

Witness Name: Courtenay Hildyard  
Statement No: WITN2344001  
Exhibits: **WITN2344002-**  
**WITN2344006**  
Dated: 12<sup>th</sup> February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF COURTENAY HILDYARD

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

I, Courtenay known as Courtney Hildyard will say as follows:-

#### **1. Introduction**

1. My name is Courtney Hildyard. My date of birth and address are known to the Inquiry.
2. I intend to speak about my infection of hepatitis C (HCV) which I contracted from infected blood products in 1983.

#### **2. How Infected**

1. Apparently I suffered a bleed following circumcision whilst a baby in Salford, Lancs and other than suffering from nose bleeds throughout my childhood I had few problems. Growing up in North Yorkshire I pursued an active, adventurous life as did most of my peers in post war 1940's rural England.

From an early age I was passionate about sport particularly cricket and roller skating. The natural world, bird watching, scouting and farm work constituted a large part of my early life and teenage years.

2. Nose bleeds were a part of my life and later on in the 1950's bleeding as a result of tooth extraction caused problems. It seems to have been sufficient to describe me as a "bleeder" and a diagnosis of haemophilia does not seem to have been an option. Perhaps because my mother had also had bleeding problems and at that time it was not thought that women could be haemophiliacs and only carriers of the gene. In the 1950's I was selected to represent my Grammar School at rugby, hockey, badminton and athletics. I acted as captain of the hockey and badminton teams in my final year and selected to play roller hockey for the England junior and later senior teams.
3. In 1963 Dr T J Muckle diagnosed me as having a low adhesion platelet figure and this has been largely overlooked since the diagnosis. Intending to study medicine I moved to Newcastle in the 1960's but instead started to work in the Pathology Department at the Royal Victoria Infirmary. In 1970 I suffered a prolonged bleed following dental extraction at the Dental School in Newcastle. Following investigations by Dr Boon of the Haematology Department I received a diagnosis of von Willebrands Disease with low Factor VIII and reduced platelet adhesion. I am issued with an identity card to that effect. I work until 1973 in the Biochemistry laboratory at the RVI (Royal Victoria Infirmary) as a Senior Technician.
4. In 1973, having sold my first house I was able to pay cash for a large terraced house in Jesmond which is to become the start of my property portfolio. As a result of my supposed abilities as a roller skater I am offered work on the film 'Rollerball' and after six months in Germany I continued to work in both the Film and Advertising industries. I returned to Newcastle in 1976 in order to marry Anne who I met when we both worked in the NHS. Anne is now working in research at the RVI.

5. Between the years of 1979 and 1982 Anne was back at University to complete her second degree whilst I sold our properties in Newcastle. Our plan was to buy property in London where it was still possible to acquire a house for under £20,000 in either Islington or Highbury. We were able to dispose of our Newcastle holdings for over £100,000.
  
6. An investigation in 1977 concluded that I suffered from an extremely mild form of haemophilia A and not von Willebrands disease as originally thought. I was issued with another identity card confirming the diagnosis. On 26th October 1981 I had an operation to remove a spermatocoele thought to be the result of a sports injury. After reviewing my own medical records these show that I was treated with Factor VIII on the morning of 27<sup>th</sup> October 1981 and cryoprecipitate the evening of the same day. Exhibited before me at WITN02344002 is the page from my hospital records detailing the transfusion.
  
7. Anne obtained her degree in 1982 and is employed as a Craft Instructor working with the mentally ill. I established a commercial photographic studio in Newcastle (The Picture Company Ltd) and the first truly independent contemporary art gallery in the North East (Gallery 7). At this time Anne and I were happy and enjoyed life.
  
8. We owned a 1930's style apartment in Newcastle in 1983 (Eskdale Mansions) and after several years have succeeded in persuading the Forestry Commission to release a 17<sup>th</sup> century farmhouse on the edge of the Yorkshire Moors. Exhibited before me at WITN02344003 is a photograph of the farmhouse. We succeed in the purchase at auction and paid cash for the house and land. Our plan was to settle there and raise a family whilst owning rental property in the city. Our dream home that we would never be able to live in albeit the struggle to hold onto the house has dominated our lives for the last thirty five years.

9. In June 1983 I complete the Newcastle half marathon and was approached by the Public Relations officer for Newcastle City Council, Roger Neville, with a request to evaluate a local park, Jesmond Dene. The park was a proposed venue for a roller skating spectacular. I was approached as a result of my supposed reputation as a competent roller skater. Jesmond Dene is a steep sided valley with a wealth of narrow paths linking the different levels and quite unsuitable for large scale public activity. This I found to my cost after discovering Council repair work in the form of an unmarked excavation concealed around a bend on my chosen route down the valley.

10. I sustained minor injuries as a result of the fall just a badly bruised hip and knee but this resulted in a visit to RVI as my knee was badly swollen which I presumed to be the result of a joint bleed. Peter Jones, who was the consultant in charge of the Haemophilia Department at the RVI, admitted me for treatment and advised the transfusion of a coagulant. I assumed that he meant blood and on that basis I refused treatment. Blood, like all bodily fluids, is only as clean as the donor is healthy and transfusions should, in my opinion, be considered with some degree of caution. My years in the NHS had taught me that a cavalier approach was sometimes prevalent. My own solution would have been complete bed rest and cold compresses.

11. Peter assured me that his treatment was perfectly safe and on that basis I agreed to the transfusion. I was aware that a product was available that is not sourced from humans which I now know to be DDAVP (Desmopressin). Before treatment Peter asked the nursing Sister, Maureen Fearn, to confirm that I have not been treated before and this request has since provided food for thought. After reviewing my own medical records they show that I was in fact treated with a number of units of cryoprecipitate. Exhibited before me at WITN02344004 is the page from my hospital records detailing the transfusion. I underwent a minor operation to exclude infection, although it seemed to me that I suffered a bleed only and the transfusion caused a mild reaction. After a week or so I was allowed to go on holiday to a friend's villa in Portugal for three weeks in the care of my wife with my leg encased in a splint. Whilst on

holiday I became ill and develop jaundice and managed to spoil everyone's holiday.

12. On my return to Newcastle, non-A, non-B hepatitis was confirmed as the culprit and my transfusion as the cause. Unable to work for over a year I lost my photographic studio and the gallery narrowly avoided bankruptcy. Sam Wallace, my Bank Manager at Lloyds in Newcastle who has been transferred to Head Security in the North West returns to find me a changed man. To the department threatening me with bankruptcy he sent a note asking "what have you done to this man, when I left he was a rising star?"

13. Peter Jones assured me that I would make a complete recovery and would have no further problems. Naively trusting his prognosis and desperate not only to recoup our losses but to restore some semblance of sanity to our world we returned to London under the illusion that all will be well. We were in shock when Anne became pregnant but aborts when struck by a metal briefcase wielding commuter. We did not discuss this further as our financial situation and my health raised questions as to our future.

14. With some difficulty I managed to renew my union membership and resumed work at Pinewood Studios. Anne worked initially as a freelance home economist in advertising and TV commercials before becoming Food Editor for Woman Magazine and Advertorials Editor for BBC Good Food and M&S Magazines. We were told that I am HLTII negative and therefore should be pleased. This did provide huge relief even though the true significance was not fully appreciated at the time.

15. Over the next few years I returned to see Peter Jones on several occasions even though we were living in London and I continued to feel unwell as if I still had hepatitis. I am reassured by Peter Jones that my blood chemistry results are normal except for a slight rise in enzyme levels. The meaning of this is not explained nor do I think to question the fact.

### **3. Other infections**

1. In 2002 I had septic arthritis in my left knee. Over the years my troubles have stemmed from injuries to my left knee. I was in Whittington hospital in London for 2 and a half months and it took a long time for me to recover from this. I survived thanks to the amazing medical staff who believed my hepatitis had diminished my immune system so much that I became vulnerable to a disease that normally attacks people who are much older than me. During my stay in hospital our cottage was once again emptied by burglars.
2. A supposed liver cyst was being monitored for a number of years and raised AFP was noted after I had an operation to repair a severed artery on my head. In 2015 I had a transarterial chemoembolization (TACE) procedure of (HCC) liver lesion. Following this at the end of 2015 I had an operation at Newcastle Freeman Hospital which was an LAT assisted ablation of (HCC) liver lesion. In June 2018 I was recalled from the Inquiry opening by my consultant Stuart McPherson to discuss suspect scan findings and raised AFP enzyme levels. My liver lesion has resumed activity and required further ablation therapy. The operation is not possible until December so I was considerably concerned at the delay.
3. The operation was arranged for the 18<sup>th</sup> December 2018 and I was put under general anaesthetic for it to take place. When I came around from the anaesthetic I was told that the operation was not possible as the tumour had moved into my Portal vein. Thankfully I am cared for by a dedicated team and SIRT surgeon, the excellent Dr Peter Littler, who scramble over the Christmas period to acquire radioactive Itrium beads to implant around the tumour (SIRT procedure).
4. On the 18<sup>th</sup> January 2018 the SIRT procedure was completed and the beads installed into my liver in an attempt to destroy the errant cells. I remained in isolation for 2 weeks to prevent radiation exposure to others. It has been a difficult 3 weeks since then and I am having hospital check ups every week. I

am currently awaiting my CT scan which will take place 3 months post SIRT procedure to confirm it has been a success or not.

5. It is my understanding that some years ago the NHS requested NICE to delay the release of Harvoni, the drug that has released so many of us from the curse of hepatitis C (HCV), because the NHS did not have sufficient funds. It was during this time of delay that my cancer was discovered, treatment of which was delayed pending the availability of the anti viral drug. I understand that at the same time insurance companies in the USA were giving out Harvoni "like sweets" obviously realising that, unlike our miserly Government, the financial logic in a decision that would reduce expensive treatment in the future.

#### **4.Consent**

1. I was certainly tested without my knowledge. I was certainly tested for HIV in the mid 1980's which I only came to know about when I received a letter to tell me that I was negative.
2. Consent wise I didn't want the blood initially and had no reason for it. Peter Jones lied to me as I thought it was a manufactured product. I would not have allowed the transfusion to go ahead if I had have known what blood I was receiving.

#### **5.Impact**

1. Peter Jones informed me that my Factor VIII levels were normal in 1986 and I could consider myself 'cured' and was removed from the haemophilia register in Newcastle. Exhibited before me at WITN02344005 is the letter where Peter Jones describes me as cured. We feel somewhat isolated as a result and believe that it indicates a certain abdication of responsibility; Anne and I have become aware that we are not cognisant of all the relevant facts surrounding my treatment. We become involved in litigation being assembled

by a firm of solicitors, Mallen and Souter, in Newcastle where a whole generation of young haemophiliacs have been lost. I was refused legal aid as a result of a medical report by Dr [GRO-D] who states that I was treated with Cryoprecipitate which he believes to be the correct treatment. He also stated that given my alcohol consumption I would have succumbed to liver disease in any case. Where the latter conclusion comes from is a mystery given that I have only ever consumed alcohol (wine and beer) in moderation and have been teetotal for most of the last thirty years. As an additional aside Dr [GRO-D] is now Medical Director (haemophilia) at Pfizer Europe a USA pharmaceutical company.

2. At a juncture in my life in the early 2000's when it seemed that all I value in life was lost I manage to rub salt in the wounds by studying to become a counsellor, a painful but rewarding process. Our financial situation took a turn for the worse when the National Westminster Bank Insurance Company refuse to honour payment on policies for our mortgage and bank loans on the grounds that the serious nature of my illness was known when we signed the agreements. To our minds their decision was made with the benefit of hindsight and we signed in good faith. We had been told that my illness was not a serious one and that I would make a complete recovery and that I no longer suffered from haemophilia and was cured according to Peter Jones.
3. I was unable to access any financial help and given that I became so difficult to live with Anne and I agreed to separate in name alone, sadly this has become a reality with time. Anne has continued to give me total unconditional support for which I will be forever grateful. For the duration of my treatment I lived at our house in the country without mains electricity and 6 miles from civilisation.
4. In comparison to the other sections in my statement the impact section is much shorter. This doesn't mean I haven't been impacted by the infection it's quite the opposite. I find it very difficult to talk about the emotional impact of

receiving contaminated blood and am in denial about it. I try not to think about it and push it to the back of my mind.

## **6.Treatment/Care Support**

1. My business had begun to make some financial sense when in 1993 I collapsed and am unable to work. My GP, Dr Anna Skalicka, instigated an investigation into my hepatitis as at this time it had become possible to identify which hepatitis virus I had contracted. Blood analysis indicated high viral activity and confirmed hepatitis C (HCV) which was previously known as non-A, non-B hepatitis. It was apparent from results obtained by my GP from Newcastle that my liver enzyme levels had gradually increased throughout the eighties. Had we been made aware of the significance of these findings and the true state of my health we would certainly not have left Newcastle and the outcome could well have been very different for us.
2. In 1994 I was referred to the Hepatology Department at the Royal Free Hospital in London. In August I commenced a six month course of Interferon on the basis that the chances of success of the treatment were between 25% and 40%. We discovered that in reality this means less than 10% for someone with such a long standing condition and of my particular genotype.
3. Interferon has many facets to its side effects hence this was a time not without its moments and accidents. A dislocated shoulder and a fractured scapular had some connection to the effect on my mental and physical faculties. After a dreadful 6 months and a long haul to recover from the treatment I can only agree with a veterinary surgeon we meet who describes that he 'would not give Interferon to a dog; it is a drug looking for an illness to cure and that illness is not Interferon.' My treatment did one thing for which I am grateful; it put an end to any ideas I might have had about continuing my work. I doubt that I would have had the common sense to stop without Interferon treatment but would have worked myself to an early demise.

4. My GP in London referred me to the Haemophilia Department at the Royal Free Hospital for investigation in 2003. I saw Professor Christine Lee who obviously did not believe a word I say regarding my history given that my "blood results are normal and whatever the nature of the bleeding disorder it does seem to have resolved and we can be sure of that." Subsequent correspondence in my medical notes between her, Peter Jones and my GP support my initial concerns and give me cause to question my diagnosis and subsequent treatment. There is no evidence of a response from Peter Jones in my records. Exhibited before me at WITN02344006 is a letter from Professor Lee to my GP. Professor Lee has recently tried to justify 'the use of contaminated blood products as haemophiliacs were not expected to live longer than 20 years without the use of these products.'
  
5. In 2006 I was referred to see the dedicated Dr Pratima Choudhry at the Royal Free Hospital in London as I had an impending tooth extraction. I was told that although I did suffer from haemophilia it was no longer the case. I did, however, still have a bleeding problem with a low platelet adhesion that even after further tests they were unable to identify.
  
6. Attempting to do work that I was not up to I have had a number of accidents since 2007 which have led to operations. I was doing repair work that I was not physically capable of doing have been doing on houses to try and move them along to sell them. One operation was in January 2014 where I had a traumatic pseudo aneurism embolization after a builder dropped a trowel on my heads during house renovation work and in my medical records it is noted that I had raised alpha feta protein levels (AFP) again in 2014.
  
7. In July 2015 I commenced treatment for 6 months for the hepatitis C (HCV) infection with Ledispavir/Sofosbuvir (Harvoni) and Ribovrin. This was undertaken at the Freeman Hospital in Newcastle under the consultant Dr Stuart McPherson and Sister Caroline Miller. On the 29<sup>th</sup> April 2016 I received confirmation that the hepatitis C (HCV) virus had cleared after 33 years!

8. In January 2017 I was admitted to the RVI with LVSD and MR and arrhythmia suspected to be exacerbated by long term infection. I commence my first long term medications of my life; beta blockers, ace inhibitors, anti-coagulants and diuretics. I have since stopped all medication as it was making me a zombie and they were deadly.
  
9. I certainly haven't received any form of psychological support or counselling over the years and this would have been of benefit to me.

### **7.Financial Assistance**

1. My wife Anne, from whom I have been separated for 20 years, continues to provide support and encouragement for me. Hepatitis destroyed me financially, physically and mentally and I became impossible to live with. In order to help me remain solvent Anne has now placed her home on the market along with the farmhouse which we paid cash for only months prior to my being given hepatitis and a home we have never been able to live in. Both properties are now heavily mortgaged.
  
2. A great deal of money has been spent over the years trying to work and stay afloat and update property that I was unable to manage but have been forced to sell. Unable to access bank loans I have juggled credit card 'interest free' loans the tune of over £40,000. I no longer have the ability or indeed the heart to continue this process and am in the process of instigating insolvency proceedings. For me this is not good news. I have given my all since 1983 to avoid bankruptcy and to bring back some security for those who are dear to me.

### **8.Other Issues**

1. It has never been admitted that it was a known fact within the NHS that blood collected in the USA offered a potential health risk. The fact that the dangers would be multiplied many thousands fold following fractionation have been ignored. The claims by USA pharmaceutical companies that their products were safe were never challenged and there was no test in existence that could prove or disprove their assertions. At least 3 USA companies have since admitted that they lied about the safety of their products.
  
2. No one person has been asked to justify the import of blood known to be contaminated nor to explain why strict guidance rules were not implemented for the use of Factor VIII concentrate. The company Cutter Pharmaceuticals even labelled their product to the effect that it was assumed infection would result from transfusion. Evidence from the early 1970's recommended that Factor VIII 'should only be used for the treatment of severe haemophiliacs in life threatening situations.' If this advice had been adhered to the claim that there was insufficient product available in the UK was invalid and as such the reason to import these products.
  
3. In 1972 I had worked in the NHS laboratories service for 10 years and was employed as a senior technician in the Biochemistry Department of the Royal Victoria Infirmary. The Regional Blood transfusion service was situated two floors below the Pathology Department in which I worked. Every day donor attendants and technicians would be dispatched to various centres to collect blood. All the personnel carriers and storage vans were emblazoned with the logo 'A GIFT OF LIFE'. Blood for use in the General Hospital was ordered from the Transfusion Centre by the hospital haematology laboratory, tested and released to the wards as required.
  
4. To many of us working in hospital laboratories the Blood Transfusion Service was a thing of pride and was thought to be the envy of the world. Donors were all volunteers and safeguards were in place to ensure no one who suffered jaundice could become a donor. In contrast blood collection in the USA was considered at best to be second rate by the mode of its collection

and the spectrum of donors used and was thought to carry a considerable risk to the health of any recipient; we thought of it as "Skid Row blood". Donors were paid and often came from poor disadvantaged communities where sickness and drug use were rife. These observations relate to whole blood fractionation to produce cryoprecipitate requires few donors and is relatively safe. The production of Factor VIII concentrate has been claimed to require up to 10,000 donors and some say even as many as 60,000 donors.

5. In 1983 the then Public Health Officer for the UK, Spence Galbraith, requested that all blood products from the USA should be removed from NHS hospitals. At a meeting with the Advisory Committee this request was declined. Once again those attending the meeting include medics from Porton Down; haematologists like Dr Charles Rizza who was involved with pharmaceutical companies, DOH and NHS officials and most of the details of this meeting have been removed.
6. In the 1980's Dr Charles Rizza openly advocated the use of 'previously untreated patients' (PUPS) at the Oxford Centre, 'in order to evaluate the infectivity of blood products.' He has since changed his tune and insists that all patients were informed of the potential hazards of treatment. Charles Rizza was also a member of the specialist committee that monitored the import of blood products from the USA in 1973.
7. I received my hospital records from Freeman Hospital in December 2017 and for the first time I found out that it would appear that I was treated with Factor VIII on two occasions in 1981 and 1983 not Cryoprecipitate as previously believed. As per the Lancet Report in 1975 and the Journal of Haematology Factor VIII was intended to be used only for "the treatment of severe haemophiliacs in life threatening situations." We presume that this referred to UK products only at a time when drug use was low in society but the simple logic of numbers involved in the process of fractionation were inescapable. If these guidelines had been implemented by the DOH (Department of Health) and the NHS thousands of lives would have been saved and much suffering

avoided. As my statement shows I certainly wasn't a severe haemophiliac and for a number of years before treatment I was told that I wasn't a haemophiliac at all so there was certainly no reason for me to be given Factor VIII. My recently acquired Haemophilia Transfusion records show that one of my two treatments with Factor VIII have not been recorded. The transfusion from 1983 is missing from the National Record.

**Statement of Truth**

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

Signed. **GRO-C**

Dated. 12 February 2019.