Witness Name: Lesley Brownless
Statement No: WITN1111001
Exhibits: WITN1111002- WITN1111007
Dated: 21 November 2018

WRITTEN STATEMENT OF LESLEY BROWNLESS

INFECTED BLOOD INQUIRY

Introduction

1. My name is Lesley Brownless. My date of birth and address are known to the Inquiry. I was diagnosed with Hepatitis C (HCV) stage 1 in 1995.

2. At the moment (November 2018) I live with my husband and my son, Luke. My daughter moved out in November 2018 with her young baby. She left her dog with me and I have a dog of my own. I miss both my daughter and my grandson already. It had been quite a busy time having them back living with us as we had no space, but I loved having them with us; we all did. It has been a difficult time for my daughter recently, but she is settled now so that has made me feel really happy. My other daughter recently found out she was pregnant, and so we are all excited about another new addition to the family.

How I became infected

3. I suffer with mild Von Willebrands disease, and therefore, occasionally received blood products, which is how I became infected with Hepatitis C and am at risk for Vcjd. I was given numerous types of blood products, different types from two different hospitals. **(WITN1111002).**

4. I received blood products at Newcastle Royal Victoria Infirmary (RVI) around 1970 up until 1975 and then Leeds St James University Hospital from 1975 onwards to the present day. Treatment was generally given as a precaution for pre-planned minor surgery and nose bleeds.

5. I do not have my medical records from the RVI Newcastle but I do clearly remember having two minor procedures in July 1975; one was a tooth extraction and the other one was the removal of a facial mole **(WITN1111003)**. I have got all my haematology records from Leeds St James.

6. I can remember that when I was a child I sometimes suffered from nosebleeds. Von Willebrands disease means that your blood clots however the clot does not stick to the wound. Von Willebrand factor is a bit like the glue that helps the clot form a plug over a wound. It has been described as similar to having mild haemophillia. I have a mild bleeding disorder.

7. I was never told of any risks associated with receiving blood products. As an adult from the time that I could consent to treatment/procedures myself, I was not warned about the risks of receiving blood products. I started receiving blood products around the age of 10. I remember if I had a nosebleed my mum was told to take me to hospital. It was hard for her as she was a single mum and I had 2 siblings. We did not always have access to a car.

8. My mum would telephone staff at the hospital to say that I was having a nosebleed and she would be told to telephone an ambulance. She would then have to get my brother and sister out of bed (as it was sometimes at night) and take us all to the hospital. I understand that after my mum spoke with staff, blood products would be removed from the freezer to give it a chance to defrost whilst we travelled to hospital. More often than not my nose would stop bleeding while we were in the ambulance. When we arrived at RVI I would be given the blood products even if my nose had stopped bleeding.

9. At no time was my mum told about any of the risks or infections associated with blood products or blood. If she had been warned of the risks she would not have let me receive the blood products because my disorder was not life threatening or even that serious; there was no way she would have put me at that risk of harm, but no one told her anything about the risks.

10. No advice was given to my mum prior to any treatment I received when I was a child and no advice or warnings was ever given to me as an adult. My mum has written a short statement to confirm she was never warned of the risks **(WITN1111004.**

11. No information was given to me then or given to me now. The treatment is all prepared and given to you. To be fair, I probably never knew what I was having. Looking back I used to have **Cryoprecipitate** and it is only in recent years that I have realised **Cryoprecipitate** was the frozen one and it was given through a drip. My mum told me that when I was a child I would have something in a second drip which was to counteract the cold.

12. I was diagnosed with HCV in 1995. I think I received contaminated blood products in 1985/86. I was 25 years old.

13. In 1995 I used to receive a bulletin from the Haemophilia Society, every quarter I think it was, with all sorts of information about what they were doing and general information. I can remember seeing on the front of it something with regard to at least 90% or something of people who have had blood products had been infected with Hepatitis C. It took a while, I don't know whether it was once or twice but then the penny dropped, that's me I thought – I have received blood products. No one contacted me personally to tell me about what had happened or to warn me directly. I was not contacted by my Haemophilia Centre to discuss the possibility that I had been infected even though I was a patient at the centre.

14. I went to the centre to enquire about HCV and they tested me. I went back to a clinic appointment and saw Dr **GRO-D** Consultant Haemotologist and was told I

was Hepatitis C positive. I was given very limited information and was led to believe it was all rather trivial and not to worry as all his patients were infected.

15. At future appointments he was rather flippant about HCV as if it was trivial; nothing to worry about and that I was worrying and being a bother about nothing. He made me feel as if I was a nuisance. Either he did not know the seriousness of the issues or he had decided not to tell me; to keep the truth from me.

16. I went away and did my own research. The information I found was very worrying reading. I had numerous appointments following diagnosis where bloods were done to check various levels. I was offered some treatment and also offered a liver biopsy. I asked if I needed them and Dr **GRO-D** replied with: *Well not really but it seems you won't be happy until you get something.*

17. Looking back, I remember thinking *am I just being stupid? Am I worrying over nothing?* I did not know what the prognosis was or what was going to happen to me and quite frankly I was terrified. Dr **GRO-D** had said all his patients had the virus, so I wondered if worrying made me silly. It makes you feel like that. The information was not out there as far as I was aware. Even my GP once said to me you probably know more about it than I do, but that is because I did my own research and found a little of the limited information available.

18. When I found things out I would ask questions at my appointments and say this is what I know about it and this is how I am feeling, but then medical professionals wrote things into your records that you had been surfing the web which just made you appear paranoid. It makes you feel bad doing that. I became so upset with the way the consultant was that I began skipping appointments; my records will show that with many entries stating DNA (did not attend).

19. I should have been given more information; I should have been kept informed. I should have been offered counselling to help me deal with the bombshell. Having Von Willebrand's disease was not a big thing in my life, it was mild and

you just got on with it. I had three little babies at that time and then this bombshell was dropped on me without me being offered any help or assistance.

20. At that point when I was diagnosed my children Robyn, Luke and Lucy were very young and I was not very well. Once the professionals were aware of the contaminated blood products and the risks of infection they should have called me; I was on their register, I saw people working at the centre and they should have known that and they should have told me what was happening.

21. This was a very dark time for me being a single parent of a 4 year old daughter and 2 year old boy/girl twins. I could not get my head around what would happen to them if I was to die and this led to great anxiety for a long time. I was never offered any form of counselling and was made to feel like I was making a fuss over nothing. I had been poorly for some time before diagnosis and things started to make a lot more sense, however due to little knowledge available to me about HCV it effected my mental wellbeing terribly. I kept thinking about HIV too and was adamant I did not want testing (although I was never asked) as I could not have coped during the weeks waiting for the results. I think the only advice I was given was to use condoms and don't drink alcohol.

22. I think I was infected in 1985. I had attended the A&E department at St James Hospital in Leeds with a painful neck, and they decided to treat it as a possible bleed. As a mild sufferer of Von Willebrands I was not prone to spontaneous bleeds like someone with Haemophilia may have been and looking back this could have been something as simple as a pulled muscle or something similar and did not require blood products to treat it. This was the first time I recall being given blood products via a syringe as opposed to through a drip. I even commented to the nurse administering it saying *I hope there are no Aids in that* to which she replied *no its all heat treated now*.

23. I also remember the product as being warm as it went into my system. Within 20 minutes of the infusion I broke out in hives all over my body and from this day on I have suffered from a chronic itch that I always described as coming from inside (my blood) and not from my skin.

24. I was not diagnosed until 1995 during which time I had three children. My first was born at the end of 1990. I now know, but I did not know at the time, that they had already tested me for HIV in 1985; I only found that out in 2008 or 2009. I have seen letters in my records from when I was pregnant with my first child in 1990 from the Obstetrician to Haematologist asking about my HIV. I had no idea that I had been tested for HIV until I got my records.

25. The lack of information either from the doctor or medical profession caused me to be more anxious because it caused me to do my own research and obviously some of it was true but also there was some scary bits as well which made me even more anxious. I wasn't well anyway so that added to it. Dr **GRO-D** played everything down. When I had appointment to discuss my liver function tests he would just sit and shake his head and say they are plum normal. Eventually I asked him what he meant by plum normal and he said well they are up and down, they are up and down, they fluctuate all over the place which I can see from my records now that they did. He said if they were climbing I should be more worried, but that being up and down was completely played down.

26. Once again I was made to feel that I was making a fuss over nothing. I am one of those people - I get anxious, I have to put everything in its place and know in my head that everything is OK and I am not going to die tomorrow, it is just the sort of person I am. Once I have things in place and deal with it I am OK. Your head is all over the place and as I said at the time I had three young children that could potentially be orphans if anything happened to me, I just kept thinking what do I do, how do I get this tidied up in my head.

Other Infections

27. I do not think I have contracted any other infections. However, I constantly worry as to what may be on the horizon that we do not know about. I know I am at risk of VCJD, which is a great worry. **(WITN1111005** I have suffered with various types of cancer. I believe that being infected with HCV increased the risk of me developing cancer and that risk eventuated.

Consent

28. I believe that I/my blood were tested without my knowledge or consent. I was told in 2008/9 that I did not have HIV. It transpires that I had an HTLV111 test in 1985 and the blood sample was stored and used for whatever purpose (probably research) in 1985/86 and 87. **(WITN1111006)** Why would they keep an old sample and re test it over the years except for the purpose of research. I was never told that I had been tested for AIDS.

29. I have got proof in my records that doctors tested me for HTLV3 which was negative which is for HIV. I was tested for that in 1985 only became aware of it in 2008 or 2009 and it was at the time I was having treatment, the consultant checked through my records and said it was negative. That is the first time I have ever heard it because I did not want testing because I could not deal with it in my own head to go through the 6 weeks' wait for the result.

Impact

30. The mental and physical effects on me through having been infected have been devastating. I have spent almost 30 years of my life on Anti-Depressants and pain killers. Not being physically able to get up each day and go to work and provide for my family was something I have struggled to come to terms with. I had a very promising career as an entertainer (singer) and had to give it up due to debilitating fatigue, pain and depression.

31. I also had a burning ambition to study law which I intended to pursue once my children started full time school. My quality of life was not as it should have been. I had 3 young children that I struggled to look after and without the help of my Mother, who eventually had to reduce her working hours to support me and my children I don't know how I would have coped.

32. Money was very tight so it was very rare the children could be treated to something special. So they missed out on not only my time but also from a

financial aspect. Even given the opportunity to have a rare day out I could never plan ahead as I never knew if I would actually have the energy to get out of bed.

33. I later went on to be diagnosed with Fibromyalgia which has very strong links (medically recognised) to Hepatitis C. Because of the stigma attached to being infected with a virus like Hepatitis C I could not share my fears with anyone except my immediate family (excluding my children). People could not understand why I could not work and thought I was probably just being lazy and living off benefits. That in itself was so hard to accept. If the opportunity arose for a new relationship it was difficult to decide when the right time was to tell that person, and if you felt you could trust that person to not tell others should the relationship not work.

34. I went through 1 year of treatment in 2008/09 at which point I achieved SVR. It was at this point I told my children of my infection. This all came at a cost. I had recently married in 2007 a childhood sweetheart who now lived in Canada. He came to live with me in the UK in September 2007 and I began treatment 5 months later. My mood swings were unbearable my hair fell out and pain became unbearable at times. It affected my skin and nails and teeth and had problems sleeping. I felt so ill during treatment that the marriage failed before it had even properly begun.

35. My new husband left in November 2008 and returned to Canada and I have never seen him since. We divorced a couple of years later. GRO-C

GRO-C

GRO-C

36. The treatment itself was grueling. I was given a little booklet when I started treatment that did not prepare me for what was to come. It listed some minor side effects to expect. I was never told about any long term side effects that may occur. I was told the effects during treatment would subside once treatment had

finished. This did not turn out to be the case. I felt worse than before I started treatment and still do to this day.

Treatment/Care/Support

37. I did not have trouble accessing treatment.

38. I was not offered any counselling. I wish I had been offered counselling because I believe that it could have been very helpful at a very distressing time.

Financial Assistance

39. I initially received the £20,000 Skipton fund payment and after paying off debts and replacing some much needed household items I had enough to take my children on their first holiday abroad. We had a lovely time however it was marred with the realisation that it was a one off holiday. Had I been able to work we would have enjoyed annual holidays making lots of memories. I wrote to Tony Blair on 26 March 2001 about the impact of HVC, however I never received a reply **(WITN1111007).**

40. When Caxton was established in 2011 I received a visit from Rosamund Riley and another member of Alliance House. They came with a check list and I was allowed some help towards a 3 piece suite (£500 only) a washing machine and some repairs I needed doing at my home. I really did appreciate that. They also offered to help with some credit card debts I had run up whilst putting my kids through college.

41. This did not come easy. It took that many months to help with the debt that by the time they would pay it the debt had almost doubled as I was borrowing to pay the original debt. They were trying to negotiate with my creditors a reduced fee for settlement. I was so worried it would affect my credit rating for the future but they insisted I went through that process. If they had of paid the amount agreed in the beginning I would have been debt free.

42. There was a precondition that I had an appointment with a money advisor who wrote a report to them stating there was nothing they could really advise because I had too much outgoing to income. They sent me back to the money advisor a second time when I asked for help.

43. My washing machine payment was made in £10 vouchers; I had to stand and count the vouchers out in the store. This was so degrading I actually cried afterwards. The repairs I needed doing had to be decided once I got 2 quotes. When the job was done I had to produce a cheque to the tradesman. The cheques had Caxton Foundation printed on them and all it took for them to find out who they were was to google the name and realise I must be infected with HCV.

44. Can you imagine asking for a clothing grant and having to get 2 quotes for everything for myself and the children. 2 t-shirts 6 pairs of socks 1 nighty and yet they always had a set amount they would give anyway so I could never understand why they would put people who were ill through this kind of trauma.

45. They had guideline amounts they were prepared to give but they refused over and over to make this information available. Then after all this I had to send in copies of all the receipts. It was so time consuming and difficult considering brain fog and problems concentrating were some of the symptoms related to the Hepatitis C.

46 During a meeting with the CEO Martin Harvey he told us we were welcome to call into Alliance House if we were in London to see how they operate. Some months later we (a group of us in London for a meeting regarding Contaminated Blood) did just that and were made to feel very unwelcome. Martin Harvey was no longer there due to ill health. The staff publicly stated we were intimidating and they were tempted to call the police. I myself was mortified that they would stoop to these levels to the very people they were paid to help.

47 I always had grave concerns as to how much money went on paying Alliance House staff along with running costs as opposed to money actually spent on helping victims.

Other information

48 I need to know why this was allowed to happen, who sanctioned it and why. I also need to know why this has been covered up for all these years and why have victims been treated with the contempt that they have by all professional bodies involved.

Statement of Truth

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

Signed GRO-C

Date 21/11/18