Witness Name: Anne Hildyard
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Dated: 1 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANNE HILDYARD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Anne Hildyard, will say as follows:-

1. Introduction

1. My name is Anne Hildyard. My date of birth is GRO-C 1945 and my address is known to the Inquiry.

2. I live alone in London where for the last 34 years I have worked as an Editor in various jobs, both full time and freelance. I have had to work past retirement and I am still looking for work now at age 74.

3. At the moment, my personal financial circumstances are extremely dire. I am struggling to pay a mortgage on my flat in London, and since

my husband was too sick to work, we have never managed to get ahead and clear our debts.

2. How Affected

1. Courtenay and I were married in 1976 in Newcastle. Courtenay had a very mild form of haemophilia A which did not prevent him from leading a full and active life. Courtenay was very fit and he enjoyed many sports including roller hockey, squash, badminton and running. Courtenay owned properties and we bought an apartment in a mansion block.

2. However, in 1983, Courtenay suffered mild injuries from a skating accident. He was admitted to the Royal Victoria Infirmary in Newcastle under the care of Doctor Peter Jones. Dr Jones advised that Courtenay should have a transfusion of an Anticoagulant. Courtenay had worked in the NHS for years and had strong connection in the transfusions service. He knew about hazards associated with blood transfusions and made it clear he did not want one. Dr Jones assured Courtenay that the treatment was perfectly safe and asked for confirmation that he had not been treated before.

3. After a couple of weeks, we went on holiday to Portugal where Courtenay became ill and jaundiced. This was diagnosed as Non-A, Non-B Hepatitis. He was very ill for a year and lost his business as a result. Dr Jones assured Courtenay that he would make a full recovery and have no further problems. However, it quickly became apparent that Courtenay was not going to make the complete recovery promised by Dr Jones.

4. It is important to note that Courtenay only had an extremely mild form of haemophilia A. When he was told to accept a transfusion by Dr Jones, Courtenay was told that it would be Cryoprecipitate but it has since transpired that it was in fact Factor 8 product that he received.

Both of those products are supposed to be used by severe Haemophiliacs and not mild Haemophiliacs.

5. Courtenay found out retrospectively that he had been given Factor 8 blood product in 1980 when he had a minor operation for the removal of a Hydrocele. At the time he was told it was Cryoprecipitate, but subsequently found out from the records that he actually received Factor 8.

6. No information or advice was provided to me or to Courtenay about the risk of being exposed to infection. Rather, Courtenay was assured by Dr Jones in 1983 that the treatment was entirely safe. Both Courtenay and I worked for years in Biochemistry in the NHS and we knew about the dangers and risks associated with blood transfusions. Doctor Jones misled us or rather, lied, when he said that the transfusion was completely safe. Our naivety in believing him cost us Courtenay's business, health and our married life as well as causing huge amounts of debt that we have never been able to pay back.

7. Despite Courtenay feeling frequently unwell, in 1986 Dr Jones told him that his factor 8 levels were normal and that he should consider himself "cured". Courtenay was then removed from the Haemophilia Register in Newcastle. However, over the next few years, Courtney continued to feel increasingly unwell. In 1993, our GP Doctor Anna Skalicka of Elizabeth Avenue Practice in London did some blood tests. Doctor Skalicka confirmed to Courtenay that he was infected with hepatitis C.

8. Doctor Skalicka was sympathetic and tried to help as much as she could. However, we still did not understand why we had not been given this information years earlier and had not been adequately warned about the dangers of infection and the consequences of contracting the virus. I don't feel that we were adequately advised as to the risks

associated with hepatitis C. I had a test myself which fortunately for me proved negative.

9. After finding out that Courtenay had been infected with hepatitis C, and that the only likely source of infection was the treatment insisted on by Dr Jones back in 1983, I then began to understand the reason why Dr Jones had taken Courtenay off the Haemophilia Register. I believe this is because Dr Jones wanted to remove responsibility for Courtenay away from himself and his hospital.

3. Other infections

1. Courtenay had an HIV test which was fortunately negative. However, by the time Courtenay was diagnosed with hepatitis C he had chronic liver disease and the damage had already been done.

2. Courtenay is currently on the vCJD at Risk Register due to the potential risk of exposure to this infection. After being told he was at risk of vCJD, no further testing or information was provided to us.

4. Consent

1. I strongly believe that Courtenay was tested without his knowledge or consent. I believe he was not given adequate or full information and that he was potentially tested for the purposes of research.

2. The reason I believe this was because Courtenay had explicitly stated to Dr Jones that he did not want a blood transfusion, yet Dr Jones insisted that it was safe. We now know that the Haemophilia Units all over the UK were instructed to treat previously untreated patents (PUPS) to see if the rate of infection with hepatitis C progressed at the same rate in humans that it had done in animals when tested on them. Dr Jones was quite clear in asking Courtenay whether or not he had

been treated before and I believe this question was asked for the purposes of research.

5. Impact

1. The physical effects of Courtenay's infection with hepatitis C were predominantly that he felt unwell most of the time, suffered from acute and sudden exhaustion and was eventually diagnosed with ME (Myalgic Encephalomyelitis.) He suffered from constant anxiety, anguish and a precarious mental state.

2. Courtenay went on to suffer with chronic liver disease, cirrhosis, septic arthritis, chest surgery, a broken collar bone, an aneurysm and arrhythmia. The long term hepatitis C infection has eventually caused Courtenay to develop liver cancer requiring radiation treatment on his liver.

3. Because no treatment was offered by the Doctors for the hepatitis C infection, we turned to a Homeopathic Doctor and used what income we had for expensive supplements to assist Courtenay's liver function. Although our GP sympathised, she tried, but could not get any funding to help. Despite various Health Secretaries assuring us they would do everything they could, the help we needed never materialised.

4. As a result of his hepatitis C infection Courtenay suffered with bewilderment, anger, anxiety and suffering the effort of trying to remain positive and still tried to get some enjoyment from daily life whilst enduring such horrible illness. His relationships with his friends changed and some friends had dropped away, perhaps because they were worried about infection or unable to comprehend the abnormality of what had happened to Courtenay.

5. Lack of money meant that our social life was severely curtailed.

6. I have suffered too. Before being aware of the terrible consequences of Courtenay's blood transfusion, I became pregnant but was devastated to lose the baby when I was knocked over in a tube station.

7. Once we both realised the dreadful implications of hepatitis C, it was irresponsible for us to try and have another baby so I feel that I have been robbed of any chance of a family life. When I think of what mine and Courtenay's life might have been, it upsets me so much, living in the shadow of this ghastly injustice is grim everyday.

8. The effect on me has been to turn me into someone I don't like being: an angry, bitter and disappointed person. I have huge anxiety over the suffering that Courtenay has had to endure and I have suffered the frustrating experience of sending appeals for help to every Health Secretary and being fobbed off with weasley letters and obfuscation. We have been ignored and treated like pariahs. It has been a case of "blame the victims" as if it was our fault that unscrupulous doctors inflicted contaminated blood on victims without giving them an informed choice.

9. One of the worst aspects has been to see how my husband who was a sports man with such positive life force and ambition has been ground down by this illness.

10. I feel that we have been stigmatised by the NHS and by the Government who have take 30 years to recognise that contaminated blood is a scandal. We have protested at the House of Commons, written letters and petitions and have been totally ignored and brushed off until now.

11. Some members of both of our families seem unable to cope with what we have been through and have stayed away, offering sympathy but little else.

12. Because of the virus and his poor health, Courtenay had to give up a promising career at Pinewood Studios as an Associate Producer. At the time he represented a group of photographers who valued his input and were very disappointed when he had to give up owing to ill health. The six months that Courtenay spent taking Interferon in 1994 finally resulted in Courtenay being unable to attempt any constant work again.

13. I have worked solidly for 52 years and now at age 74. I am still working albeit for very little recompense. Because of debts incurred and never cleared, the financial effect of this criminal action by the NHS has only accumulated and I will have to work until I become too decrepit to continue.

6. Treatment/Care/Support

1. In 1994 Courtenay commenced a course of Interferon. The mental and physical effects of Interferon were devastating. After six months of taking this treatment, Courtenay felt so terrible he wanted to be alone. He lost about 20kg, his personality changed and his mental state was very unstable. I remember that he was told by a Doctor at the Royal Free Hospital in London that he "wasn't very stoical" which sums up for me the lack of empathy from members of the medical profession about this disaster.

2. The Interferon was not effective and Courtenay was then without treatment again until in July 2015 when he commenced Anti-Viral Treatment for the hepatitis C infection with Ledipasvir / Sofosbuvir (Harvoni and Ribavirin). I understand that licensing of these anti viral drugs was held off by NICE for a long period when it would have been

much more helpful to Courtenay if they had been made available earlier. Courtenay was cleared of the HCV (hepatitis C) virus on the 29th April 2016 after 33 years. Unfortunately, the damage caused by the virus was irreversible.

3. Neither myself nor Courtenay have ever been offered any counselling or physiological support to deal with what has happened to us.

7. Financial assistance

1. The process of applying for financial assistance has been made extremely difficult for people like Courtenay. Courtenay suffered from brain fog as a result of his illness which made it very difficult for him to understand and apply for any help. In addition, having to go through the details of a tragic and sad past has a very lowering effect on the mood of somebody already affected with anxiety and depression. Also, it is assumed that all applicants have a computer and are able to use it which is not always the case. It seems ironic to me that the latest fund is administered by the NHS themselves who are ultimately responsible for the ghastly position of the victims and applicants.

2. From the various meetings I have attended, I gather that there have been a lot of complaints about the means testing of people who should not have to prove their right to benefit from the funds. I believe the organisations were mostly funded by a discretionary charity rather than the Treasury. As that money does not belong to the Government, I cannot see the justification for means testing. We are now onto the fifth or sixth organisation that are tasked with handling the distribution of the legacies. I can only assume that some of the others failed by mismanagement or worse. I may be naïve about this but a lot of the funds must have been used for administrative salaries and one questions what the value of these legacies could have been to the victims if handled in a different way.

3. I have never received anything from any of the funds. I have never applied for financial assistance and I do not know whether or not I am eligible.

8. Other issues

1. When I have heard it said by Politicians and Medical Professionals that Doctors did not know at the time of the effects of the pooled blood given in transfusions, I would like to mention two instances that disprove this justification. Firstly, in 1965, I was on holiday in Athens and the friend I was with ran out of money and decided to sell her blood. Since we worked as Lab Technicians in a Biochemistry Department in Newcastle General Hospital, we were shown around the Laboratories. However, they would not take her blood as she told them she had in the past suffered from jaundice. Such a basic precaution, I cannot understand why this would not be taken in the case of my husband.

2. Secondly, in 1978 I was working in a Radioimmunoassay Laboratory at the Royal Victoria Infirmary in Newcastle when a blood sample came into the lab that was handled by one of my colleagues who was a Doctor. The Ward was negligent in that they did not label the sample as dangerous as the patent had hepatitis. Had they done that, the Doctor would have worn a mask, gloves and a gown before handling the blood sample. As it was, he developed hepatitis and was extremely ill for several months.

3. My point is that it has always been known that blood is a dangerous substance and should be used circumspectly which is why it was hard to believe that anyone from the medical profession would knowingly administer pooled blood from abroad to patents.

4. 35 years on it is hard not to feel somewhat resentful when other groups such as Grenfell and Windrush are (justifiably) offered immediate help,

sympathy and promises of compensation whilst it has taken 30 years for victims of the contaminated blood scandal to even hear an apology. In fact, for Grenfell, after only a year an Inquiry was promised. It has taken us more than 30 years to achieve the promise of the same result and every other civilised country involved in the infected blood scandal has accepted blame, compensated the victims and dealt with those responsible.

5. Despite the apology from David Cameron and his brief acknowledgement that this was the worst ever scandal in the NHS, there has still been no move to adequately compensate the victims and their relatives who have suffered for more than 30 years incurring debt, being unable to work and not being able to live a normal life.

6. The affects of the contaminated blood are with us everyday. I have been robbed of the chance to have a family (which I view as an infringement to my rights under Article 12 of the Human Rights Act). Never a day goes by when I do not feel anxiety. Living in the shadow of this ghastly scandal is grim. Because of the financial problems caused by Courtenay being too sick to work, we have never managed to get ahead and clear our debts and apart from 3 years at college, I have solidly worked now for 52 years.

7. For years and years I feel that we may have been too passive. It took us all a long time to realise the enormity of the contaminated blood scandal and what happened and many of us misguidedly trusted that the Government would do the right thing and help us. I now realise what a mistake that was and I hope that the Inquiry takes seriously what victims have been through and seeks to put right the mistakes of the past and adequately compensate the victims.

Statement of Truth

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

Signed GRO-C ....

Dated...1 march 2019...