WITN2050012).** A meeting at the Medical Research Council that year also found that NHS products were implicated in hepatitis transmission, not just commercial products **(WITN20500013).**

43. In 1980, the Medical Research Council's Blood Transfusion Research Committee formed a Working Party on Post Transfusion Hepatitis, with the mission "*to promote research to assess the nature and size of the problem of post transfusion hepatitis in the UK, with particular reference to changes in transfusion practice, e.g. the use of products prepared from pooled plasma from large numbers of donors and the introduction of commercial products from abroad*" **(WITN2050014).**

44. That same year, UK Haemophilia Centre Directors agreed at their annual meeting that smaller pooled concentrates and NHS concentrates carried a lower risk of hepatitis transmission than large pooled commercial concentrates, but no decisions were made relating to the continued use of imported products **(WITN2050015).**

45. By this time, it was common knowledge that factor products carried a risk of hepatitis transmission. This was confirmed in a book written in 1980 by Dr Peter Jones, Director of the Newcastle Haemophilia Centre, which would have been required reading for the medical profession, and in particular for those with an interest in bleeding disorders **(WITN2050016)**.

46. A three-year study of the rates of hepatitis transmission to haemophiliacs from 1977 to 1980 suggested that mild haemophiliacs might be given factor VIII concentrate from a smaller donor pool, as the risk of contracting hepatitis from large pooled concentrate after the first infusion was 90-100% for both NHS and commercial FVIII **(WITN2050017).** Funding to extend this project was sought

but it was refused by the Medical Research Council **(WITN2050018).** Another study of the hepatitis transmission rates of different FVIII commercial products was conducted which illustrated the risks attributed to each product **(WITN2050019)**.

47. By 1983, the risk of hepatitis transmission by blood products was very well documented. Commercial blood product labels contained warnings about the risk of hepatitis **(WITN2050020)**, and the UK Haemophilia Hepatitis Working Party had recognised that the risk of contracting NANB hepatitis on first exposure to blood products from the US or UK was 100% **(WITN2050021)**.

48. However, at this point the first cases of AIDS were reported, and the conversation shifted for several years to address the more urgent issue of HIV transmission, which will be dealt with in subsection B.

49. By 1985, with the introduction of heat treatment to inactivate HIV, global attention around blood products shifted back to hepatitis. Research conducted by the Blood Products Laboratory (BPL) had revealed that NANB hepatitis could lead to chronic liver disease, rather than just an acute episode of hepatitis **(WITN2050022)** and that it could be transmitted by blood transfusion, not just blood products. The WHO confirmed an urgent need for a reliable serological test for NANB hepatitis in June 1985 **(WITN2050023)**.

50. Some clinicians at this point still seemed wilfully unappreciative of the seriousness of hepatitis, despite the well-documented risks. Professor A L Bloom, Chairman of the Haemophilia Centre Directors expressed a desire to phase out cryoprecipitate and increase treatment with factor concentrates. However, this was criticised by others as hazardous, due to the known risk of hepatitis causing chronic liver disease related to treatment with large donor pool concentrates **(WITN2050024)**.

51. Over the next several years, discussions in Parliament centred on ascertaining the seriousness of NANB hepatitis, and identifying the point at which decision makers first knew of the risk of hepatitis transmission from blood products.

Addressing the second question, in May 1987, Mr Tony Newton MP, the then Minister for Health speaking on behalf of the Government, noted that "it became evident in the UK in 1974 that the use of imported factor VIII was associated with non-A non-B hepatitis" **(WITN2050025)** and at a meeting between the National Blood Transfusion Service and BPL in March 1987, it was noted that "awareness of the serious nature of non-A non-B hepatitis in haemophiliacs was shared by clinicians and BPL scientific staff alike" by 1981 **(WITN2050026).**

52. From about 1987 to 1991, discussions also focussed on the development of a screening test for HCV. The Department of Health convened an Advisory Committee on the Virological Safety of Blood, one of the main purposes of which was to reduce hepatitis transmission.

B. Risk of Infection – HIV

53. In 1982, the emergence of AIDS in the US complicated the issue of infection by blood products, due to the high fatality rates and social stigma associated with AIDS. Initially the method of transmission of AIDS was not known. In August 1982, American pharmaceutical company and producer of blood products Hyland wrote to the American Pharmaceutical Manufacturers Association that the link between blood products and AIDS was unproven and needs further evidence, but that "efforts should be made to 'clean up" clotting factor concentrates to minimize the risk of disease transmission **(WITN2050027).** By November 1982, pharmaceutical companies had started to take steps to stop high risk groups from donating plasma.

54. By early 1983, the risks posed by AIDS and the fact that it could be transmitted by blood and blood products was known by US pharmaceutical companies **(WITN2050028).** To reduce these risks, companies began investigating opportunities to inactivate the AIDS virus (now known as HIV) by heat treatment of blood products – research around which had already been started several years prior as part of efforts to inactivate hepatitis.

55. In the UK, however, experts held conflicting views about the risk of HIV to British haemophiliacs and what should be done to combat this. The Haemophilia Society informed patients in May 1983 that, according to advice from Professor A L Bloom Chairman of the Haemophilia Centre Directors, AIDS had only been reported in the US and there would be no need for patients to avoid factor products **(WITN2050029).**

56. However, Dr Spence Galbraith, an eminent doctor and researcher in communicable disease prevention, wrote to the DH to explain that all blood products made from blood donated in the USA after 1978 should be withdrawn from use due to the risk of AIDS, given the current lack of knowledge about how exactly AIDS is transmitted and the mortality rate of 63% within one year of diagnosis. He noted that there had already been two cases of AIDS in British haemophiliacs, and that this low incidence did not mean there was a low risk of others becoming infected **(WITN2050030)**:

> *Although this number of cases of AIDS associated with the administration of factor VIII concentrate is very small in relation to the number of individuals receiving the product, this may NOT indicate that the risk is small because (a) the earliest cases of AIDS reported in the USA developed symptoms in 1978 and therefore USA blood products manufactured from donations before 1978 are very unlikely to have been contaminated. Indeed, the earliest reported date of onset of AIDS in a haemophiliac is October 1980, (b) most of the reported cases of AIDS have been diagnosed in 1981 and 1982. In 1981 and the first six months of 1982 456 cases were reported out of 506 since January 1979, 249 of them in 1982, (c) the incubation period is long, between several months and two years and may be as long as four years and therefore one would not expect to see many cases due to USA blood products until a year or more after 1981/82 donated blood products had been given.*

57. At a meeting of Haemophilia Centre Directors convened to discuss this issue on 13 May 1983, discussion turned to new measures which had been taken by the US from March 1983 to prevent high risk donors from donating, and the risk that 'pre-March' plasma might still be provided to the UK market. However, it was agreed that no restriction should be placed on the use of imported FVIII

other than to continue with the policy of using only NHS material for children under 4 and for mild haemophiliacs **(WITN2050031)**.

58. The subject of conducting clinical trials involving products less likely than others to transmit hepatitis was discussed by Haemophilia Centre Directors for the next several months, with most Directors agreeing that clinical trials to test allegedly "hepatitis-reduced" products should not include previously untreated patients due to the risk of transmitting AIDS. Some Directors, such as Dr Bloom, disagreed **(WITN2050032),** arguing that it is important for hepatitis reduced products to be subjected to formal clinical trials in mild haemophiliacs.

59. In July 1983, the Committee on the Safety of Medicines decided that it would not be possible to withdraw imported factor products and replace them with cryoprecipitate "*on the grounds of supply*", and that "*the perceived level of risk does not at present justify serious consideration of a solution*" **(WITN2050033).**

60. Donor screening for HIV was eventually introduced by US pharmaceutical companies at the end of 1985 and in the NHS by the end of 1986; and heat treatment was introduced in 1984 (Scotland) and 1985 (England), effectively removing the risk of HIV transmission. However, the following issues remained:

    a. From 1983 to 1985, between the emergence of AIDS in the UK and the introduction of heat treatment to inactivate HIV, many haemophiliacs were infected with HIV;

    b. In December 1986, Baroness Trumpington confirmed in the House of Lords that heat-treated stocks of unscreened factor products were still being used; although not for routine treatment, but for "clinical trials". It is not known how long these stocks were held or which trials they were used for **(WITN2050034).**

C. UK Self- sufficiency in blood products

61. In the mid-1970s, around the same time that the risk of hepatitis from blood products was first identified, discussions in Parliament about how to reduce this risk began to focus on the goal of becoming self-sufficient in blood products and no longer requiring imports from the US.

62. In 1975, the WHO recommended that countries aim for self sufficiency in blood products to avoid the risk of infection **(WITN2050035).** That same year, Health Minister David Owen began to speak out about the need to increase UK production of blood products, both in order to reduce the risk of hepatitis and reduce the costs of importing blood products from abroad, as this was significantly higher than the cost of producing them in the UK. Dr Owen authorised special finance of £500,000 to fund this goal of self-sufficiency by increasing plasma production, based on the fact that health authorities had spent £500,000 from 1973 to 1975 on imported concentrate, and set a deadline of two to three years (until 1977 or 1978) to accomplish it **(WITN2050036).**

63. By 1978, self-sufficiency had not yet been achieved. In Parliament, Health Minister Mr Moyle noted that while the production target set for 1977 had been met, the demand for FVIII had increased to an extent that it was impossible to meet given the capacity of the fractionation laboratories **(WITN2050037).** More funding was allocated to blood product laboratories to accommodate this. Meanwhile, at the annual meeting of Haemophilia Centre Directors in November 1978, Dr Chalmers of Addenbrooke's Hospital stated that self-sufficiency should be pursued urgently as it was "very dangerous to rely on the commercial concentrates" and Dr Peter Jones stated that "in view of the high cost of commercial material" it would be better to invest in upgrading British fractionation plants than to continue to spend large sums of money on foreign materials **(WITN2050038).**

64. In 1980, an inspection of the BPL fractionation plant at Elstree revealed that the plant was unsafe and hazardous, and that it would need to be refurbished in

order to continue producing blood products **(WITN2050039).** Ministers briefly considered the idea of hiring a commercial company to oversee the refurbishment and manage blood product production going forward, but decided against this as it risked jeopardising the UK's policy on voluntary blood donation. The cost of refurbishing the laboratory was quoted at £20 to £30 million, compared with the cost of importing blood products at £4 million annually **(WITN2050040).**

65. The Health Minister announced a grant of £11 million to upgrade the laboratory, but it was noted that this would not pay for the full refurbishment that was needed and that even with this upgrade it would be necessary to import products from abroad. In the House of Lords, Lord Avebury asked why the Government would not sanction further capital expenditure on the blood laboratories to reach the goal of self-sufficiency, and Lord Cullen of Ashbourne responded that while self-sufficiency was a long term aim, and we would like to be able to spend the £30 million to rebuild the laboratory, "*we are not anxious to do so*" **(WITN2050041).**

66. In July 1981, a D R Harris of the DH wrote to the Treasury noting that the Government was now spending approximately £10 million annually on imported blood products, but that these were "less safe" than NHS products because of the hepatitis risk **(WITN2050042).**

67. By 1983, self-sufficiency had still not been achieved, and the concern about AIDS gave more urgency to the issue. After the US instituted a policy in March 1983 to eliminate high risk donors from the donor pool, concerns arose at a meeting of Haemophilia Centre Directors that some products already made from pre-March plasma would still be exported **(WITN2050043).** In Canada, these same concerns led to a decision by blood product company Connaught Laboratories to start evaluating US plasma sources' policies before purchasing their products **(WITN2050044).** The deadline for self-sufficiency was eventually moved to 1986 by Parliament as attention was diverted toward developing heat treatment to inactivate HIV **(WITN2050045).**

68. In July 1985, another episode of "World in Action" was released entitled "Bad Blood", which followed the Government's progress toward self-sufficiency from David Owen's announcement of funding in 1975 to the redevelopment of the BPL laboratory. When asked "What would be Government's reaction if Factor VIII still had to be imported after 1987?" Kenneth Clarke was quoted as saying "I'd be quite appalled" **(WITN2050046).**

69. In 1987, Dr John Cash wrote an article for the British Medical Journal which stated that the Government was "*no longer committed to self-sufficiency in blood and blood products*" and explored why it had been difficult for this goal to be met, claiming that self-sufficiency could only be achieved through the formation of a national Blood Transfusion Service removed from direct regional health authority funding **(WITN2050047).** Ben Plowden wrote an article for the New Society magazine explaining that while doctors have been aware of the risk of infections being transmitted through imported blood products and have been aiming for self-sufficiency since the mid-1970s, this was not achieved. He proposed that as a consequence, not only have many haemophiliacs been infected with hepatitis, but that between 1983 and 1985, the Government was aware of the risk of HIV transmission but haemophiliacs continued to be treated with unheated, imported factor products and many were infected with HIV **(WITN2050048).**

70. Over the next few years, David Owen, now in the House of Lords, made efforts to investigate why the goal of self-sufficiency had still not been met since he introduced the goal in 1975. He was given the following reasons for this by the DH **(WITN2050049):**

    a. His funding of £500,000 did increase the production of FVIII from 2.9 million units in 1975 to 11.8 million units in 1977;

    b. A £2 million capital investment in the blood products laboratory 1980 raised production to 21.6 million units in 1982;

c. The demand for FVIII continued to increase at a faster rate than products could be produced, rendering self-sufficiency impossible; and

d. In 1984, production was lowered in order to focus on heat treatment for the inactivation of HIV.

71. By 1989, with both heat treatment and HIV screening available, the Government's focus turned to the development of a screening test for HCV, which was then introduced UK-wide in 1991. Self-sufficiency in the production of blood products was never achieved.

D. Heat Treatment, Screening and Lookback Exercises

72. Even once the risk of hepatitis was well known, it was still not possible for doctors to screen blood for NANB hepatitis because the infective agent which caused it had not yet been identified. The first discussion of screening of blood for NANB hepatitis infection was in 1978. Researchers at the London School of Hygiene and Tropical Medicine conducted a study in which they injected chimpanzees with commercial Factor IX and all of them developed NANB hepatitis **(WITN2050050).** The researchers stated in their report that "*work is in progress in an attempt to isolate and identify this virus*" and that they were urgently investigating "methods for the inactivation or removal of the infective agents".

73. In 1979, researchers at the University of London concluded that "*until blood donors can be specifically screened for the virus of non-A non-B hepatitis, it would seem wise to restrict the use of blood concentrates to life threatening situations*" **(WITN2050051).** If that advice had been followed, I and many other victims would not have had their lives devastated by contaminated blood.

74. By 1982, as it was still not possible to test blood for NANB hepatitis, interest started growing among researchers around the possibility of developing heat treatments that could inactivate NANB hepatitis in factor products. The urgency

of this intensified as it was recognised in the British Medical Journal in March 1983 that NANB hepatitis could potentially lead to chronic liver disease, whereas it had previously been thought to only cause minor acute symptoms **(WITN2050052).**

75. However, the emergence of HIV in UK haemophiliacs in 1983 shifted the conversation around heat treatment away from hepatitis. In May 1983, Haemophilia Centre Directors met to discuss the possibility of conducting clinical trials to assess the efficacy of heat treatment in inactivating HIV or hepatitis. It was raised that a controlled clinical trial would be needed in respect of heat-treated products, and the following note was made in relation to this:

> *Haemophilia Centre Directors had been of the opinion that a meaningful trial could only be conducted in patients who had not previously been treated with Factor VIII, i.e. newly diagnosed mild haemophiliacs. However this is a particular group of patients for whom the directors have recommended that only NHS material should be used* ***(WITN2050031).***

76. The documented high risk of contracting hepatitis from blood products contributed to an ethical issue facing researchers considering potential clinical trials on the efficacy of procedures to inactivate HIV in factor products. Haemophilia Centre Directors Hepatitis Working Party were able to access a selection of commercial products which had been heat treated by variety of methods to inactivate HIV, and were faced with the question of whether it was ethical to use these products on previously untreated haemophiliacs, given that the commercial heat treated products carried a small risk of HIV transmission and NHS non heat treated products carried a 100% risk of NANB hepatitis **(WITN2050053).**

77. In September 1983 the Annual Report of the Hepatitis Working Party of the Haemophilia Centre Directors concluded that because of the 100% rate of hepatitis transmission from NHS material, ‘*"the ethical problem of exposing mild haemophiliacs to commercial material must be considered by each director*" **(WITN2050024).**

78. Pressure to introduce NHS heat treated products increased, as US pharmaceutical companies competed to market their products to the UK market. These products were all heat treated at different temperatures and using different methods, none of which had been verified by a clinical trial in the UK. In October 1983, Haemophilia Centre Directors agreed that a heat-treated product would be made available to haemophilia centres in the next 2-3 months, "on the basis that it is no worse than the existing product" **(WITN2050054).** It was also noted at the meeting that "*neither Dr Boulton, Dr Ludlum or myself [Dr Craske] considered it appropriate to discuss publicly the details of our current 'clinical trial' of heat treated FVIII.*"

79. In May 1984, it was noted at a meeting of the Central Blood Laboratories Authority that a clinical trial for heat treatment of NHS FVIII would begin that summer.

80. In December 1984, heat treated NHS product was introduced in Scotland which inactivated HIV but did not inactivate hepatitis.

81. Eventually it was announced that heat treated NHS product would be available in England by April 1985. However, there were disagreements about how to "fill the gap" in England until then. A letter from DH (the recipient(s) of which are redacted in the copy we received) in November 1984 stated that the use of commercial heat treated FVIII for the inactivation of HIV "*requires to be balanced with the introduction of a screening test for all donations*" as the commercial heat treated products that were available did not inactivate NANB hepatitis and were not yet licensed in the UK **(WITN2050055).**

82. The Director of Newcastle Haemophilia Centre expressed that he was unwilling to treat patients with unheated NHS products when heated products were available, due to the HIV risk, and sanctioned funding for his district to purchase enough commercial product to treat all patients on a named patient basis **(WITN2050056).**

83. In February 1985, it became clear that the production of 8Y (NHS heat treated product) was lagging behind the April 1985 target date. At a Central Blood Laboratories Authority meeting, it was emphasised that a poor decision now (i.e. not introducing the product soon enough) would create problems in the long term **(WITN2050057).** It was later confirmed in Parliament that the product would be licensed for use by September 1985 and should be prescribed on a named patient basis until then.

84. In 1986, attention returned to developing heat treatment that would inactivate NANB hepatitis. A clinical trial was proposed at a meeting of the Advisory Committee on the Virological Safety of Blood, but it was noted that "a prospective study in 'virgin' haemophiliacs had demonstrated 100% infectivity rate with NANB hepatitis, and so a clinical trial with a control group would be unethical" **(WITN2050058).**

85. In 1987, Scotland updated its heat treatment processes so that its product would be successful at inactivating hepatitis, and in 1989 it was discovered that the English products had been successful at this since their introduction in 1985.

86. From 1986, work was also being done to develop a screening test for HCV, as it was known by this time that it could cause serious chronic illness. The infective agent which causes HCV was identified around 1988, and crude screening tests started to be developed over the next few years before the test was introduced nationally in 1991.

87. However, criticisms were made that steps were not taken quickly enough from 1987 to 1991 to develop and introduce the test. A research note from the Scottish Parliament in 2000 outlines several occasions when criticisms were made in the media and within the Blood Transfusion Service **(WITN2050059)**:

    a. A 1987 Lancet article noted that the UK needed to follow the lead of the USA and Europe in donor screening;

b. In 1990 it was noted at a Blood Transfusion Service, Western Division meeting that the UK was still falling short of US and European standards;

c. An article in the Scotsman claimed that the UK had opted not to use the screening test available because of "the effect it would have on the supply of blood and blood products".

88. In the summer of 1990, HIV tests were introduced as part of the screening process for factor products. HCV testing was introduced in the USA in July 1990, and the plan was made to introduce it in the UK in July 1991. In the end, the date for full roll-out of testing was moved to September 1991, even though the test was available in some regions before then. This made the UK one of the last western countries to introduce the HCV test.

89. H L Lloyd, Director of the Northern Region of the National Blood Transfusion Service, disagreed with the Government's decision to hold back from introducing testing in any region until all regions were prepared. He noted in a letter of 7 May 1991 that "*not to test now that we have the ability to test would be indefensible under the current product liability legislation*" and that while individual Directors might take different views, his region would begin testing earlier **(WITN2050060).**

90. In fact, this may have proved a sensible approach; in 1992 Dr Gunson announced at a meeting of the DH's Advisory Committee on the Virological Safety of Blood that a case was being brought against North West regional health authority by a patient who had contracted HCV from blood before the test was introduced **(WITN2050061).**

91. Once HCV testing was introduced, opinions differed on whether to conduct a lookback exercise to investigate the origin of HCV infections and counsel donors who tested positive. At a meeting of the Advisory Committee on the Virological Safety of Blood in February 1991, it was decided that donors testing

positive should not be informed of their infection as standard, "*leaving the option for those carrying out research*" **(WITN2050061).**

92. At a meeting of the Advisory Committee on the Virological Safety of Blood in May 1991, Dr Gunson had also proposed to the committee that no action be taken for donors testing positive for the first time, but that donors should be 'seen' if their next donation tested positive. The committee agreed that there was no reason to test donors with a history of jaundice **(WITN2050062).**

93. In 1998, recombinant factor products were introduced, which completely removed the risk of virus transmission as they were no longer made with human plasma. These products were first given only to children, and then slowly introduced to the adult UK population, although five years later it was noted in the House of Lords that the UK still had the lowest availability of recombinant products in the developed world **(WITN2050063).**

E. Financial Assistance, Litigation and Inquiries

94. In 1987, as heat treatment became available for both HCV and HIV and the immediate risk of infection lowered, many infected blood campaigners began to focus on campaigning for Government-provided financial assistance for infected people.

95. In March 1987, the Haemophilia Society made a formal call for compensation for haemophiliacs infected with HIV. This was met with resistance from the Government, which held the position that compensation should only be provided where fault can be attributed and that in this case fault could not be found.

96. In November 1987, Mr Newton announced the provision of a grant of £10 million intended as ex gratia financial assistance for haemophiliacs infected with HIV. He clarified that this grant was not intended as compensation, stating that "*until we reach forward in the law to accept some form of strict liability, in*

cases where fault is not an essential ingredient the only way that the Government can deal with such catastrophes is not by compensation as it is ordinarily understood but by offering a generous ex gratia grant" **(WITN2050064).**

97. The grant facilitated the formation of a new charity, the MacFarlane Trust (MFT), which haemophiliacs could apply to in order to receive a one-off payment of up to £20,000.

98. The issue of whether it would be more appropriate to provide compensation instead of ex gratia payments was debated in the House of Commons in 1989, but the Government expressed the view that the money provided to MFT was sufficient and comparable to payment schemes in place in other countries. A further £24 million was provided to the MFT in November 1989.

99. In 1990, a legal claim was initiated on behalf of haemophiliacs infected with HIV, alleging that the DH a) failed to provide information about the risks of treatment with blood products to haemophiliacs and b) delayed in providing patients with heat treated products. By January 1990, there were 750 claimants in the claim.

100. When asked in written questions to the House of Lords about the potential settlement of this litigation and how much it had already cost the Government, Health Secretary Rt Hon Kenneth Clarke MP stated **(WITN2050065)**:

> *If it were accepted in this action that ministers did owe a duty of care this would likely lead to very large numbers of costly and time consuming claims against the Department, licensing authority and CSM." The secretary of state fully recognises the force of the argument that the resources likely to be taken up by this litigation would better be used to alleviate suffering. However, it would not achieve this purpose if the likely consequence of compromising these actions were to encourage other expensive litigation in future.*

101. The Court of Appeal handed down its judgment in September 1990, holding in favour of the DH. Kenneth Clarke released a statement on the judgment which included the following excerpts **(WITN2050066)**:

a. *In my opinion, on the factual information before me at the moment, this tragedy was no one's fault. The doctors and staff gave the patients the best medical treatment available in the light of medical knowledge at the time.*

b. *I believe it would have very grave consequences for medicine in this country if compensation was paid whenever a patient who had been treated properly by his or her doctors later suffered awful side effects or died. We rely on the clinical judgement of the medical and other professions when patients are treated.*

c. *If at any stage I am advised that there is evidence that this tragedy was probably caused by the fault of someone in the NHS or in my Department or in one of its agencies, the Government will pay compensation for the victims of that error.*

102. In March 2004, a discussion in the House of Lords noted that the MFT "*does not make ex gratia payments*", that the funding is needs based and dependent on health and financial circumstances, and that just over £35 million had been awarded thus far **(WITN2050063)**.

103. The MFT/MFET continued to be the source of all financial assistance for haemophiliacs with HIV until the introduction of the devolved Government schemes in 2017.

Hepatitis Assistance and Calls for an Inquiry

104. In January 1989, investigations were undertaken into a potential claim on behalf of people infected with HIV by blood transfusion instead of blood products.

105. In September 1992, as was mentioned in subsection D, paragraph 90, a case was brought against the North West Regional Health Authority by a patient who had contracted HCV from infected blood.

106. In 1995, the Canadian Government held an Inquiry to investigate why more than 11,000 Canadians were infected with HIV and HCV from blood products derived from US plasma.

107. In 1998, the House of Lords considered whether to provide financial assistance to haemophiliacs infected with HCV. It decided that, like in the case of HIV, compensation would not be provided as that would only be appropriate "*where the NHS or individuals working in it have been at fault*." It also decided, in response to the Haemophilia Society's request for financial assistance, that haemophiliacs with HCV should not receive financial assistance because the 'circumstances' of HIV were different to those of HCV; namely, the stigma around HIV at the time the original decision was made, the fact that it was generally considered a sexually transmitted disease and that haemophiliacs could inadvertently infect their partners were all important considerations which do not apply to hepatitis C **(WITN2050068)**.

108. In 1999, the UK Government considered a request to hold an Inquiry into contaminated blood and HCV, but refused the request. It released a statement saying "*We are asking UK haemophilia centre directors to ensure that all those who might possibly have been infected with Hepatitis C are offered counselling, testing and treatment. We do not propose a further inquiry*". At this point there was still no financial assistance available at all for those infected with HCV. **(WITN2050069)**:

109. In 2000, the Scottish Parliament discussed High Court litigation that had arisen on behalf of haemophiliacs infected with HCV under product liability legislation. The claimants argued that they were infected either a) between 1985 to 1987 when Scottish products were heat treated but before the process was successful at inactivating HCV, or b) between 1987 to 1991 when some early HCV tests were available but were not in widespread use.

110. In 2001, a new HCV steering group was formed within the House of Lords. The group conducted a consultation exercise with input from the NHS and the

Haemophilia Society. The Haemophilia Society included in its submissions, a request that a public Inquiry be held, but the Government responded that financial assistance would not be made available and there would be nothing to be gained from a public Inquiry.

111. In November 2002, the House of Lords again confirmed that compensation would not be appropriate for people infected with HCV, because the NHS was not at fault.

112. In 2003, the House of Lords considered a proposal by the Haemophilia Society that the Government provide £56.23 million per year to infected haemophiliacs for the next 10 years. Peers noted that the Government was currently facing negligence claims amounting to about £4.4 billion, and that these could be avoided if the Haemophilia Society's proposal were accepted. However, they also recognised that publicly funded legal claims only succeed at a rate of 24%, so the full amount of £4.4 billion would not likely become payable.

113. In March 2004 it was leaked to the press that the Government was planning to require haemophiliacs who contracted HCV before 13 December 1990 and had outstanding legal claims against the DH to sign a written promise not to sue in order to be eligible for financial assistance payments of £20,000 **(WITN2050070)**.

114. Later that year, the Government introduced the Skipton Fund, a Company Limited by Guarantee providing financial assistance to both haemophiliacs and non-haemophiliacs infected with HCV. People began to question the fairness of the differences between the Skipton Fund scheme and the schemes provided by MFT and the Eileen Trust (a charity for non-haemophiliacs infected with HIV). For example, the Skipton Fund did not provide assistance to bereaved spouses/partners, or dependant children of infected people who had died. The House of Lords responded as follows **(WITN2050071)**:

> *Unlike the MacFarlane and Eileen Trusts, which administer schemes for those infected with HIV, the ex gratia payment scheme for those infected*

with hepatitis C as a result of National Health Service treatment with blood or blood products, known as the Skipton Fund is not a charitable trust. It has been designed to make lump sum, ex gratia payments to those living with the hepatitis C virus and has not been designed to compensate for bereavement. For these reasons it is distinct from the HIV payment schemes.

115. In 2006, the Government again considered a public inquiry, and again declined to hold one. The House of Lords held as follows **(WITN2050072)**:

> *We do not accept that any wrongful practices were employed in relation to inadvertent infection of blood which led to Hep C, and we do not consider that a public inquiry is justified as we do not believe that any new light will be shed on this issue as a result.*

116. In response to a question about why an Inquiry would not be considered, as the Canadian Government had conducted one, the House of Lords gave the following response **(WITN2050072)**:

> *Subsequent inquiries found that wrongful practices had been employed and criminal charges were laid against the organisations, including the Red Cross Society, who were responsible for screening blood. There was no such wrongdoing in the UK and it is unfair to compare the two schemes.*

117. In April 2006, the Scottish Government considered whether to hold its own Inquiry into the transmission of HCV by NHS blood. Concerns were raised about the inadequacy of lookback exercises which had been conducted for people with HCV, and the delay in introducing widespread HCV testing. It was agreed that an Inquiry should be held, and this led to the Penrose Inquiry, which concluded in 2015.

118. In February 2007, The Archer Inquiry was announced. This was an independently funded Inquiry, chaired by Lord Archer of Sandwell QC, and held no legal or official status so was unable to compel witnesses or demand the disclosure of documents. In 2009, the Archer Inquiry report recommended that direct financial relief be provided from the Government in the form of an initial capital sum followed by prescribed periodical payments to those infected with

HIV or HCV from infected blood, to remove the need for individuals to apply to various Trusts and Funds for financial assistance.

119. After the Archer Inquiry reported in 2009, and with further pressure of the successful *R (March) v Secretary of State for Health* 2010 judicial review which challenged the UK Department of Health's decision not to implement Recommendation 6(h) of the Archer Inquiry, the Government conducted a review of the payment mechanisms already in place (the Trusts and Funds) in 2010. However, the Government ultimately decided to provide further funding to these existing Trusts and Funds, rather than to provide payments in a centralised manner from public funds as recommended.

120. At the time, there had already been ex gratia payments made available to haemophiliacs infected with HIV from the MFT since 1988 and to non-haemophiliacs infected with HIV from the Eileen Trust since 1993. After the Archer Inquiry reported its findings, the Government established the MFET Limited in 2010 which provided infected beneficiaries of the MFT and Eileen Trust with regular non-discretionary annual payments. By contrast, the only financial assistance available for people infected with HCV was in the form of lump sum payments from the Skipton Fund. There were no discretionary payments available for bereaved spouses/partners of people who had died from HCV or dependant children and there were no annual payments.

121. The Government did eventually establish the Caxton Foundation to provide discretionary payments to those infected with HCV, but at a much lower value to the payments available from the MFT. In addition, in 2011 the Skipton Fund began providing non-discretionary annual payments to some beneficiaries whose liver disease had progressed to a later stage, deeming them 'Stage Two' beneficiaries. There were still many people infected with HCV who did not meet the criteria for Stage Two payments from the Skipton Fund, who would therefore receive nothing at all annually. Anomalies clearly remained in terms of the financial support for HCV victims and their families which contrasted starkly with the statement made by Andrew Lansley in the House on 10th January 2011

where he is recorded in Hansard as stating the following. *"I hope that by getting rid of the anomalies and recognising in particular, through the work of the clinical expert group- the impact on those with hepatitis C, we are giving the support that those who were damaged should expect".* http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110110/debtext/110110-0001.htm#1101109000002

122. After the release of the Government review in January 2011, I submitted an FOI to the Department of Health asking for any and/all evidence submitted in connection with the decision to change any and/all systems in connection to contaminated blood. After receiving the FOI information, I went through this in detail, highlighting areas of inconsistency. **(WITN2050073)**. One particular area of interest in the 2011 review document was the suggestion that it was the opinion of the Expert Working Group that the Skipton Stage One payment level was appropriate, so I wrote to each member of the Expert Working Group asking various questions including each of their opinions on the level of stage 1 payments and whether they were asked to comment on this within the Expert Working Group **(WITN2050074)**. I received a response from Professor Brian Gazzard and we corresponded several times in his capacity as Chair of the Expert Working Group **(WITN2050075)**. As a result of this work, we identified that any suggestion the Government experts agreed that the stage 1 payment level was appropriate was entirely misleading. In fact, the Expert Working Group were not even asked to comment on this.

123. In order to understand and compare the differences in the criteria and levels of support between the HIV beneficiaries and HCV beneficiaries we gained access to the accounts of both the MFT and Eileen Trusts for each year they had been operating. It was this information which helped us to produce our anomalies and other reports **(WITN2050076)**.

124. In 2017, as a direct response to the campaigning activity of a large number of people and the litigation that I describe below, the various Trusts and Funds were disbanded and financial support began to be managed by each of the

devolved Governments. Some differences between the higher financial support for HIV infected and the lower support for HCV infected people have to some degree been addressed; however, financial discrimination remains in all of the devolved schemes. Some of the financial discrimination against HCV bereaved spouses/partners and dependant children has been addressed; however, there remain some major differences between the English, Northern Irish, Welsh and Scottish financial support schemes.

F. Destruction of Documents

125. In 1990, it was mentioned in the House of Lords that certain Government documents from the then-current Conservative Government and the previous Labour Government were withheld in the litigation due to claims of public interest immunity **(WITN2050065)**.

126. In 2003, Lord David Owen requested to see documentation from his time as Health Minister and was told that some documents were missing. He was later told that these papers had likely been marked for public immunity during the HIV litigation and then "inadvertently destroyed" during a clear out in the mid-1990s **(WITN2050077)**. The papers destroyed were from 1973 to 1985 and covered a variety of topics related to contaminated blood, including: plans for self-sufficiency in blood products, identification of HCV as a potentially serious condition with longer term effects, and the redevelopment of the blood products laboratory at Elstree. Lord Owen was not satisfied with this answer and continued to press for information on the destruction of these documents, as there was a 30-year retention rule for Government documents and his initial request was made well in advance of this deadline. He corresponded with various Government Departments as well as the Ombudsman from about 2002 to 2007 on this issue but the missing documents were never located.

127. Lord Warner confirmed in 2006 that the Government had still not been able to determine why these documents were destroyed, but it may have been

because the papers marked for public interest immunity in the 1990s had not been adequately re-archived and then had been marked for destruction. He stated that an internal review would be conducted about this.

128. It was also noted that Lord Patrick Jenkin had tried to locate his own files related to contaminated blood but was told that these had also been destroyed.

129. In September 2006, the DH confirmed that they were unable to find many applications and waivers that claimants in the earlier HIV litigation had signed in order to gain access to their £20,000 payments, and that they believe they may have been inadvertently destroyed.

Section 5: Individual campaigning activities

Demonstrations

130. In April 2010, myself and my wife, along with three other individual campaigners from the Yorkshire area, travelled to Lincoln to demonstrate against Labour Health Minister Gillian Merron at all the Hustings meetings held there during the 2010 general election campaign. We took this course of action because Gillian Merron, as Health Minister, had failed to address the needs of the community. On one occasion, we offered a bouquet of flowers to Ms Merron in remembrance of all those that had died within our community; however, Ms Merron refused to accept them.

131. In June 2010, I attended a demonstration in London organised by the Manor House campaign group. I was asked if I would provide banners and placards for the demo, which I did. We met at the Trafalgar Square meeting point where I set up the banners and placards, some of which were very large, and handed them out to other campaigners in attendance on the day. We marched down Whitehall, past Downing Street, at which point several campaigners together with Lord Morris of Manchester entered Downing Street to hand over flowers and various letters to Number 10. We proceeded down Whitehall and onto

College Green, opposite Westminster, where several of us were interviewed by the press. After leaving College Green, we went over the road to the Houses of Parliament where we went to lobby our own MPs. Many campaigners in attendance on the day were wearing campaign T-shirts which bore the slogan 'Silence is violence – 4,800 infected and counting' and were told either to remove them or turn them inside out, before being allowed to enter the Houses of Parliament. Diana Johnson was not happy that we had to do this, and she made a complaint to the Serjeant at Arms. After lobbying our MPs we then proceeded back up Whitehall to demonstrate outside the Department of Health building at Richmond House.

132. As the above demonstration proved a success, Tainted Blood decided to hold a demo prior to a Westminster Hall debate that was taking place. This 'static' demonstration took place on Wednesday 13 October 2010 at Old Palace Yard (College Green, opposite Westminster). I was asked if I would organise it and seek permission from the Metropolitan Police, which I did. I also provided the banners and placards used in the previous demonstration. On the day of the demo I was asked if I would like to be on the Tainted Blood committee, and I agreed.

133. In 2014, CBC organised a demonstration in David Cameron's constituency in Witney with about 30 attendees. David Leadbetter (a CBC team member until 2018) had been having meetings with his MP David Cameron to discuss the issue of contaminated blood and didn't seem to be getting anywhere, so we thought it would be a good way to get his attention to demonstrate in the town centre. This was the first demonstration that Russell attended and the first time I met him and his wife Beatrice **(WITN2050078)**.

134. In April 2016, CBC, along with other campaign groups, held a demonstration prior to a further Westminster Hall debate that was taking place. Again, my role included obtaining Police permission for the demonstration and providing

banners and placards. The demonstration was well attended and took place in front of the King George V statue, opposite Westminster.

Correspondence with MPs and Government

135. Before starting CBC, I campaigned as an individual by writing letters to my then MP, David Davis, MP for Haltemprice and Howden to raise his awareness of the problem of contaminated blood, but found him to be dismissive of what was clearly an important issue for me as his constituent. Mr Davis was reluctant to see me at his surgery, and when I eventually did get to see him, it was a struggle to persuade him to help in various ways including the signing of Early Day Motions, which are motions on the parliamentary order paper that do not get debated but nonetheless are an opportunity for MPs to express their views about an issue. He seemed to only want to do the bare minimum.

136. In 2010, I wrote a letter to Kenneth Clarke MP to ask why he didn't provide any statement to the Archer Inquiry which would have been extremely easy to do as the Archer Inquiry took place in offices just across the road from Westminster. Mr Clarke wrote back to me on 24 March 2010, stating **(WITN2050079):**

> *In my opinion, my involvement was very fringe as I was not the Minister directly responsible. Indeed, I was not considered sufficiently involved to be called as a witness by any of the inquiries that have taken place. I am afraid that I suspect that I have been drawn occasionally into campaigning on the subject simply because I am still active in politics and therefore still a minor celebrity.*

137. I have met many times with Diana Johnson, my MP for Hull North. I first met with Diana in 2010 and spoke with her about my story and the key issues affecting our community. She was genuinely shocked and surprised as she had never heard of this issue before and wanted to learn more. I provided her with more and more information, and she took it seriously, wanting to help in any way that she could. Diana became politically active on this issue, and started the All-party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood. Diana also instigated a letter dated 7 July 2017, signed by all Leaders

of the Opposition (which importantly at the time also included the DUP) which called on Theresa May and the Government to commit to a full independent public Inquiry **(WITN2050080).** Four days later, on 11 July 2017 Theresa May announced the Inquiry. I believe this letter made the Governments' decade's long refusal to hold a Public Inquiry untenable and was the catalyst that finally convinced Theresa May that this Inquiry needed to go ahead.

138. Diana has been relentless in fighting for our cause and I feel fortunate to have such a dedicated and caring MP and would like to thank her on behalf of myself and our community for her continued support. A summary of Diana's involvement in campaigning on the infected blood issue, including speeches given, debates, and urgent questions in Parliament, is attached **(WITN2050081)**.

139. In November 2010, there was a meeting with the Health Minister, Ann Milton in Westminster together with my MP Diana Johnson and other campaigners. The meeting started with Ann Milton stating that she would not be taking questions but handing out coloured scraps of paper and asking us to explain our issues in writing. We were made to feel like children, and I wondered why we had gone to the time and expense of travelling down to London to be treated like this. I took the opportunity to speak with Ann Milton and asked her why we had not been informed prior to the meeting that we wouldn't be allowed to ask questions, as I wouldn't have gone to the time, trouble and expense of travelling to London if I had known. Ann Milton's reply was "*Your MP should have informed you*". My MP, Diana Johnson, was stood to the right hand side of Ann Milton when the comment was made; Diana said "*Wait a minute - you never gave me any information to pass onto my constituent*". It became clear to me that Ann Milton wasn't interested in engaging with us properly during this meeting. I became angry and left.

140. As mentioned in Section 2 above, in 2011 I attended a meeting with the Health Minister, Ann Milton, in London. I brought a copy of the Government's 2011 review and went through it at the meeting, highlighting many areas of the

inconsistencies in the report and noting that these could provide opportunities for making a claim for discrimination against the DH. I handed Ms Milton a letter putting the Department of Health on notice that I intended to challenge the review concerning the criteria for the Skipton Fund payments as I believed they were discriminatory, misleading and unlawful **(WITN2050082)**.

141. After CBC was formed in February 2012, we felt that we needed to meet and engage with relevant MPs and Ministers to introduce our group and promote our issues and in November 2012, we held separate meetings with Diane Abbott (Labour Shadow Health), the APPG on Haemophilia and Contaminated Blood, and Anna Soubry, the new Health Minister **(WITN2050083)**.

142. In March 2013, CBC wrote to Stephen Timms, the Shadow DWP Minister regarding contaminated blood victims and the benefit system **(WITN2050084)**.

143. In December 2017, after the Infected Blood Inquiry was announced by Theresa May, a meeting with the Minister for the Cabinet Office, Damian Green, was arranged to discuss the Inquiry and I attended on behalf of CBC to present our aims and objectives we wanted including in any Inquiry **(WITN2050085)**.

144. As mentioned in section 3 above, in 2019, I was one of twelve members of a working group consisting of campaign group representatives and attended a meeting with the Minister for the Cabinet office, David Liddington and Health Minister Jackie Doyle Price.

145. In January 2020, I attended a meeting with the Minister for the Cabinet office Oliver Dowden and Health Minister Nadine Dorries on behalf of CBC **(WITN2050086)**.

146. I have attended and taken part in numerous meetings of the APPG on haemophilia and contaminated blood over the years with my MP Diana Johnson. CBC have worked with the APPG to raise many issues over the years, relating to the divisive and discriminatory way those with HCV and their families have been treated **(WITN2050087)**.

147. Throughout my dealings with MPs and Government officials, I have realised that the only way to put pressure on the Government was through a combination of media interest and, perhaps most importantly, litigation. My experience is that it did not matter how "right" we were about the injustices that had been done to us, the Government was not interested in doing the right thing unless it was either embarrassed in the media or was told to take action by the courts. That may seem cynical but it is my experience and is why our campaigning activities concentrated on both media coverage and litigation as we felt that these were the only effective ways to force the Government to do the right thing. I have been deeply involved in both threatened and actual litigation against the Department of Health on several occasions which I will detail in section 7 of this statement.

Media involvement

148. As I began to campaign more publicly around issues of infected blood in 2010, media interest started to grow in my local area and I was featured in several newspaper articles. On 5 and 7 July 2010, I was featured in articles in the Hull Daily Mail **(WITN2050088)** which discussed the fact that my wife and I were asked to remove T-shirts we were wearing at the protest in June 2010 which bore the slogan 'Silence is violence – 4,800 infected and counting' before entering the Houses of Parliament. House of Commons officials apologised for this after the first article was published. On 14 October and 20 October 2010 and 13 January 2011 I was featured in further articles in the Hull Daily Mail which largely focussed on my campaigning around the issue of equalising the financial assistance available to those with HCV and HIV, and those with HCV who were classed as 'Stage One' by the Skipton Fund **(WITN2050088)**.

149. In 2011, after the Government review, I went on BBC Radio Humberside to speak about the inconsistencies in the report. I discussed the Government's failure to provide financial assistance for the majority of the HCV community

and stated that I believed their failure to address this was because of the numbers involved.

150. Later that year, I continued to express to the media that I was unhappy with the outcome of the January 2011 review and was contemplating bringing a legal action to force the Government to equalise the payments available to those infected with HCV and their families. On 21 August 2011 I was featured in the Sunday Express about this, and on 28 October 2011 I was featured again in the Hull Daily Mail **(WITN2050089)**. On 9 February 2012 the Hull Daily Mail published an article which documented the formation of CBC as a campaigning group and our call for a public inquiry **(WITN2050089)**.

151. On 26 March 2015, I was featured in an article by the Daily Record after publicly setting fire to the Penrose Inquiry report on the streets of Edinburgh, in which I expressed my concerns about the outcome of the Penrose Inquiry **(WITN2050090)**.

152. On 23 September 2018 I was featured in a Sunday Times spread about the Infected Blood Inquiry which provided context about the infected blood scandal and profiled a number of campaigners and other infected and affected people **(WITN2050091)**.

153. Over the years CBC has been operating, myself and other team members have been involved in numerous press work including TV, radio and newspaper articles.

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

154. I submitted a written complaint to the Charity Commission on behalf of CBC on 17 April 2013 to raise concerns about the Caxton Foundation's governance and operations. Our complaint raised two issues **(WITN2050092):**

a. The Trustees listed on the charity's website were different to those contained in their financial statement;

b. The charity had distributed personal data from beneficiaries to a private company without their consent, allegedly for the purpose of assisting beneficiaries with preparing benefits applications.

155. I received a response to my complaint on 2 May 2013 which confirmed that the Caxton Foundation had not informed the Charity Commission of any change of Trustees and that the Charity Commission would contact Caxton to ask them if the Trustees had been changed and if so, to amend their record accordingly. They did not respond to my data protection complaint as they said this was outside of their remit and should be directed to the ICO. **(WITN2050093)**.

156. I then wrote to Ann Lloyd at the Caxton Foundation and let her know of my complaint to the Charity Commission and the response I had received. **(WITN2050094)**.

157. A Caxton Foundation Partnership Group meeting was held on 11 June 2013, which I attended and at which the issue of the Trustees was discussed. In the minutes of this meeting it is recorded that **(WITN2050095)**:

> *The decision had been taken to incorporate the Board of the Caxton Foundation (ie make it a limited company) to address individual trustee liability concerns. This was not the usual model where charities often had full dual registration with the Charity Commission and Companies House, in which cases the trustee board had the same members as the company board of directors, and the individuals operated in a dual capacity. For Caxton, this meant that technically the charity only had one trustee, Caxton Trustee Ltd, which was the corporate trustee; it was therefore technically incorrect to refer to the board members as trustees, although within the organisation the term 'trustee' to refer to board members was used colloquially. When the incorporation had taken place last year, there had been some administrative oversight and Caxton had not registered Caxton Trustee Ltd as the new corporate trustee.*

158. I wrote to Companies House on behalf of CBC on 17 April 2013 to express concerns we had about discrepancies in the Skipton Fund financial statements. Our complaint was worded as follows **(WITN2050096):**

> *The discrepancies I refer to are that the data reported in the individual 2007-2011 reports does not match with the same data reported in the 2012 annual report. The 2012 report lists one more Stage 1 claimant in each of years 2007-2011 than is listed in the individual annual reports for those years – making a total of **5 more claimants**; and the 2012 report also lists **3 more claimants** of the Stage 2 [and hence annual] payment in year 2009 than is listed in the individual 2009 report. The 2012 report also states that during the year there were 148 Stage 2 claimants whereas the correct number is 125. This amounts to a further **23 more claimants** for the Stage 2 and annual payments.*
>
> *If these incorrect and excessive claimant numbers were to be used then the total over-payment for Stage 1, Stage 2 and annual payments up to the end of March 2012 would amount to about **£1,764,000**.*

159. We received a response to our complaint on 25 April 2013 stating that Companies House could not investigate the conduct of a company and that we should instead contact the Insolvency Service. We wrote to the Insolvency Service on 1 May 2013 expressing the same concerns from my letter to Companies House, but never received a response.

Section 7: Litigation

160. In 2011, after the Government released its review document highlighting their lack of support for Stage One HCV victims, as well as bereaved spouses/partners and dependant children of all HCV victims, I came to the disappointing but inevitable conclusion that the only way forward would be to challenge the Government by way of litigation. I went through the report with a fine tooth comb, detailing all areas of the report which I felt the Government had not addressed adequately. My first points of contact with a view to litigation was to communicate with Michael Vian Clark of Michelmores solicitors and Vijay Mehan of Fentons Solicitors. I sent each of them a copy of my 'generic points of discrimination' and my 'thoughts for discrimination' documents detailing my concerns with the Government review **(WITN2050097).** Michael

Vian Clark thought that one of the most striking anomalies was not between the 2 stages of Hep C, but between HCV and HIV in that they hadn't treated "like with "like". Michael suggested it would be helpful if I wrote to the Health Minister, Ann Milton raising similar questions to those I had raised with him and I therefore wrote to Ann Milton on 1 July 2011. **(WITN2050098).** For various reasons, including the fact that Michael Vian Clark left Michelmores, neither of these approaches progressed, although I remain grateful for their time and advice which they provided.

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163. In about 2014, CBC requested Leigh Day to investigate bringing a judicial review claim against the DH and the Skipton Fund for discrimination in the provision of financial assistance. Russell found out about Leigh Day because he had read about a previous discrimination case they worked on and thought a similar legal argument might apply to our case. We sent in our documents to Leigh Day and they instructed David Lock QC to review the papers that we had assembled as a result of our research work. We then had a consultation with David and he provided written advice on the complex issues. I remember feeling encouraged because it seemed to me that the legal team that we now had had really taken time to read through and understand the documents and properly got to grips with the arguments that we were victims of injustice. Initially, the legal advice was to focus on mono HCV Stage One individuals as they received the least which created the greatest contrast when compared to those with HIV however, with the encouragement of CBC, the JR was broadened to include Stage One's who were also infected with HIV. I should mention that, at this stage, Leigh Day and David Lock worked to provide us with

legal support without any guarantee that they would ever be paid and, as it turned out, did a vast amount of work without getting any payment.

164. The main issues in the case were that the Skipton Fund provided regular non-discretionary support for people in the Stage Two category of beneficiaries, who had serious liver damage, but nothing for people in the Stage One category, whereas the HIV trusts did not have stages and provided the same non-discretionary regular support to all infected beneficiaries, and in contrast to payments made to some HIV bereaved spouses/partners and dependant children, no similar payments were available to bereaved spouses/partners and dependant children of those infected with HCV.

165. Leigh Day wrote pre-action protocol letters to the Government threatening to bring judicial review proceedings against the Government because of the unlawful discrepancies between the levels of support for HCV victims as opposed to HIV victims. We were all set to issue judicial review proceedings to challenge the schemes when the Government responded by saying that such an action was not needed because the Government had decided to review the schemes.

166. The Government conducted a review and then announced changes to the financial assistance schemes, including the addition of a new category called the Special Category Mechanism (SCM), for people whose liver damage is not serious enough to put them in Stage Two, but who still have serious health implications arising out of their HCV diagnosis. This action introduced non discretionary regular payments for Stage One beneficiaries for the first time; CBC had been told on many occasions by members of our own community that this would never be achievable. Even then, the Government delayed bringing in the new categories for another 12 months on the pretext that it had to consult on the definitions to determine who would be eligible for the SCM payments.

167. I do not believe the Government would have agreed to review the schemes and eventually bring in substantial changes if it were not for the pressure that our threatened litigation put on the Government. If it hadn't been for Russell

thinking to contact Leigh Day, and the committed work of the Leigh Day team, including our barrister David Lock QC, there is no way the Government would have introduced the SCM and regular non-discretionary payments for Stage One, nor the discretionary payments for bereaved spouses/partners and dependant children of those with HCV. I will be eternally grateful to everyone who helped us.

168. CBC were roundly criticised by Tainted Blood and the Manor House campaign groups for undertaking this course of action, as they felt our legal action could be detrimental to reaching a prompt, full and final resolution. Their criticism was expressed in a document posted on Facebook **(WITN2050099)**, which claimed that our legal action would risk delaying or interfering with the outcome of the Penrose Inquiry.

169. We did not believe our action would be detrimental to any other initiative; in fact, it is widely accepted amongst the communities of victims of this scandal that the Penrose Inquiry turned out to be a complete whitewash and delivered no benefits whatsoever to our community. I believe the success that came about as a result of our judicial review has vindicated our decision to relentlessly pursue this litigation, not least because it is the only action in recent years that has proved successful in creating some level of equality, as well as having the practical benefit of putting money in people's pockets for the majority of the infected and affected members of our community. The judicial review also had the benefit of creating a broader level of equality moving forward. This was hugely important in order to make sure most of the infected persons falling into the "stage one" category, bereaved spouses/partners and dependant children of those with HCV would no longer be forgotten and left behind, which was one of CBC's key objectives from the beginning.

Section 8: Other Inquiries

170. I have never had any involvement with any other Inquiries.

171. In the mid-2000s, I became aware that the Government was holding the Archer Inquiry. At the time, I believed that the Archer Inquiry would provide all the answers and sort out the inequalities in financial assistance. However, I now recognise that, whilst the Archer Inquiry did its best and was an important step, it was not as well-resourced as the Infected Blood Inquiry is today and had no powers to force Government to hand over documents or co-operate to the same extent as the present Public Inquiry. It delivered an impressive report as a private Inquiry, but the report was limited because it did not have the powers to compel ministers or anyone else implicated to give evidence. The Government disclosed evidence to the Inquiry, but only behind closed doors and there was no power to apportion blame to anyone for what happened. I felt Lord Archer was working under a set of constraints which meant that he would never get to anything like the full truth of what had happened.

172. While the Penrose Inquiry was in progress, CBC were openly very critical of the way it was progressing including the Maxwellisation of the warning letters to those who had been challenged or criticised, and their responses, which extended the length of the Inquiry by about eighteen months **(WITN2050100)**. The community was also not able to have access to any of these documents which highlighted a clear lack of transparency. Also the number of core participants that wanted to give evidence was repeatedly cut back to the point the community didn't feel their issues were being adequately addressed. We felt it was a whitewash. I attended the release of the final report of the Penrose Inquiry in Edinburgh, at the Auditorium in the National Museum of Scotland on 25 March 2015. Lord Penrose himself did not turn up and passed responsibility of delivering his statement onto his Secretary Maria McCann. The statement excused the reasoning for giving infected blood and blood products to patients, stating there were 'few aspects in which matters should, or more importantly could have been handled differently'. It was noted there was no reference to patients that were given blood or blood products for non-life threatening elective procedures who subsequently became infected. The Penrose Inquiry made only one recommendation which was to advise those who had been given a

blood transfusion in Scotland before September 1991 should be tested for HCV. There was a growing sense of disbelief in the audience at what we were hearing which quickly turned to anger and frustration with calls from the audience for the Penrose Inquiry banners to be removed from the stage which they were. I felt, and it was clear from the response from the audience, we viewed the Penrose Inquiry as a whitewash. I took a copy of the report outside where the press had gathered and set fire to it on the streets of Edinburgh in protest.

Section 9: Haemophilia Society

173. As a haemophiliac, I am a member of the Haemophilia Society. I have never been involved in a specific role – such as a Trustee or part of management. However, if the issue of infected blood is resolved by this Inquiry and health permitting, I would like to get more formally involved with the Haemophilia Society.

174. CBC has also engaged with the Haemophilia Society on demonstrations, and, as I have mentioned in section 7, I worked with them to prepare the legal case to instruct Thompsons to investigate.

Section 10: Trusts and Schemes

175. CBC was heavily involved with the Caxton Foundation. We were part of the Caxton Foundation Partnership Group and we attended five meetings on behalf of CBC members (four in London and one in Birmingham). CBC also produced three in-depth reports on the Caxton Foundation Partnership Group meetings on 11th June 2013, 28th November 2013 and 5 August 2014 **(WITN2050101)**.

176. Our first contact with the Caxton Foundation was with the original CEO Martin Harvey. Six people from the CBC team at the time met with Martin and Nick Fish (who was the Skipton Fund Manager) in July 2012 in Coventry. This was

before the Caxton Foundation Partnership Group existed. We found them to be very approachable and willing to meet with us and our new campaign group. There were various issues with the support that beneficiaries of the Caxton Foundation were experiencing, so we met with Martin Harvey to discuss this.

177. Shortly after we met with Martin, he left his position as CEO due to ill health and was replaced by Jan Barlow as CEO and Ann Lloyd as Chair of the Caxton Foundation. CBC found them to be very different to the way in which Martin Harvey approached our group. They simply ignored our attempts to approach them and it took over six months before they actually met with us. We felt that we were being treated with complete contempt, which didn't help the relationship moving forward.

178. As part of our statement, we would like to highlight several examples with regard to the way in which we were treated by the replacement CEO and Chair.

179. We corresponded with both the Caxton Foundation and Health Minister to raise the following issues in 2013 and 2014 **(WITN2050102)**:

a. Their insistence on changing the name "beneficiaries" to "clients" without any consultation with their beneficiaries even though CBC explained to Jan Barlow and Ann Lloyd they had no authority to change the wording as their own Trust Deed stated quite clearly they could not do this ;

b. Their lack of knowledge of the Caxton Foundation's previous commitments agreeing to a beneficiary meeting in Birmingham even though it was minuted in the Caxton Foundation Board Minutes ;

c. Caxton Foundation board members' conflict of interest. For example, Charles Lister was a Caxton Foundation Trustee and he was also on the Caxton Foundation National Welfare Committee (NWC), a role in which he was involved in the decision-making process regarding beneficiary grants. Some described this as "*putting the fox in charge of the chicken*

coop", even though he previously worked for the Blood Policy team in the Department of Health – a Government department which was involved in decision making policy for contaminated blood and blood product victims. Margaret Kennedy was a later appointed Caxton Foundation Trustee who had spent her career in the NHS.

180. On 12 June 2014, it was finally announced that the term beneficiary would remain in use, rather than client **(WITN2050103).**

181. Following this, we, along with members of Manor House Group and Tainted Blood, sent a letter to Ann Lloyd at the Caxton Foundation on 23 June 2014 raising several further issues, including querying the appropriateness of the appointment of Margaret Kennedy to its Board of Trustees given her background in the NHS. **(WITN2050104).** We then attended a meeting at the Caxton Foundation on 5 August 2014 in which this topic was discussed, and it was argued that the Foundation could not discriminate against Margaret because of her occupation **(WITN2050105).**

182. CBC would also like to highlight the way in which we were treated after visiting the Caxton Foundation offices in April 2013. In April 2013, the CBC team went to the offices of the Caxton Foundation at Alliance House to drop off a copy of a report we had written and to briefly introduce ourselves to the staff. The Caxton Foundation had distributed leaflets encouraging potential beneficiaries to visit the office, so we felt welcome to do so **(WITN2050106).** We arrived at Alliance House and spoke to the receptionist explaining that we had some paperwork to drop off to the Caxton Foundation offices and the receptionist directed us to the upstairs office. On arriving at the door, I pressed the buzzer and a lady called Kat answered and invited us into the corridor. I explained who we were and that we had some paperwork to drop off. Kat led us down the corridor and at the end of the corridor there was a door to the right-hand side which led into the Caxton Foundation office. Kat then walked into the Caxton office, leaving us in the corridor with the door leading into the office ajar, I opened the door wider and we then stepped into the office, briefly introduced ourselves to the staff and

handed over our paperwork. We were in the office for a very short period, literally a few minutes, we then said goodbye and left.

183. A few days later I received a letter from Ann Lloyd about our visit, accusing us of barging into their offices and causing concern to staff **(WITN2050107)**. I telephoned Ann Lloyd to ask for an explanation, as the letter made accusations which were simply false. During that telephone conversation, I labored the point that they had accepted one version of events without speaking to CBC and hearing our account of what happened, for balance. After some time discussing this issue, Ann Lloyd finally accepted that she should have spoken with us first before drawing any conclusions. CBC followed this up with a letter confirming what myself and Ann Lloyd had discussed in our telephone conversation **(WITN2050108)**.

184. One of the CBC team at the time of our visit, Nicholas Sainsbury, was also an MFT beneficiary. A private letter was sent to him berating us for our visit to the Caxton Foundation offices, and was then posted on the MFT forum by Roger Evans (Chair of the MFT), a forum where other MFT members were able to see it **(WITN2050109)**. We considered this action by Roger Evans to be a breach of confidentiality. Nicholas then wrote to Roger expressing that our visit was cordial and asking him to take the letter down from the MFT forum **(WITN2050110)**, but Roger replied accusing Nicholas of "whipping up bad feeling" between himself and the MFT, refusing to take down the letter and suggesting that Nicholas apologise for our office visit **(WITN2050111).**

185. After the Caxton Foundation board meeting on 2 May 2013, we were then very surprised and disappointed to see that the meeting minutes they posted on their public website documented our visit to the office in such a way that made us all sound like criminals and terrorists. The minutes referred to our visit as an "intrusion" and thanked staff members for their "calm handling of the situation". This was a corruption of the facts; our visit to Alliance House was cordial, polite and respectful and at no point did we barge in or intimidate anyone and we find any suggestion that we did, highly distressing and insulting.

186. We wrote to Ann Lloyd in September 2013 raising some of these issues **(WITN2050102)**, including the description of our office visit in the May 2013 minutes. The issue was raised and discussed again at the Partnership Group meeting on 28 November 2013, at which the Caxton Foundation confirmed that the leaflet inviting beneficiaries to visit their offices no longer applied, and that they would not remove the portion of their minutes condemning our visit from their website **(WITN2050101).** This is an example of the disrespect and contemptuous way in which we were treated by the management of the Caxton Foundation and the MFT. **(WITN2050112).**

187. From 1 November 2017, when EIBSS was introduced, to the present day, I have attended several EIBSS focus group meetings. I have never had any problem with the EIBSS management; I have found them to be nothing but approachable, professional and courteous and they have been willing to listen when I have raised issues with them.

Conclusion

188. Our extensive campaigning and research work has led me to conclude that the Government, including those Governmental bodies over whom it has or has had responsibility, has made three key failings over the course of the infected blood scandal:

a. First, there has been a complete failure by the Government or any other Governmental body to accept **responsibility** for this scandal, notwithstanding the tireless efforts of campaigners and campaign groups such as CBC. Instead, as our evidence demonstrates, there is a long history of infected and affected persons being treated as irritants by the Government. My experience suggests this to be the case particularly in relation to HCV. I cannot underestimate the importance to victims of some kind of responsibility for this scandal being acknowledged. This

need is even more acute when victims have suffered at the hands of the state, which should protect its citizens instead of harming them. This point is important and underlines the negative and distressing experience of victims and campaigners over the last few decades. CBC prepared a report summarising the position of those infected with HCV entitled 'Hepatitis C and the Transfusions of Doom' and circulated this to MPs in 2013 **(WITN2050113).**

b. Second, there is a long history of the Government **misunderstanding and/or minimising the effects** of viral hepatitis and in particular HCV. This means that the Government response to HCV infected and affected persons has been thoroughly inadequate, as well as discriminatory compared with other categories of victims, because it was based on a false assessment of the consequences of having HCV. This is the case in terms of the health and psychosocial impacts, as well as societal impacts such as stigma. It is patently clear from the evidence given by victims and experts in the first stages of this Inquiry that the effects of HCV are broad and all encompassing, as well as in the majority of cases chronic. The Government's assessment of the impact of living with HCV has been desperately at variance with the experience of victims. In particular, the Government has repeatedly clung to the fact that it is possible to clear the HCV virus when it is not (at least yet) possible to clear the HIV virus. Whilst that is true, the Government response appears to be based on the idea that, once a person clears the HCV virus, that person is "cured" and their medical problems associated with having carried the virus for many years are over. This is simply not true. The disabilities caused by carrying the virus remain for life and victims continue to face a hugely enhanced risk of a large number of life threatening conditions, as the expert evidence presented to the Inquiry has clearly identified. We are angry that the Government has responded to the HCV community by continually misrepresenting the life long and devastating continuing effects for HCV victims of having carried the

virus, even if the primary virus has now been "cleared". CBC prepared a report on this subject, detailing our case for removing the distinction between Stage 1 and Stage 2 Skipton beneficiaries, in 2013 **(WITN2050114).**

c. Third, and linked to my second point, there has been a total failure by the Government to **understand what victims and their families required**, in order to make up for the fact that they were infected and harmed by the state. This includes adequate financial assistance or compensation, proper access to treatment, and counselling for the psychosocial impacts of infection at the hands of the state. Instead of receiving adequate support, assistance and treatment, victims infected with HCV in particular were subject to general societal and medical ignorance and stigma around HCV and its causes and symptoms. Victims of this scandal were often stigmatised in the way that HCV sufferers are in general. Many victims' symptoms were missed or misdiagnosed over long periods of time because of this ignorance. Having infected large numbers of people with the virus, the Government should have raised the profile of, and focused many more resources, on HCV, as it eventually did with HIV.

189. In conclusion, I wish to emphasise that my work as a campaigner and with CBC has primarily been aimed at addressing the gaps and omissions in the Government's response to the infected blood scandal. This has therefore often been focused on the response to those infected with HCV and their families. Whilst paying tribute to those who have campaigned on behalf of people with HIV, both as a result of infected blood and more generally, it is sadly the case that HCV has always had a lower priority for treatment and financial assistance.

190. Those infected with HCV are, unlike those with HIV (either as a result of infected blood or otherwise), a more disparate group with no unifying condition (haemophilia) or lifestyle feature. I pay tribute to the hugely effective

campaigning activities of those affected by HIV which, as I see matters, has given these victims a higher profile in the mind of DH officials and elected politicians than HCV victims. I wish to make it clear that CBC and our community do not complain in any way about the way that HIV victims have been treated and still feel that, despite their high profile, they have not been given proper financial assistance or compensation. But I also invite the Inquiry to recognise that it has always been far, far harder to raise the profile of HCV victims because, by and large, HCV is seen by both the medical profession and politicians, as a condition were the patient is responsible for taking bad lifestyle decisions and thus being responsible and hence blameworthy for their own condition. HCV is generally seen as a condition of drug addicts and sex workers, and neither of these groups attracts most public or professional sympathy. Further, when HCV results in damage to a person's liver, it is often put down to excessive alcohol consumption as opposed to being a condition caused by the hepatitis virus. So we have always faced the mountain to climb in the minds of the medical community and politicians that we are campaigning for a community with a blameworthy disease with blameworthy consequences. I am convinced that the negative associations of both HCV and liver disease have blighted both the medical community and the Government's response to the victims of NHS contaminated blood who contracted HCV.

191. I have complete confidence that Sir Brian and his team do not see our community in this way and understand that HCV victims of NHS contaminated blood are just as deserving as all other victims, and will recognise the prejudice that we have fought against over so many years. This Inquiry has highlighted so many examples in the evidence of prejudice by members of the public and medical professionals. We have known this prejudice in our community and have been raising these matters for many years. At last, the forgotten voices of our community are being heard. Having fought this battle with my colleagues and many others over the years, I am convinced that both the overall inadequacy of the Government response for all victims and the disparity in payment schemes which has, in particular, consistently shortchanged HCV

victims is an institutional response which has only been possible because of the prejudices against those with HCV and liver disease.

192. We now look to Sir Brian and his team to produce a report which will highlight the way our community has been exposed to these injustices and make proposals to right the wrongs we have suffered for so many years.

193. We also ask Sir Brian to recognise that because of the hard fought decades long campaigning including CBC's JR litigation, the scope and level of ex gratia payments have now been improved in many areas. As a result of these improvements CBC, are aware that many people within our community would prefer the option of remaining on the ex gratia support (albeit with security of payments for life) over the option of "one off lump sum" compensation and CBC are hopeful that if Sir Brian's report recommends financial redress, that he also recommends that no member of our community be forced to accept "one off lump sum" compensation over the ex gratia support they receive and secondly that following the inquiry no member of our community should find themselves worse off financially.

194. I would like to end my statement by thanking all CBC team members past and present for their contribution to the work that has taken place since the inception of Contaminated Blood Campaign in 2012. To continue the fight through all the difficult times has been particularly demanding and has had a tremendous impact on our day to day lives where we have often prioritised the campaign over and above our own families and personal circumstances.

Statement of Truth

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

Signed GRO-C

Dated .....14 August 2020.....