

Witness Name: **Colette WINTLE**

Statement No.: **W1056001**

Exhibits: **None**

Dated: **19 November 2018**

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF COLETTE WINTLE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15th October 2018.

I, Colette Wintle, will say as follows: -

Introduction

1. My name is Colette Wintle. I was born on the GRO-C 1959 and my address is known to the Inquiry Team. I am a woman with haemophilia and a victim of the contaminated blood products scandal. I was infected with Hepatitis C, B, and suffered a further repeat infection of Hepatitis C, as well as exposure to Nv CJD. My health has deteriorated constantly over many decades and I now have cirrhosis of the liver, in addition to other medical conditions which have arisen due to chronic long- term illness and subsequent damage to my liver which is irreversible.

2. I was forced in to early retirement in 1998 aged 38 and unable to return to the workplace. I have one daughter who is now 24, and my husband GRO-B who is my sole carer and provider. The impact of my chronic ill health has had a very negative and damaging effect on our family life.
3. I intend to speak about my experience of being infected with multiple viruses through my NHS treatment and the impact of this on my life, the nature of my illness, how the illnesses affected me, the treatment received and the impact it had on me, my husband, our child and my family, and our lives together.

How Infected

4. I was infected with contaminated blood products during the 1970's 1980's and (possibly) 1990s through NHS treatment for my haemophilia. The first occasion was as a child aged 17 in 1976 whilst I was resident in Scotland. I was treated for the first time ever with commercial factor 8 which exposed me to hepatitis C.
5. My second treatment with infected blood products was in 1982 after I had moved to live in Kent in England, I was treated at a local hospital with more American made Factor 8 which caused me to be chronically ill with Hepatitis B. I then experienced a further Infection with HCV in 1985 following further treatment with American made factor concentrates. Finally, I was exposed to NV CJD in 1993.
6. My last infection with HCV and my exposure to Nv CJD both occurred at the same London Hospital. I would like to make it clear that at the time of exposure to all of these viruses, neither my parents nor I knew, nor were we ever advised that I was receiving pooled plasma blood products from the USA.
7. I am a symptomatic Haemophilia A carrier with reduced Factor VIII levels and have an additional bleeding disorder, Factor XI deficiency, which was diagnosed in 1996. My condition is considered to be mild Haemophilia however my bleeding

history has been fairly substantial over my lifetime thus far, and remains unexplained from a medical perspective.

8. I was first treated in 1976 with commercial imported blood plasma called Haemophil (manufactured by Baxter Pharmaceuticals) and Profilate (manufactured by Alpha Pharmaceuticals) at the Glasgow Royal Infirmary in 1976. The plasma products I received were treatment for my haemophilia, which I was given pre and post operatively following a routine tonsillectomy. My parents were required to give written consent for my operation as I was still a child but did not receive counselling on my haemophilia care. Neither of my parents were consulted by the haematologists looking after me about the known risks involved with the use of US blood products, and more shockingly I have since discovered that by 1976 the haemophilia doctors knew all the commercial blood products were contaminated with hepatitis viruses.

For me, this begs the question as to why doctors would knowingly use high risk clotting products and worst still, even after they realised how dangerous they were, why they would continue to use them on haemophilia patients for a further 10 years.

9. My parents had naturally assumed I was being treated with British produced clotting factors, so it was a complete shock for them to learn many years later that I had actually been infected through imported concentrates. My parents felt that this was a total betrayal of the trust that they had placed in the NHS and the doctors charged with my care. It was 29 years after my first infection before I discovered from my records what the doctors had injected me with; the worst part was that a doctor had struck a line through the original proposed treatment of choice which was Cryoprecipitate, and instead Factor VIII was written over it. Had I been treated with Cryoprecipitate then I would likely not have been infected. Crucially one doctor made a pertinent remark to my mother on the day I was discharged from hospital, he said *"Mrs O'Donnell your daughter will never be the same again"* Was he hinting

that he knew I had been exposed to dangerous and high- risk treatment? My mother deeply regretted not challenging him on this remark, but we both believed it was significant.

10. I was originally under the care of Dr Andrew Douglas at the Royal Infirmary from my diagnosis in 1962. He pioneered the haemophilia centre in Glasgow but subsequently left to go to Aberdeen Royal. At that point my care was transferred to Haematologists Dr Walker, and Dr J F Davidson at the Glasgow Royal Infirmary.
11. According to my hospital medical records I was first exposed to commercial US blood plasma on a series of dates from 7 June 1976 until 23 June 1976. I had never been given blood products prior to this, nor did I receive any between 1976 and 1982 despite many bleeding episodes of a severity that would have warranted their use (by the thinking of the time).
12. I was next exposed to commercial blood plasma products in 1982 at the Kent and Sussex Hospital Tunbridge Wells, by Dr Colin Taylor prior to having a spinal stretch under general anaesthetic.
13. In 2002, I met with Dr Taylor and challenged him to provide me with batch numbers of blood products he had given to me; he admitted that he had destroyed all my blood records. His excuse was that he was not duty bound to keep such records until after 1989. This I discovered went totally against the instructions of the DOH that Haemophilia Directors must ensure proper record keeping was in place certainly by 1982. I pointed out to Dr Taylor that Haemophilia is a life- long condition and that I felt that all of my treatment records should have been kept.
14. I asked Dr Taylor where he procured factor concentrates for his patients and he told me that he had purchased Factor VIII from a company called Immuno who were based in Switzerland. Immuno were later linked to Baxter who bought

them out in the 1990's. I understand that Immuno sourced their products from the US. I became infected with hepatitis B from the treatment he gave to me in 1982 and was chronically ill for two and a half years.

15. Dr Taylor also told me, in a conversation with others present, that *"it was a mere oversight I forgot to warn you of the known risks of hepatitis"*. He also disclosed that he worked closely with the Haemophilia Director of the Oxford Haemophilia Centre Dr Charles Rizza and the relevance of this will become clear in the evidence to come in further statements.

16. From 1982 until 2002 I was a registered patient at the Royal Free Hospital Haemophilia Centre. I was placed under the care of Dr Eleanor Goldman, Professor Pasi, and latterly Professor Christine Lee. In 1985 I required treatment for severe nose bleeds and I was infected again with hepatitis C. I was treated with factor VIII made by Alpha Pharmaceutical. I was not given a diagnosis of my condition until 1991 and was shocked to discover in my hospital records some years later, that it was known to Dr Goldman and my GP, that I had chronic Non-A Non-B hepatitis. This was referred to in a letter between them years before I was told. The particular batch number of that treatment was registered in my legal case in the US courts in the early 2000's and accepted by the judge adjudicating the case, to have been confirmed as a contaminated blood product, made and sold by Alpha Pharmaceuticals. The case was concluded in 2011 and the judge returned all the UK cases under "forum non conveniens", on condition they would be heard in the UK. I am still waiting to have my case heard in the British Courts.

17. In June 1987 I married my first husband Keith Wilcox. In early springtime of that year, we attended the Haemophilia centre for advice GRO-C GRO-C as I was intending to join Keith to live in Oman where he was working at that time. We had a meeting with Dr Goldman to discuss haemophilia treatment options GRO-C whilst living abroad,

and indeed what the legal requirements were to acquire a visa for being domiciled in that country.

18. There was discussion on the issue of my having had Hepatitis B which I had recovered from, but according to recent blood tests, they showed that I had not raised sufficient immunity to protect me against further exposure to the virus. I was therefore in need of further immunisation which I was given prior to my moving abroad. Throughout this process there was no mention of the fact that it had been recorded in my records that I had had a further attack of Hepatitis Non A Non B in 1985 from treatment given to me by Dr Goldman.
19. Neither Keith nor I were aware of my HCV status which is particularly shocking given that Oman did not at that time allow any persons to live in the country with known viruses such as Hepatitis C. Not only did failing to tell me of my diagnosis put Keith at risk, but could have placed me in an appalling position legally had I become ill whilst living in Oman and my HCV status had been discovered.
20. Furthermore, I had specifically requested a medical letter addressed as "*to whom it might concern*" to highlight that I would require specific haemophilia care in the event of an accident, and to confirm that I was clear of hepatitis. I revisited that letter some years later and realised that there was mention of Non A Non B hepatitis but I had not understood the significance of this because it had never been mentioned to me or my ex-husband. Keith would be willing to confirm the chain of events which occurred that year, and to state categorically there was never any mention of my having active HCV.
21. In 1993 I was treated with a blood plasma batch made by BPL in the UK which exposed me to the infective prion which causes Nv CJD. I was not informed by my haemophilia doctors until 20 September 2004 and then, only because the

Health Protection Agency insisted in writing that the UKHCDO Haemophilia Doctors inform all of their patients.

22. At no point prior to, during, or after any of the infections I suffered was I, my parents or my partners given any information whatsoever about the risks of contracting viruses from commercial blood products, nor were we given the opportunity to give informed consent regarding the blood products I was given throughout my haemophilia care. None of the hospitals which treated me were willing to give me the batch numbers for concentrates which were administered to me when they were requested and only supplied them after I threatened legal action. I did eventually acquire most of my records, with the exception of the Kent Hospital who destroyed my blood records as I set out above.
23. I received my Scottish health records from the Glasgow Trusts following an interview with Channel Four Television who were investigating patients missing records. I had to write several times for all my records, which I was repeatedly told did not exist as they were 26 years old at the time of my request. Following a series of letters to the CEO, and Head of the Glasgow Trusts they were finally located and sent to me in or around 2005. I was also able to retrieve my blood treatment records from the Royal Free Hospital in 2002 but with the same difficulty again of obtaining the full treatment records.
24. For clarity, my records show that there was never any attempt to discuss the risks of treating me with commercial factor concentrates despite clear evidence that their risks were known to haemophilia doctors and that, in 1976, it was known that all US pooled plasma was infected.
25. I feel that I was never given adequate information to help me to understand and manage any of the infections I suffered; in 1991 I was told, as many other haemophiliacs were, that Hepatitis C was just like having a "bad flu" and I believe haemophilia patients with these infections were often referred to as "the worried

well". Considering how debilitating the symptoms were, that was a shocking attitude when patients were already dying of liver cancer by this point in time.

26. It is clear from my records that doctors deliberately withheld my results of tests for viruses which were known to them but not shared with me, and the only way I found out was by accessing my medical records long after my exposures to contaminated factor concentrates.

27. In 1982 I was repeatedly ignored by three GPs when I reported feeling very unwell months after I received Factor VIII concentrates. It was only through the assistance of a doctor friend working on the same ward I worked on at the Kent and Sussex Hospital that I ended up with a diagnosis of Hepatitis B, Dr Nigel Heaton observed my obvious struggle to carry out my nursing duties one particular day, and spotted the fact I was glowing yellow. He independently took a blood sample from me and sent it to Kings Hospital in London for investigations. One week later I was informed by him that I was ill with Hepatitis B.

28. My last exposure to HCV was a further example of the persistent failure to inform me of my HCV status. On this occasion, I went for genetic counselling in 1991 shortly prior to my second marriage and at no stage was I told that I was infected with HCV despite the risk **GRO-B** was being put at through us not knowing my HCV status. **GRO-B** had an absolute right, as did I, to know of my HCV infection and what the risks of transferring this to him were. I do not understand why my doctors waited until late 1991 before telling me; worse still, I discovered from medical records years later that my doctors knew I had HCV in 1985 and never told me.

Other Infections

29. As I mentioned above, I was exposed to Nv CJD in 1993 at the Royal Free London. At the time when BSE and CJD was being reported in the news, I approached the

doctors at the Haemophilia unit to ask if I was one of the haemophiliacs who was at risk. I was told to stop worrying about it and that I was not a victim. I was immensely stressed and very worried about the implications of exposure to a further pathogen on top of everything else. My instinct was that I was not being told the truth.

30. In 2004, the Health Protection Agency England insisted that all Haemophilia directors would have to inform their patients who were on the "at risk" list and so I received a letter asking me to confirm if I wished to know if I had been exposed to Nv CJD. I wrote back confirming I did and to my horror was advised that I had indeed been exposed. I wrote to the CJD Surveillance Team in Edinburgh and managed to secure the information needed about the donor and acquired the batch number of the blood I had been exposed to. It disgusts me that the doctors charged with my care neither invited me to come and discuss the risk of CJD nor did they apologise for lying to me in the mid-1990s.

Consent

31. I found evidence in my medical notes, that I was tested for Hepatitis G at the Royal Free, but this was done without my knowledge, or consent, nor was I given adequate information about why the doctors were investigating this particular strain of hepatitis. I assume it was for the purposes of research but that was never discussed with me, and the test sheet had no signature of authorisation of the doctor who ordered it to be done.

Impact

32. Over the years the knowledge of discovering that I was exposed to so many viruses, has had a huge effect on my mental and physical wellbeing. Knowing that the doctors I entrusted with my care could have deliberately put me in such a

vulnerable position of being exposed to the risks of HIV, HCV, and HBV plus Nv CJD is beyond belief. The anger I have carried for so many years is as strong now as when I began my journey of discoveries in to who knew what and when, and which doctors betrayed me throughout my haemophilia care. I struggle every day with the knowledge I have gathered of all of the wrongdoing and I have in the past considered suicide because I simply could not cope with the physical and mental pain. I almost carried out that desperate act a few years ago, but I realised I would leave behind unresolved grief and anger which would have been hellish for my family. That pain has also impacted on my husband, our relationship, and that of my daughter's life too.

33. When you have been exposed to multiple viruses, the immune system is under such sustained attack, it leaves the body in a chronically inflamed state which causes further medical complications or conditions which have resulted from the infections. For example, I suffer from costochondritis, an inflammation of the tissue between the ribs which creates constant pain throughout the torso. I also have Fibromyalgia, arthritis in my joints and very marked deterioration in the discs of my spine. This is in addition to constant muscle and bone ache and chronic insomnia.
34. The treatment(s) which I received for my HCV both in 1999 and 2015 were horrendous in that the side effects were many and too awful to bear. My first treatment caused me to lose large clumps of my hair, peripheral damage to the blood vessels in my legs, numbing of the lower limbs, loss of appetite, and physical pain all over my body which was indescribable. Following the second treatment in 2015, I am still suffering hair loss albeit less dramatic but ongoing, and I have increased bruising due to damaged blood vessels all over my body. None of these side effects have any known treatment. In respect of my HBV I struggled to eradicate it and had to have three lots of vaccines post recovery from the initial infection. The complications faced by exposure to Nv CJD I believe are still unfolding for many and I know that being on the "At Risk Register" means that I will be treated differently in respect of surgery and any medical equipment used

for intrusive testing. I have to attend a specified dental clinic at the Queen Elizabeth hospital Birmingham for all dental care as I am aware that people have been rejected for dental care in the haemophilia community due to alleged risks.

35. I have not faced any difficulties or obstacles in accessing the appropriate treatment(s) for HCV, but I understand that this is often a postcode issue for many people and dependent on hospital budgets, as to whether someone is offered treatment.
36. In my view all antiviral treatments ought to have been automatically made available to all victims of the contaminated blood disaster. In addition, pain is probably for me the hardest problem to deal with. Taking the level of pain control I require through medication is simply not an option for me as it would put further pressure on my already damaged liver. The only option for me is alternative therapies to alleviate my symptoms but I am unable to afford things like hydrotherapy, massage and liver support supplements, because the level of financial support I currently receive from the government is inadequate.
37. I think it is important to recognise that the mental and physical effects of the treatments I (and many others like me) have received are often not acknowledged by health providers at a grass root level, so in my experience I have struggled to get the level of support I feel I should have been offered, or been able to access through my GP. There is no fast track system in place to get treatment I have needed urgently put in place. Considering the complex nature of suffering with the condition of haemophilia plus living with multiple viruses caused by NHS treatment, the lack of availability of the health care services I need is like a final insult.
38. My infected viral status has undoubtedly impacted on how I have been treated by medical care providers, in that I have in the past often been operated on last, due to having had HB/CV and having been exposed to Nv CJD. Having those conditions leaves you feeling "dirty" which is a terrible state of mind to be in, and

is not helped by the fact that there is often such a lack of knowledge amongst NHS staff who are not aware of *“the worst treatment disaster in the history of the NHS”* and the fact that I (and those in similar positions) were only infected because of the actions of those charged with our care.

39. The worst experience for me has been that, on several occasions, I have been asked by NHS staff if my infections were due to life style choices such as drug abuse or alcoholism. Such assumptions and accusations are commonplace for haemophiliacs but deeply hurtful and unacceptable.
40. Over many years I have found myself having to explain and justify why I am unable to work and why, which means having to reveal very private information to friends and people I meet in social circumstances. Throughout my daughter’s younger life I had to protect her from the knowledge that I was chronically ill, but it became impossible to hide the physical effects of my illness and there were more occasions than I care to remember when I simply could not join in family outings having fun with her when she had a right to expect me to be there for her. In fact, she came to resent me for the absences and emotionally punished me which was very painful to accept.
41. It has taken many years to try and rebuild my relationship with my daughter and for her to understand why I was an absent parent. My husband has borne the pressure of being a lone parent, trying to support me and financially supporting our family. Whilst my husband and I have always enjoyed a happy and stable relationship, I know that from the day I was diagnosed with Hepatitis C, it has put tremendous pressure on us both [GRO-C] which I feel deeply aggrieved by, since none of our circumstances were either of our fault.
42. My [GRO-C] have not always been there due to the pressures of their own lives but as there are [GRO-C] who have haemophilia and have also been exposed to the same viruses, they clearly had an insight and

understanding as to what I am going through. The friends we have made over the years have been educated by me through my campaigning, so I have not experienced bias or stigma, but I know for many the opposite is true.

43. During my school years, having the condition of haemophilia most definitely affected my education. Trauma from falls, bleeding episodes and suffering daily haemorrhaging from my nose, meant time away from education. In my early teenage years, I lost a lot of time away from the classroom due to severe period pain and blood loss which left me weak and anaemic. By the time I was sixteen I was struggling with exams but did leave school with several qualifications at O' level grade. I was unable to continue my education beyond this point because I was extremely ill with chronic tonsillitis which resulted in the operation I referred to earlier, during which I was treated with contaminated blood products. I never recovered my health after this event and the rest of my working life was affected.
44. I was forced out of my nurse training by my employers in the NHS following my diagnosis with Hepatitis B in 1982 and was not allowed to return to my training after I had cleared the virus, thus closing a door on that career. A few years later having secured a job with an airline and a permanent contract with a proven successful track record as an employee, I was shocked to discover that my contract was removed due to a prejudiced decision by a medical officer working for the airline, who advised my manager, that I should be got rid of on the basis of my haemophilia status. Incredibly, I had not had a single day of sick leave from work. It had been concluded in my absence whilst on leave, without any opportunity to defend my position that I did not deserve to be employed because I had a bleeding disorder. I approached the Haemophilia Society for help and legal advice but was rejected at the time by GRO-D who had no interest in my case.
45. Throughout my working life I have suffered considerable financial losses either from being made infected by the NHS and unable to work, through having

employment taken away from me due to my health status or through losing a career due to the ignorance and prejudice of my employers. Being forced in to an early retirement has left me with a significant loss of earning capacity, the loss of my career and potential career, the loss of opportunity to provide for my family, the inability to get life insurance or mortgage protection, and worst of all, the loss of my health for most of my life.

46. Clearly, this has also impacted on my husband who has been forced, through circumstances, to become the sole financial provider for our family and to carry the weight of that responsibility. I have felt terrible guilt that I am the cause of my husband's burden and I have a deep frustration that I can do nothing about it.

47. In summary, my life has not been what it could or should have been because of what has been done to me by the people who were supposed to be caring for me.

Treatment/Care/Support

48. In terms of obtaining treatment, care and support in consequence of being infected with HIV/HCV/HBV, other than antiviral treatment no other means of support have been offered to me by my doctors in either Haemophilia care or Hepatology care. Because there is no fast tracking for people in my situation, I am at the back of the queue for any care I need; for example I have been waiting three years for orthopaedic care to have further spinal injections to treat nerve pain from collapsed discs.

49. In 2010 I met with the then Health Minister, Anne Milton who advised me that the government were willing to offer counselling or psychological support to be made available to victims in consequence of being infected through contaminated blood. However, the funding set aside was such a small sum of money that it would not have met the needs of an infected victim and their families beyond a few sessions,

never mind the whole infected haemophilia community. It had also been set up in such a way, that you had to go through the trust funds set up by government to access counselling. Needless to say, no one took it up. In my view, counselling will be far more appropriate when resolution on compensation has been reached. Only then can I benefit from long term counselling to address the terrible traumas I have been put through. The government's response past and present has been wholly inadequate.

Financial Assistance

50. The only financial assistance I have received was from the Skipton Fund which became operational in July 2004. I received the initial ex-gratia payment of £20,000 on providing evidence of having chronic Hepatitis C, and a further lump sum of £25,000 for proving that I had developed Cirrhosis of the Liver.
51. In 2011 following a financial review the Skipton Fund announced they would pay a further lump sum of £25,000 and a monthly or quarterly payment for Stage Two Hepatitis C victims. The decision to implement this scheme was taken by the Health Secretary, John Reid "*English hepatitis C patients should receive these payments on compassionate grounds*" I also believe that it was in response to the outcry of campaigners who had not received any sort of compensation for being infected with HCV, unlike victims with HIV positive status who received ex-gratia lump sums and ongoing monthly support. My first monthly ex-gratia payment began in April 2011.
52. I first became aware of the Skipton Fund from reading an announcement in a press release in August 2003. I then wrote to the Department of Health to express an interest in applying to the proposed scheme. My name was added to a confidential mailing list and I was updated by letter to advise me of when I could apply and what criteria for eligibility was required by the Skipton Fund.

53. I was able to provide documentary evidence from medical records and letters of support from my hospital consultants. Fortunately, I had undergone a specific surgical procedure which proved beyond doubt that I had developed Cirrhosis of the Liver; I was therefore able to secure the full ex gratia entitlement available at that time. Others were not as fortunate, and many people were rejected if they could not get their doctors to support them or provide medical proof of the advanced stages of disease.

54. I have never felt the amounts paid in ex- gratia form or indeed the arbitrary monthly payments eventually paid out from 2011, could possibly reflect the level of severe harm and damage caused to me by the care I received from the NHS. In my view, the trusts are an insulting and derisory begging bowl system, which have totally failed victims who have suffered a shattering tragedy of such proportions it is difficult for many to envisage. The government continue to ignore the plight of the most vulnerable patient group in the NHS, so it is quite ironic that whilst the Skipton Fund was set up “on compassionate grounds” that sentiment has now been lost since the changes implemented with the financial reviews of 2011 and 2015.

55. I have never received any financial recompense or assistance for dealing with my hepatitis B infection or exposure to Nv CJD; indeed the government have made no attempt to recognise the damage caused to me from these additional infections (whether financial, psychological or otherwise).

56. The trust funds have also caused enormous stress to victims due to the nature of how they were set up to (in my view) deliberately divide the haemophilia community. By separating the viruses people were infected with and paying differing amounts of financial support, the government created divisions amongst members of the same family, all of whom were infected in identical ways through their NHS treatment.

GRO-C

GRO-C

GRO-C

Other Issues

57. I have been campaigning for 25 years as an independent campaigner and also worked closely with Carol Grayson, her late husband Peter, Peter Mossman who set up the Manor House Group and other campaigners ,many of whom fell victim to the “Haemophilia Holocaust”. During that lengthy period of time, I have engaged in writing to every MP representing me, written to countless health ministers in government, members of the House of Lords and worked closely with the late Lord Morris of Manchester who regularly phoned me for advice before speaking at debates in the House of Lords.
58. I have met with several health ministers at the Department of Health and handed over research and documentary evidence of government negligence, and cover-up. I have attended numerous open debates at Westminster and have been present at several APPG for Haemophilia group meetings as well as House of Commons debates.
59. I have given countless interviews to radio and television programmes as well as all of the mainstream press in Scotland and England and I was instrumental in getting Meridian Television to make a documentary called Blood Brothers which highlighted the tragedy that has befallen the haemophilia community. I would also like to think that my efforts in lobbying the Haemophilia Society in representing female haemophiliacs has culminated in having women with bleeding disorders finally acknowledged both by the Society itself and the medical profession.

