Witness Name: **Carol GRAYSON**
Statement No.: **WITN1055001**
Exhibits: **None**
Dated: **6 November 2018**

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROL ANNE GRAYSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 October 2018.

I, Carol Anne Grayson, will say as follows: -

Introduction

1. My name is Carol Anne Grayson. My date of birth and address are known to the Inquiry. I am the widow of Peter Longstaff, a haemophiliac infected with HIV, hepatitis B and C and exposed to new variant CJD who died in 2005 as a direct result of receiving contaminated NHS blood products. Much of his treatment was proven to be imported from the United States including Arkansas Prison by tracing the batch numbers through US lawyers.

2. Peter's younger brother Stephen Longstaff (my brother-in-law) was also a haemophiliac who died of AIDS in 1987.

3. I intend to speak about my affected status as a wife, mother, daughter-in-law, carer, campaigner, researcher and widow. In particular, the nature of Peter and Stephen's illness and my illness, how their and my conditions, illness affected them and how that impacted on my own health the treatment they received and the impact it had on both them and I and our lives together

How Affected

4. Peter was born with a hereditary condition named haemophilia A (he had less than 1% clotting factor).

5. Stephen was a moderate to severe haemophiliac.

6. I have the details of Peter's treatment batch numbers (to be submitted at the appropriate time). Initially he was treated with British Fresh Frozen Plasma and Cryoprecipitate from volunteer unpaid British donors. Later in 1973 he was switched to factor concentrates mostly from "high-risk" unpaid US prison and "skid-row" donors though some treatment came from British Blood Products Laboratory (BPL).

7. Stephen was one of the early haemophiliacs to die in the UK age 20 and his medical records no longer exist. Peter was part of the 1991 HIV litigation and received an "ex-gratia" payment in 1991. Peter's mother as next of kin received an ex-gratia payment for Stephen's estate.

8. Peter's imported blood batch numbers were checked and accepted by US lawyers and also accepted by four international pharmaceutical companies Baxter, Bayer, Armour and Alpha (companies whose names have changed over the years). The case was transferred back to the UK courts on "forum non conveniens" ...The judge ruled that for UK haemophiliacs responsibility for "duty of care" lies with British

authorities as they were aware of high -risk sources from prior to the date of importation of US products and continuing after importation began. The hepatitis risks of pooled US plasma were clearly documented in the media, books, medical journals and letters as well as Department of Health documents.

9. Peter was a patient of the Newcastle Royal Victoria Infirmary (RVI) from birth which had a regional Haemophilia Centre under Dr Hamilton and Dr Jones. He was later treated at a centre in the grounds of Lord Mayor Treloar School where he was advised to go by his Consultant being a severe haemophiliac. His education was often interrupted by bleeds and from being a child he was prescribed very strong painkillers such as pethidine when he bled (detailed in a letter). This was the usual case for haemophiliacs in the 1960s and 1970s. Stephen who was several years younger also attended this school. I am informed by staff at the school in a recent letter that the treatment centre was staffed and managed by the Department of Health and entirely independent of the college. I have a letter from 1973 regarding factor concentrate treatment at Treloar seeking permission from Peter's mother Alice, who had little education and would not have known what questions to ask. She never learnt to inject Peter with factor concentrates.

10. Peter and another haemophiliac whom I know were to take part in a prophylactic trial of factor VIII concentrates at Lord Mayor Treloar in a DHSS and MRC approved trial (I have several letters dated 1973 and the doctors are named).There is also an extraordinarily detailed (and intrusive) social/financial assessment of the family including the father's wages, that they owed a sewing machine, vacuum cleaner and tape recorder along with many other personal details.

11. Peter also told me that haemophiliacs were treated at a naval hospital nearby, I believe this may have been at Portsmouth.

12. Peter was told by a consultant it is likely he was infected with hepatitis B and C from his first exposure to US factor concentrates which would have likely been in

1973. He was infected with HIV sometime in the late 1970s/early 1980s confirmed by the first available test in mid 1984/1985. We understand the first HIV tests may have been used on the blood of haemophiliacs prior to its official introduction date. I have some test results from the medical records in a file. The test result date is from when haemophiliacs first tested positive to hepatitis B, C and HIV as opposed to their first exposure to the viruses. It is recognized by medical experts that Peter and others would also have been re-infected with viruses over and over again until the introduction of heat- treated factor concentrate at the correct temperature to kill off HIV and hepatitis viruses.

13. Regarding exposure to v CJD, Pete received a letter in 2004 telling him he may have been exposed to v CJD and asking whether he wished to know if he was definitely exposed. Later we discovered from the medical records his first exposure to v CJD was in 1995. However through our own investigations we discovered that it was the original written intention NOT to tell haemophiliacs of their exposure. We know this from a letter leaked to us, saying haemophiliacs have been exposed to v CJD but don't tell them. We took this letter to James Meikle at the Guardian newspaper who was investigating CJD. Once published in the media this put pressure on government to carry out a look-back study. Letters were then sent to haemophiliacs asking if they wished to know if they had been exposed to v CJD or not. Pete chose to be informed as once we confronted the hospital with the leaked letter, they then admitted Peter had been exposed to CJD.

14. Peter and his family were told he had been infected with hepatitis B through his treatment and that it was "like having flu". I understand from Peter that this was in the 1970s. The first Peter and his family came to know of the many risks of imported factor concentrate treatment was through watching a 1975 "World in Action" documentary where hepatitis expert Arie Zuckerman travelled to investigate the US blood collection centres. He concluded that many of the donors he saw would have been excluded immediately in the UK on safety grounds and that the conditions were an afront to human dignity. Around 2003 my fellow

campaigner Colette Wintle and I gave a copy of this documentary to Lord Hunt of King's Heath in a face to face meeting at Westminster.

15. In 1975 Peter's father was very upset after watching the documentary and confronted staff as did Peter who actually returned his treatment refusing to take it anymore but was reassured it was no longer coming from the US. Peter states this in old interviews and in his legal fight for Recombinant (synthetic treatment) which was heard in the High Court. He recalled throwing the small plasma bottles on the desk at the centre and them accidently bouncing off and hitting a doctor. The batch numbers later showed that Peter had continued to receive US factor concentrates for years after he and his father raised concerns and years later we saw reference to this incident in the nursing/ medical records.

16. Peter and his brother and parents only heard about AIDS officially when they were called in by their treatment centre at the RVI shortly after one another to be told they had tested positive for HTLV3 as it was known in the early days. Peter and other haemophiliacs we spoke to from the same Haemophilia Centre remember both this and the shock of having their rectums examined. We think this may have been to rule out anal penetration as it was known as the "gay plague" at that time.

17. Regarding hepatitis C, Peter and I were told together of his positive test result in 1994 on return from a long stay abroad. I immediately queried why there was no pre and post- test counselling as I had been a nursing sister and knew this to be good ethical practice. (I understood from guidelines that failure to do so could mean staff would be at risk of disciplinary action even being struck off as there can be very serious consequences for not telling someone a positive result such as infecting their partner or conceiving and infecting a child). We then contacted lawyers to take legal action in 1994 only to discover that Peter had signed an undertaking (which I refer to as the "waiver" my own name for it) which meant he had waivered his rights away to take further legal action for hepatitis C not knowing that he was infected.

18. Later when we got hold of test results, we realized that Peter had been tested for hepatitis C in 1992 and not told his positive result. We were very upset as we had been away for a year and whilst we were fully insured for known conditions (HIV and haemophilia) because we had not been informed of Peter having hepatitis C we were not insured for this. We thought not telling us was highly irresponsible.

19. From talking to another haemophiliac at the same centre (who died of hepatitis C) who was told he had tested positive for hepatitis C in 1989, we believe at that time a first test may have been used and tested out on haemophiliacs including Peter at the RVI. However government did not want to introduce this test as they claimed it found too many false positives and too many donations would have to be destroyed. This meant the official hepatitis C test was not introduced in the UK until 1991.

20. I know from documents shared with me from a documentary maker (which I still have) that other countries did introduce the first test in 1989 to test blood donations saying it was "better to err on the side of caution" even if too many false positives and blood had to be destroyed than to risk people being infected. Later many other haemophiliacs across the UK discovered they had also been tested without their knowledge and permission and we contacted Action for Victims of Medical Accidents (AVMA) in 2000 and I replied to a letter they wrote when they set up in the same year which was published in the British Medical Journal (dated October 24th 2000). Pete and I and other members of the haemophilia community filed official complaints to the General Medical Council (GMC) asking them to investigate in 2003.

21. Haemophiliacs often gave blood for clotting levels but special permission would have had to be sought for testing for infectious diseases with pre and post-test counselling from someone trained in this area. (I was myself trained in this area during my nursing profession and in fact helped develop the first nursing guidelines in the UK where my day to day practice included pre and post- test HIV counselling

from the introduction of the first test.) I believe the initial tests may have been carried out on haemophiliacs before the official introduction date going by dates of test results and date the test was officially introduced.

22. Non-consensual testing also formed part of a larger complaint to the police and to Europe filing a petition for a number of issues to be investigated. Dyfed -Powys was the investigating police force in 2003.

23. From my own research findings and looking at the history of the dangers of pooled plasma from the Korean War as highlighted by our legal representative Sam Stein QC on our behalf, I consider that to allow the introduction of pooled plasma in the US in the 1960s without first developing a way to eliminate hepatitis was extremely dangerous and unethical. The introduction of factor concentrates should have been found illegal given the extraordinarily high risk of developing hepatitis from the very first exposure to factor concentrates. Also no-one seemed to have studied the Nuremberg Code with regard to experimentation on humans with new so called "treatment" and acceptable level of risk. I allege all points of the Nuremberg Code in this regard were repeatedly violated.

24. Doctors and scientists were so intent on introducing factor concentrates they ignored the risks highlighted to them in medical journals of the day. Money that was granted to find a way to eliminate hepatitis was suddenly withdrawn in the 1960s and the factor concentrates considered dangerous by hepatitis experts were suddenly introduced. Doctors started saying at a later date that "the benefits of treatment outweighed the risks". My husband had managed on Cryoprecipitate for years, yes he had to travel to hospital for treatment but that was all he knew. Had he been told the risks he would have waited until a way to virally inactivate factor concentrates was developed. This happened very quickly when AIDS arrived. However this should have been done in the 1960s prior to putting factor concentrates on the market. It was done the wrong way round ignoring the

Nuremberg Code and consequently the treatment killed thousands of haemophiliacs and some of their family members.

25. The UK blindly followed introducing factor concentrates here ignoring all the risks as highlighted at that time by hepatitis experts including J Garrott Allen and others in medical journals of the day. Garrott Allen had an ongoing correspondence with William Maycock (see letter in my dissertation). Garrott Allen warned of the risks in relation to prison blood in medical journals in the the 1960s and in a letter to Maycock dated 1975.

26. There was also a very important book called "The Gift Relationship: From Human Blood to Social Policy" written by Richard Titmus published in 1970 comparing paid donor system of the US to the UK volunteer system. Several haematologists told me that they read it when first published and there was a copy in the doctor's office in the RVI. I once had a conversation about the book.

27. In addition the World Health Organization (WHO) advised each country to become self-sufficient in blood products in 1975. The importance of self-sufficiency was already recognized by Lord Owen in 1974 who gave his commitment to self-sufficiency with financial investment only to find out once he left his post in Health for the foreign office, this was not carried out, nor were the changes to his commitment debated in parliament. In addition not enough funds were invested in BPL and the place was allowed to decline (Inspectorate's report highlights this in detail).

28. UK Haemophiliacs should have been told of concerns over the risks of AIDs from US products certainly in 1982 when the first cases in the haemophilia community emerged in the US. There had been a case in 1979 but this was a non-haemophiliac. American experts such as Don Francis and Harold Jaffe were very vocal at that time on haemophiliacs and the risk from blood and should be contacted to give evidence regarding the Infected Blood Inquiry. I have met and

discussed that time period with Don Francis in Washington DC and Jay Epstein as we all received awards for our work on HIV/HCV at the same conference organized by Committee Of Ten Thousand (COTT) who are US haemophiliacs given contaminated blood. Risks related to AIDS, blood and UK haemophiliacs were highlighted in a media article by Christine Doyle in the Observer in the UK in January 1983 which were discussed at a meeting of haematologists but appears to have been largely ignored (I highlight this in a Northern Echo article dated, March 14th 2018). Yet months later Kenneth Clarke was claiming ignorance of the risk through blood... how was this possible?

29. I also discovered that In May 1983 the British government had been advised by Dr Spence Galbraith (formerly of Public Health Laboratory Service, PHLS) to immediately take the US treatment off the shelves due to the risk of AIDs. Galbraith was in contact with me by phone at the time of the Archer Inquiry and personally sent me his letter to use in our BBC 2007 Newsnight programme. The treatment withdrawal did not happen, Galbraith told me that he was closed down by Joseph Smith in 1983 and asked me years later to help me litigate against him. Joseph Smith also contacted me by phone in a call lasting around 1 and half hours on a Saturday morning and admitted his alleged negligence. Only days later when he was giving evidence to the Archer Inquiry I was surprised at his sudden memory loss as his recall had been amazing; the Medical Defence Union were now involved!

30. Peter and others were told to use up unheat-treated products before they were moved on to heat-treated products. The Haemophilia Society also failed in their duty of care with regard to safety of products and made the situation worse by going to government in 1983 and asking for US products to continue to be imported ignoring the risks. (Detailed in a letter).

31. It was clear in 1983 that the Newcastle RVI Haemophilia Centre did not want haemophiliacs to learn about the risks as we obtained documentation showing that

Peter's consultant made an official complaint to a national Press Complaints Body over an article written by journalist Susan Douglas of the Daily Mail which highlighted the risk of AIDS to haemophiliacs from US prison blood and highlighted the first 2 cases of AIDS in the UK. I was in touch with Douglas who also confirmed this to me many years later. We also obtained UKHCDO minutes where it was recorded that Peter's consultant was on the payroll of a pharmaceutical company and would have to leave the room whilst an issue was being discussed as there may have been a "conflict of interest". The RVI pharmacy also told us years later they were unhappy that treatment for haemophiliacs was bypassing the hospital pharmacy and not being recorded by them.

Other Infections

32. We discovered ourselves that other viruses were in the blood such as parvovirus and other forms of hepatitis but we weren't told if haemophiliacs were regularly tested for these and other strains of hepatitis such as hepatitis E. As mentioned we have detailed Peter's exposure to v CJD and it is documented in detail the difficulty we had regarding obtaining guidelines for nursing at home in the community and disposal of blood- stained objects such as clothing due to the difficulty of killing the prions. At one stage this resulted in men in full bio hazard suits coming to our home to remove our carpet when Pete bled onto the carpet. (Documented in official letters, photos and media articles)

33. With regard to the question of consent in the form which I have already answered. I answer yes to all of the following.

Consent

34. Does the witness believe that the person close to them was treated or tested:

    a. without their knowledge, or yes

b. without their consent, or yes

c. without being given adequate or full information, or yes

d. for the purposes of research? yes

Impact

35. Stephen was terrified of what would happen to him after being told he was HIV positive. He wore gloves all the time even in the house, afraid he might infect others. He was afraid to go out due to stigma and prejudice and became ill very quickly. He was only 20 but had AIDS related dementia, developed a rare form of cancer, Karposi's Sarcoma and went blind. He did not want to celebrate his birthday know he was dying, became very upset over being given a cake, retreated into himself, was very confused, anxious and depressed. The house was daubed in anti-AIDS slogans detailed in media articles of the time, which we still have. His mother initially had her own cup at work due to fear of infecting others. There were concerns over the family attending church and holding Stephen's funeral in church in case parishioners would no longer come to church and drink from the chalice. Stephen was buried in a lead lined coffin. Death certificate confirms AIDS related medical problems in January 1987 but bizarrely states "natural causes"!

36. Peter's father died of a heart attack in 1989 (age 58) whilst campaigning (detailed in a media article at that time). His doctor stated it was due to stress of seeing his youngest son Stephen die, attacks on his family home and knowing that Peter would probably die young too. My mother-in-law was deeply depressed having lost her son and husband and being very worried over losing Peter.

37. Peter had chest infections due to HIV and low immunity. He would get chills and fever. He was prescribed dapsone, for chest infections but that made him much worse. Dapsone is "an antibacterial medicine belonging to the sulphonamide class of antibiotics." He improved considerably once we decided he should come off the dapsone though this was against medical advice (after we discussed our concerns over the drug and that after some time it would not work). We were criticised for doing this however some years later doctors took haemophiliacs off Dapsone. Peter did not want AZT as straight away he became ill and stopped it. We believe some haemophiliacs may have died due to the treatment itself during the early days.

38. Pete once had to be rescued from his home by police and his GP after a mob gathered outside shouting knowing there was someone inside with the AIDS virus.

39. Peter would get terrific night sweats where the bed sheets and mattress would be soaked and the sheets would have to be changed several times. During the worst of these sweats we would use separate beds so I would not be soaked also and could try to get a few hours sleep though this was very difficult. (I would like to add that once Pete died, I was then charged bedroom tax for "under-occupancy" so in effect I had to pay for the state killing my husband!) Pete and I suffered from chronic insomnia as often when he was in pain with liver problems or bleeding or depressed, I would be up giving him his treatment during the night and sat with him to keep him company. He also got lots of cold sores and mouth ulcers, thrush, sores on the genitals, ulcers on his legs, body rashes and swollen lymph nodes.

40. Pete was at times extremely depressed, anxious, often in severe pain due to joint bleeds and suffering a severe grief reaction to the loss of his brother and father within 2 years. Once we started to campaign hospital staff became wary, we were treated very badly at times for speaking out. Staff who secretly supported us felt they could not do so in public and we would be asked to sit around the corner from other patients There were several incidents which were very upsetting when Pete

was admitted to hospital. Other haemophiliacs wanted campaign information from us but were afraid to upset their treating doctors in the early days so would meet us in the hospital car park so they would not be seen talking to us.

41. Incidents

a) Peter being given a towel covered in the blood of another patient whilst in hospital

b) Being denied an ambulance home and due to his mobility at that time Peter spending hours crawling up the garden path and stairs as I could not physically carry him from the taxi.

c) Pete went on a public treatment strike declining human plasma products in his legal fight for recombinant synthetic product. He was afraid to be left alone in hospital as once I was gone he was being pressured to take human plasma which he did not want and made that very, very clear. This meant when he was in hospital, I was there most of the time to protect him and this affected my life also and I developed chronic insomnia.

42. Pete developed many health problems related to hepatitis C, such as gross ascites where he gained several stones in weight due to fluid retention. Oedema in his legs, hands and stomach. This addition weight impacted on his joints and as the liver declined he bled more and more as the liver has a role in the production of clotting factors. He also had very swollen stomach, abdominal pain, itchy skin, vomiting at times, constipation, other times diarrhea, chronic fatigue and he developed phlebitis, with his legs being black blue, red and shiny stretched skin to the knees. He had very poor veins so I injected all his factor concentrates. Pete would ask for me to come to the hospital to give him his factor concentrate treatment so the doctors would not mess up his veins any further. This also meant I had to be at the hospital a lot which restricted my own activities.

43. Once Peter's penis retracted under the weight of his testicles which reached his knees, a combination of bleeding and fluid retention. He had to be measured for a truss and the person at surgical appliances said he had never seen anything like it, it was so bad. Pete lost the hair on his body as the liver deteriorated and his self-confidence. As the ascites increased he would have periods of confusion and depression. He also lost the feeling in his nerve endings, Pete had peripheral neuropathy and suffered very cold hands and feet that became discoloured.

44. In the 1990s we discovered that haemophiliacs that were co-infected were not being considered for liver transplants. By the time this policy changed and we pushed for Pete to be assessed (which he was at Birmingham) it was too late. He was then suffering from severe depression and the liver disease had progressed to the stage that he was considered unlikely to survive the anaesthetic.

45. In the last months of his life Peter was at St Oswald's hospice as by then he had fallen and broken his hip and due to us being on the first floor in a split level flat he could not be mobile. I spent most of my time at the hospice with him.

46. Peter died from a combination of HIV/HCV and in his last days in hospital he was also infected with C Difficile. I noticed the pain he was suffering was different to the usual pain and asked for him to be x-rayed. This showed his intestines and bowels had blown up He died a very painful death, lost his swallow reflex, was on oxygen with difficulty breathing and drown in his own fluid rushed from a hospital corridor back to his bed by the ambulance crew who were in the middle of transporting him back to the hospice where he wanted to die. He had been told he had only hours to live and had signed a "do not resuscitate" form.

47. There was an inquest but we only got to that stage by chance. I was having a conversation with a member of the administration team when I went to register Peter's death. When I mentioned we had had a previous legal case, she insisted that there must be an inquest and the case was referred to the coroner's office. He

concluded that all Peter had suffered was as a result of being given factor concentrates for his haemophilia and his HIV/HCV infection. The verdict was left as "open" as we were still collecting information on the US treatment from our US lawyers. I believe there was a recording made on the day of the inquest, if so I may be able to access this recording.

48. Being infected with HIV and hepatitis viruses and exposure to CJD did impact on Peter's treatment. Soon after he was infected with HIV, he had to have dental work done. Haemophiliacs were left to the end of the day. There were issues over dental treatment in those days with fear of infecting dental equipment. All his teeth were removed which he was not prepared for and he was left for some time waiting for dentures. Whenever there was any invasive procedure haemophiliacs and their partners were left to the end of the day to avoid infecting others. I heard of other haemophiliacs also having their teeth removed instead of preservation work.

49. My husband was unable to work for many years due to HIV/HCV infections, his education was already impacted by his haemophilia. Initially he could not get insurance, later we did but at hugely inflated cost if we travelled abroad. The 1991 HIV ex-gratia settlement paid due to the Special Status of Haemophiliacs is recognized in Hansard and written documents and was accepted by Virginia Bottomley ...This was that haemophiliacs had a hereditary condition and were ALREADY disadvantaged from birth and that multiple members of a family could be living with haemophilia or another bleeding disorder. (It was also known that they had been exposed multiple times to multiple viruses as was clear in the HIV litigation though much of that knowledge was not shared with haemophiliacs at that time).

50. The following quotes are from Virginia Bottomley in Hansard on the Special Status of Haemophiliacs compared to Whole Blood cases which applied to haemophiliacs with HIV but should equally have applied to haemophiliacs infected with hepatitis C.

"The Government's decision to make ex gratia grants to people with haemophilia who are also infected with the AIDS virus was a recognition of their unique position."

"In my reply of 18 January 1990 to the right hon. Member at column405 I pointed out that haemophiliacs are a group of people who by virtue of their haemophilia are already disadvantaged in respect of their employment prospects and their ability to obtain mortgages and life insurance. We have no evidence to suggest that those people who have become infected with HIV via blood transfusion were similarly disadvantaged before the illness or accident leading to the need for transfusion."

"Among the haemophiliacs infected with HIV, we understand that there are 65 pairs and six trios of brothers who are infected. We believe there may be a significant number of other cases where HIV-infected haemophiliacs are related, for example, grandfathers, grandsons, uncles and nephews, but these cannot be readily identified from the available information. In addition, there are a number of cases where the haemophiliac's spouse or partner has become infected." (Even this appears gender biased as it failed to mention females with bleeding disorders that had infected sisters)

"Members, the public and the media—whose advocates reiterated that haemophiliacs were an exceptional and specific group who merited exceptional treatment. The Government remain convinced that their case is exceptional."

51. The additional ex-gratia payment made to the Macfarlane Trust enabling lump sum payments of £20,000 to each haemophiliac with HIV was not compensation.

It recognised the wholly exceptional circumstances which haemophiliacs and their families face, that their insurance, employment and mortgage prospects were already affected by their serious disability, and the hereditary nature of haemophilia can mean that more than one member of a family may be affected. The situation of someone who has contracted HIV as the result of a blood transfusion is, therefore, not directly comparable.

52. Haemophiliacs including Peter were made to sign a controversial hepatitis waiver in the HIV settlement. I was the first to highlight this in 1994 and later seek a legal opinion which summarized that everyone but Peter knew that he would have been exposed to hepatitis C. Around 99% of haemophiliacs were known to be infected with hepatitis C by professionals involved in the HIV litigation. However this was not shared with them at the time of the HIV litigation. My husband did not know about his HCV infection until 1994 and again we were told it was "like having the flu". Articles at that time referred to those with hepatitis C as the "worried well" ... many of the "worried well" are now deceased as a result of their infection.

53. I have a document where the Haemophilia Society had a working group looking at the impact of hepatitis C however they concluded it was nothing to worry about and those investigating stepped down!

54. Stephen was also unable to work due to AIDS.

55. The impact on myself was also huge. I was rejected by my father for 5 years. He refused to speak to me or saying I must be suicidal to be in a relationship with someone with AIDS (we didn't know about hepatitis C then). This caused great distress to my mother who would be dropped off around the corner so my father didn't have to look at me, also to my sister.

56. GRO-C

GRO-C

57. I lost my opportunity to have my own family for fear of infecting a baby. I gave up my career to care for Peter, and lost my wages since 1991, my pension was affected also. Due to our financial circumstances, I was unable to afford to buy my home where we lived, Pete moved in with me

58. When I was pregnant and the baby had died inside me, I had to wait until the end of the day to have the foetus removed. I was treated as HIV positive and overheard unpleasant conversations between doctors arguing about what should happen to me due to Peter's HIV status. (Repeated tests after Peter died proved I was negative for HIV and hepatitis viruses and my blood was studied at St Thomas's hospital London due to my high level of natural immunity and to help develop a vaccine). Recently in 2018 during a hospital visit I was asked if I had been exposed to CJD, I told hospital staff my husband had and was seen as the last patient of the day as they needed to use instruments for a small procedure. I had to inform my dentist also as soon as I got together with Pete and stop giving blood.

59. The prejudice was so bad in the early days, I had a suicide pact with Pete as I did not think I could cope without him. As he got close to death, he talked to me and said I must not do this, that I was meant to stay and "deal with unfinished business" which made me very angry as I did not want to remain alone and unsupported.

60. After Pete died I had awful experiences claiming ESA benefits. I am on ESA in the support group and claiming both housing benefit and council tax reduction. I was assessed wrongly twice and left on nil income for 6 months relying on a friend to

send me food vouchers. I became extremely depressed as I could no longer pay my bills and was warned I may lose my home as the DWP stopped paying my rent. I did contemplate suicide and stopped caring for myself. The DWP assessor was caught out lying as I was accompanied by a welfare rights officer who witnessed the interview, months later my benefits were reinstated after going to an independent panel.

61. The benefits system is a system of what I term "double punishment". I wrote a numerous letters and a 70 page paper on this and also gender discrimination presented to Anne Milton (then DOH) in a face to face meeting at Westminster which I still have. The same misogyny exists in the haemophilia community as in wider society so initially partners and widows were treated badly with our losses barely considered even though some of us were the main wage earners in the family. When the infected person is alive the payment is in his name. I had a very good husband which was just as well as once I left work to care for Peter I was entirely reliant on what he got for the family as both the benefits claim and Macfarlane Trust payment were in Peter's name. Some partners suffered due to this as the infected person gave them only small amounts on which to manage. I became the first female partner to sit on the Macfarlane Joint Partnership groups representing partners and widows and still have some of the documentation.

Treatment/Care/Support

62. Peter accessed help outside of the NHS through a local AIDS organization. He had some free sessions regarding alternative therapies, such as acupuncture and massage which he found beneficial others he paid for himself. There was one social worker who we remember for her kindness and helping us access services outside the NHS.

63. Peter first asked for Recombinant synthetic product to replace human factor concentrates in the Spring of 1996 on ethical and safety grounds. He objected to

the paid donor blood trade where both donors and recipients were exploited and put at risk He also stated his fear of being exposed to v CJD as we were very concerned about the risk. The Health Authority refused but we challenged with a Judicial Review in the High Court. We lost the case on post-code lottery as although the Judge accepted our evidence, he stated it would open the floodgates beyond haemophilia and each Health Authority could choose how to spend their budget. Years later we discovered Pete had his first exposure to v CJD in the Autumn of 1996, so this could have been avoided!

64. As previously explained we discovered initially that it was not general policy for co-infected haemophiliacs HIV/HCV to be offered a liver transplant. This policy did change over the years but for many the changes came too late. By the time Pete was referred for assessment he was not in a fit state physically to take an anaesthetic due to liver decompensation or mentally as he was severely depressed.

65. I did see a bereavement counsellor after Pete died through my GP surgery. However although the counsellor was a nice woman, she had suffered a suicide in the family so it became a role reversal in the counselling sessions. therefore didn't really help me.

66. The years of caring for Pete have taken their toll. In the latter years both Peter and his mother were terminally ill at the same time so I cared for both. During the last months of Pete's life my asthma (which I was born with) became severe and one day my GP refused to let me walk out of the surgery and drove me home with a nebulizer to keep me going while Pete was in the hospice. I am now on 2 inhalors and sometimes steroid tablets and have severe fluid retention requiring diuretics which can sometimes mean the difference of a stone in weight (fluid) over 48 hours. I also have chronic insomnia and rarely sleep more than 2 hours a night which causes extreme fatigue. Early this year I had a period of weeks where I had severe muscle problems and could hardly move, struggling to lift a kettle and was

seen twice at Accident and Emergency. I am now going through various checks for cancer.

67. Since Pete died I have suffered from grief, severe depression, and diagnosed with Post Traumatic Stress Disorder (PTSD) and anxiety. I have been referred recently again for counselling however the counsellor and I do not consider this a good time to go into counselling whilst the Inquiry is ongoing so it is postponed to a later date. There is unlikely to be any resolution until the Inquiry is over. I have also been diagnosed with unresolved grief. I attended many funerals in our community and spent many hours visiting other haemophiliacs in hospitals and hospices in addition to Peter. I also suffered depression over not having children. At the time I considered having a baby there was a lot of prejudice and the worry of infecting a child was so great, we decided after I lost a baby not to try again.

Financial Assistance

68. Peter received an ex-gratia lump-sum payment, £60,000 the married person's allowance with one child in 1991 from the HIV litigation. Peter was informed of this through his solicitors. In addition he then received a monthly allowance for a married man with a child from the Macfarlane Trust. On speaking to EIBSS who checked back this was linked to Consumer Price Index.

69. Peter received two payments from Skipton Fund, lump-sums which I believe were £20,000, another £20,000 and I received a further payment of £25,000 in 2012 after he died. The Skipton Fund was embezzled at one point by a government employee who created numerous false profiles of haemophiliacs so he could keep the money himself. I recall being told he even used the bank account of a haemophiliac. The employee was later imprisoned (Story in the media). He claimed he stole to pay back the previous charity that he stole from. How was this allowed to happen?

70. The Skipton payment came after we sought a legal opinion from counsel on the hepatitis waiver in the HIV settlement that the waiver could not be "informed consent".

71. According to our counsel, the solicitor acting for haemophiliacs "did play-down the significance of hepatitis C" saying that it was "no big deal." Yet the Re-Amended Statement of Claim under the heading "Hepatitis and/or other viral infections" shows that Hepatitis C was pleaded as one of the consequences of infected blood products. Our counsel pointed out:

72. "… for example it is clearly pleaded that haemophiliacs were at great and particular risk of infection with Hepatitis B and/or NANB viruses and/or other viral infections from blood products used by them which, in the case of Hepatitis B and/or NANB could cause a serious illness of jaundice, liver disease and could sometimes lead to death, and in the case of other viral infections could cause serious illness and could lead to death. The same was pleaded in relation to the risks of commercial concentrates."

73. Our barrister concluded:-

"I have the greatest sympathy for Mr Longstaff. His life has, not to put too fine a point on it, been destroyed by the infected blood he was given. He was told by one of the key solicitors in the litigation not to worry about hepatitis C when it was plain that hepatitis C carried with it enormous risks and was a matter of grave concern."

74. The solicitor told the Newcastle Journal that the government did not want to pay out for a second virus. This lawyer told the press that haemophiliacs had to accept with the waiver otherwise government were stating haemophiliacs would lose state benefits (money would be clawed back by government)

75. The Haemophilia Society stated in their own minutes of 6th June 1991 that the Hepatitis Project team looking into the dangers of hepatitis C were discharged reason given, "the Society was in danger of creating concern and worry where they need not exist". By this time haemophiliacs had died through hepatitis C infection and others were seriously ill.

76. We later discovered our barrister was also working on an hepatitis C ex-gratia payment as part of a Working Party with the Haemophilia Society (we have papers on this) and proposals were made to government. Shortly afterwards Sec State for Health John Reid announced the Skipton Fund.

77. Peter and I have both received grants from the MacFarlane Trust over the years when in hardship and I received a grant from the Honeycombe Foundation which was money left by a widow whose husband had died from HIV and left to the Macfarlane Trust. Peter received the winter fuel payment but that stopped as soon as he died in 2005 despite my not working on grounds of ill health and suffering from chronic asthma. I wrote asking for this to continue but was declined. Now this is being started again but EIBSS wouldn't backdate to 2005. So I lost thousands of pounds in heating allowance costs over the years since Pete died and struggled to pay bills.

78. I now receive annual top-up payments up to £19,000 which INCLUDES all my state benefits the amount hasn't moved for at least 4 years despite cost of living rises according to a conversation with EIBBS last week who checked back for me. The widow/widowers payment is not linked to the Copy Price Index so we are worse off year by year.

79. Applying to the Trusts is demeaning, you have to go cap in hand with your begging bowl for grants and all your finances are assessed. Applying for grants is a hit and miss affair, depends how many others are applying, if you have had a grants before and when. The system also restricts freedom of movement against the Human

Rights Act if you want to live outside the EU you would lose benefits which would affect Trust payments. Our lives are not our own.

80. No-one has ever received proper compensation where we can live independently, we are still waiting.

81. Was the transferring over of the Trusts to EIBBS even legal? Despite the Macfarlane Trust being under a legal agreement and payments made on the grounds of Special Status, this is now being ignored and haemophiliacs had

82. No representation from any of the original solicitors in the HIV litigation to see if the move was legal? Restrictions to legal aid over the years have meant we can no longer challenge government decisions as we once did. Also the longest standing campaigners were deliberately left out of meetings with regard to the financial review so never got to have our say directly with the government appointed mediator.

83. Over the years up to Pete's death (2005) we spent over £40,000 of our own savings campaigning for justice. I have spent a lot more since then. Although some groups did receive funding, we self-funded to stay independent of the Haemophilia Society and pharmaceutical companies but our principles left us with greatly reduced savings and income.

84. The following was written upon my instructions and reflects my experiences:-

"Are infected and affected beneficiaries of EIBSS being denied money which they should have?

Yes. The 1991 settlement of the Macfarlane Trust (to which the EIBSS is the most recent administrator in England) provided that any monies paid under the scheme would be exempt from declaration for the purposes of benefits assessment. Whilst *payments under EIBSS are not required to be disclosed in benefits assessments, benefits payments do form part of a means test for the assessment of EIBSS payments which means that the same result of restricting the total amount paid by the state is achieved by simply reversing the payment to which a means test is applied.*

Additionally, there is a stark contrast between payments made in Scotland under the Scottish scheme and EIBSS. This contrast is particularly acute when the plight of widows and widowers of infected victims is considered. Widows and widowers often gave up careers to care for their terminally ill spouses at a great saving to the state in care costs; in Scotland this is partially recognised as widows are given annual payments totalling £27,750 in addition to other benefits. In England, widows and widowers are means tested and allocated to a band of payment; the method of means testing is so perverse that a widow who owns her own home might end up receiving a higher level of payment than one who rents because the renter will likely have housing benefit counted as an income for the purposes of her EIBSS assessment.

*Additionally, [*some are*] able to prove by reference to documentary evidence that [*they were*] infected in Scotland through contaminated blood products yet the Scottish government have refused to admit [*them*] to the (higher paying) Scottish scheme despite an agreement between the nations that contaminated blood victims would be admitted to the compensation scheme for the nation within which they were infected.*

[Are*] infected and affected victims of the contaminated blood scandal having to jump through hoops to receive payments?*

In England, infected and affected victims are being subjected to constant re-assessments of their EIBSS payments which is a lengthy and complex process. The last round of re-assessments was conducted during July and August which *was precisely the point at which many beneficiaries were deeply involved with the commencement of the Infected Blood Inquiry. Our point was really that if the spirit of the Macfarlane settlement is to be abided by then there is no need to assess any EIBSS beneficiary other than to establish that they meet the qualifying criteria for payments. [...] Lord Archer's recommendations from his 2009 report should be adopted in full and particularly, that non-means tested payments should be made to victims at a level which is at least on a par with that paid in Ireland, something Carol Grayson [...] has campaigned for over two decades."*

85. Peter had treatment whilst visiting relatives in Scotland and also told me he recalled receiving blood from Scotland at the RVI in Newcastle. It appears in times of shortage, treatment went up to Scotland from England and from Scotland to England but we were unable to obtain these records. It seems to have been done an a rather casual basis and may not have gone through the hospital pharmacy for recording. This meant I could not apply for the Scottish scheme which is a much better payment and the "pension" that widows receive does not affect benefits which are given in addition to the yearly pension.

Other Issues

86. Yes I have lots of other evidence and additional issues covered in our Terms of Reference. However the TOR of my campaign colleague Colette Wintle and I were delayed due to the initial delay over an incident where our phone call was listened in to by members of the Inquiry team and for which they have since apologized.

87. We have submitted our Terms of Reference which are comprehensive and still have not received an acknowledgement or reassurance that they will be included. We want to ensure that all the issues raised in our TORs are considered as that is our blueprint for what needs to be investigated.

88. Papers we wish to be examined include the following...

- Documents I hold from the original HIV litigation 1991 which I organized to be returned to the Department of Health later transferred to the National Archives at Kew in 2006 (documented in Hansard, legal letters and media) which are copies of government legal papers they claimed to have destroyed

- Documents of letters to my MP over 2 decades and the responses from government including health ministers

- Media which includes many of our interviews showing who knew what and when from the 1980s and included old videos and cassettes from documentaries as well as old print media. I have a collection of media links currently running to 107 pages with many links on each page. Our Newcastle Journal "Bad Blood campaign" which broke many key stories along with the Northern Echo, Private Eye and the Guardian detail our campaign efforts. There are also key documentaries from BBC Newsnight April 2007 where I was the researcher, documentary on Arkansas Prison blood by Kelly Duda and documentary on Louisiana State Penitentiary and US blood collection by RTE journalist Paul Cunningham and Blood Brother documentary from Meridian as well as old World In Action documentaries.

- My dissertation on contaminated blood and Questionnaire to haemophiliacs and partners (41 questions including on non -consensual testing and trusts)

- Documents from earlier legal cases

- Documents related to our fight to overturn the hepatitis waiver in the 1991 HIV litigation

- Judicial Review for Recombinant (2003 Lost) heard by Justice Charles, our QC Stephen Grime

- Documents and letters from 2004 on the false narrative of Lord Warner and others on Eire compensation and the continued use of that false narrative despite a Judicial Review (2010) under the name of haemophiliac GRO-A GRO-A against the then Sec State for Health where the government's thinking on Eire was found to be "infected with error". The case was WON using key letters obtained by March and his legal team from Colette Wintle and I from the Eire government, Irish lawyers and the Irish haemophilia Society. Eire settlement for haemophiliacs was paid out in advance of their Inquiry. It was a "no liability" settlement out of court but paid at court cost levels, paid out on the grounds of "extraordinary suffering" based on "loss and need". The case was heard under Justice Holman, March's QC was Michael Fordham. Lord Archer of Sandwell echoed my own recommendation from 1996 (I have original letters to the government where I call for "compensation on a parity with Eire" BEFORE the national Haemophilia Society). The government rejected Lord Archer's recommendations using a false narrative and DOH Self -Sufficiency in Blood Products 2006 report now disgraced and withdrawn (Recent letter sent from myself to Matt Hancock on this issue dated October 11th 2018).

- Documents regarding *DOH 206 Self Sufficiency in Blood Products in England and Wales: 1973 to 1991* withdrawn on the grounds of serious omissions, described by many as a "whitewash" of a report.

- Official complaints made to the General Medical Council (2003)

- Petition to European Parliament (0287/2004) for a public inquiry and for haemophiliacs to be compensated and receive treatment on a parity with Eire

- Brighton University Living Stories Testimony
- BPL Inspectorates Report
- Archer Inquiry Testimony
- Documents and letters regarding whether changes to the Trusts and transferring to EIBBS was legal.
- Official complaint from Peter and I to the Police (This was transferred to Dyfed Powys, 2002/2003 under GRO-D however we question whether the investigation was carried out thoroughly. We later discovered he "retired with immediate effect following allegations of financial irregularities being investigated by the Independent Police Complaints Commission." Guardian
- US haemophilia litigation against 4 US pharmaceutical companies, Reddie case documents
- Complaint to the Charities Commission regarding the conduct of the Haemophilia Society
- Haemophilia Society documents
- UKHCDO letters
- Macfarlane Trust documents
- Documents from academic medical journals

- Lord Owen documents
- Complaints to Office Supervision of Solicitors upheld regarding the conduct of our own solicitors - solicitor investigated and struck off roll, compensation received by myself (around £720 through OSS)
- My complaint and Lord Owen complaint to the Parliamentary Ombudsperson
- Death Certificates, Inquest reports.
- CJD documents
- Documents from the Retained Organs Commission
- I wish to highlight also that Stephen's brain and other organs were taken without permission which resulted in us being involved in the Organ Retention Scandal. Stephen died of AIDS in 1987, however I did finally receive his organs on the day of my husband's funeral in a small white box to cremate beside him. (All this is documented in official documents and media articles)
- Experimentation/studies on haemophiliacs and Nuremberg Code
- Non- Consensual testing
- Current blood safety concerns on Synthetic cannabinoids, e-mail to Haemophilia Society, letter to MHRA and slow response time

Statement of Truth

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

Signed GRO-C

Dated 6 November 2018