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Witness Name: Ian Joy
Statement No.: WITN2175001
Exhibits: WITN2175002-008
Dated: 11th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF IAN JOY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Ian Joy, will say as follows: -

Section 1. Introduction

1. My name is Ian Joy. My date of birth is GRO-C 1975 and my address is known to the inquiry. I am married to Nicola Joy. I intend to speak about my experience of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

2. I suffer from Von Willebrand's disease. GRO-C GRO-C. It is quite mild and it just means that my blood clots slower than most peoples but it still clots. I normally received

clotting factor as a precaution. The purpose of giving me clotting factor was to assist when getting an operation in order to make sure that I did not bleed excessively. I had no day-to-day issues due to my Von Willebrand's disease.

3. I cannot remember the names of the blood products that I received. I was 9 or 10 when I received them prior to a hernia operation. My parents, Frances and Michael Joy, will remember the details. I just know that I received clotting products on that occasion.

4. I was treated at Dundee Royal Infirmary. I have no recollection whatsoever of this, this is just what I have been told by my parents. Also, when I was informed that I had hepatitis C, this was because the medical staff knew that I was at risk and they wanted to do tests. However, I do not remember the names of any doctors.

5. I know that I received infected blood products in around 1985, at the time of my hernia operation. It must have been in the autumn, but I cannot remember clearly. There is a letter in my medical notes dated 4th October, 1984 that relates to this and I can produce a copy of this letter in evidence and refer to it as **WITN2175002.**

6. The only time that I am aware of receiving blood products is that particular time. I had other operations, but I cannot remember if I had blood products. I had operations later on when I required to be treated by a dentist, or when a lump was removed from my head when I received products but I am not sure of whether these blood products were actually blood based. I am more aware of my hernia operation because in 1996, I was asked to come into Ninewells Hospital in Dundee and this was because the medical staff there were aware of people having become infected with hepatitis C from a batch of blood products and I had received products from the batch. That is how they knew that I was at risk. There was nothing else special about the clotting blood products that I received at the time of my hernia operation

when I was nine or ten years old. The only thing special about it is that the medical professionals who treated me managed to identify the batch that contained infected blood products.

7. My parents and I were never warned that there might have been any risks attached to receiving clotting blood products. My mother will remember that blood products were recommended to them. I was not involved in this at the time of my hernia operation as I was 10 years old.

8. I found out that I was infected with hepatitis C when I received a phone call and was told that I was at risk of infection with hepatitis C and HIV. I then went to hospital for tests. Later on, I returned to Ninewells Hospital to discuss the results of those tests. This was in 1996.

9. I produce a letter in evidence dated 11th November 1998 from Doctor Porter-Boveri referring to me having genotype 1a and identify it as **WITN2175003**.

10. At the time when I was told that I was infected with hepatitis C, the doctor spoke quite extensively about what that meant and gave me leaflets. He either gave or recommended a book to me. He told me to read everything and come back to them with any questions I might have. The medical professionals that dealt with me were really good. I remember that June Ward was the haemophilia nurse. I cannot remember the doctor's name as they changed quite often. I was informed of the nature of the virus, how I had contracted it, how it would affect my liver, how the impact of the infection was different for different people, as some people get tired but some do not. I was told to be careful with my diet, with alcohol as it could affect the liver and cause more damage, and that the infection could be contracted only through blood to blood contact and not just by having sex. I remember asking several questions about whether I could still have children. I also remember that toothbrushes, needles and razors were all discussed,

as were the matters of open wounds and cuts. There are letters in my medical notes regarding my hepatitis C status. I produce these letters in evidence and refer to them as **WITN2175004** and **WITN2175005.**

11. I believe that I was given enough information to help me understand and manage the infection in my day to day life. The medical professionals who dealt with me made me aware that they were there for support. They were also open about the fact that the infection had come from that batch of infected blood products, they did not deny this.

12. I never thought that the medical professionals who dealt with me might have known about the infection any earlier than they did. I think it is a possibility, but the thought has never crossed my mind. I assume that I was told about the risk of infection as early as possible.

13. I do not really have any views about how the results of the tests and information about the infection were communicated to me.

Section 3. Other Infections

14. I do not think that I have received any other infection or infections other than hepatitis C as a result of being given contaminated blood products. I was warned of the risk of CJD and I think that they did more tests on that as well as on HIV. However, I cannot remember what they said about CJD. I think that I received a letter at some point that said that there had been instances of it, but that they knew that I did not have it.

Section 4. Consent

15. I do not think that I have ever been treated or tested without my knowledge, without my consent, or without being given adequate or full information.

16. I am aware that I have been treated and tested for the purposes of research, but I have always been asked for consent beforehand. I have taken part in trials of treatment and they made it very clear that it was a clinical trial and might not work. This is the only time that I have been aware of having been treated or tested for research.

Section 5. Impact

17. Becoming infected with hepatitis C had a series of mental and physical effects on me. Physically, I never noticed any difference due to having hepatitis C, but I would not know as I had been living with it for quite some time by the time that I was told that I was infected. However, I was never tired or lethargic. I was always fit and healthy. Mentally, it was more challenging. There were many issues which affected my life choices such as not being able to do contact sports. I used to do skateboarding and cycling and due to being infected, I did less or had to do these sports is in a safer way. I could not do martial arts. There were many things that I wanted to do but could not do. This had a large mental impact. Becoming infected made me not want to go out and do certain things. It turned my life upside down and caused me a lot of stress. I felt that I had to keep it a secret. When I was told that I was infected with hepatitis C, my girlfriend at the time broke up with me, as when she told her parents that I was infected they did not want me being with her anymore. That breakup was bad and had a negative impact on me. We had been together for approximately two years by the time that she broke up with me. Part of the problem was that people were scared and unwilling to believe the information that I provided about hepatitis C.

18. I had no medical complications due to becoming infected with hepatitis C. Some scarring was found in my liver tissue but it was not very bad, although it was not great either. It did not have a day-to-day effect, but I felt that I would not be able to have children and I was going to die young, too. I assumed that I was going to develop cirrhosis as well.

19. I received two courses of treatment in order to treat my hepatitis C. The first treatment was a combination of interferon and ribavirin. I had this treatment in around the year 2000. There is a letter in my medical records which gives details of when I was on the treatment. I produce this letter in evidence and refer to it as **WITN2175006**. Back then, I had to move in order to have the treatment as I was living in the West Coast of Scotland and I was told that I would require family support because the first few months would be really bad. I was on that treatment for a year. The treatment made me feel really tired, I had no energy and did not want to go out or do anything. I also felt very grumpy, very intolerant and very miserable. I was physically sick for the first 3 to 4 weeks. However, I experienced no hair or tooth loss. Six months after starting the treatment, I became clear of hepatitis C and was told that either I was clear or the virus was undetectable. It then came back again or the treatment never really worked, as testing had a limitation on what it could detect back then.

20. The second course of treatment was interferon and telaprevir together. This must have been in 2011. The effects were similar to the effects of the first treatment, it was hard but I do not think it was as bad as the first time. However, it made me very intolerant, especially with my children. I would say that we were more prepared for it, as we already knew what it had been like before. I experienced many mood swings and was maybe feeling close to depression although I never got any treatment for this. This was the last treatment that I was on and it was successful. The treatment lasted for a year and after a few months it went well and that is when they knew that, if I was clear after 12 weeks then I was likely to stay clear. However, I did not believe that I was actually clear until two or three years later.

21. The treatments did not cause any medical complications for me.

22. One of the obstacles that I faced when having access to treatment was that the first time around, I required to move in order to have the treatment. I was always treated at the hospital in Dundee as there was not a department in GRO-C, where I lived at the time. This meant that I had to move back to GRO-C to get the treatment from them. I was offered treatments in between those two treatments that I received, but I was not willing to try anything that did not at least have at 60% or 70% success rate. I knew that they were developing new treatments all the time as well and that influenced my decision.

23. I do not think that there were any treatments that should have been made available to me but were not. I was not really doing any research, but generally felt that they were offering everything that was available as it became available.

24. Any time that I needed dental treatment, the Haemophilia Department in Dundee provided support. I remember that my own dentist refused to see me anymore. This was my original NHS dentist. This must have been in 1996 or 1997. Our current dentist never refuses treatment, but requires that my appointment take place at the end of the day so that I am always the last patient to be treated in order for an exhaustive clean-up to be done afterwards.

25. Becoming infected with hepatitis C also had an impact on other medical treatments. The medical professionals did not know if my treatment for hepatitis C would make me infertile. However, they would not try to preserve my sperm because of the hepatitis C. I think they should have been prepared for this because becoming infertile was an accepted risk of treatment. This was prior to the first batch of treatment.

26. Becoming infected had a great impact on my family and private life. I have already mentioned that my girlfriend at the time when I found out that I was infected with hepatitis C broke up with me. During the

treatment, I was very intolerant and tired, especially in 2011. This caused arguments with my family and other issues and I was so tired that I could not do anything for a year. Apart from that, I was always concerned about passing the hepatitis C to my wife or passing it to my children. It took me a long time not to think about it, even after I got the all clear. I did not socialise a lot after the first treatment and it was not ever the same again. I became withdrawn and grumpy and I could not drink. I did not go out for a year during the treatment and it has never gone back to being the way it was before. I was very depressed when I was given the all clear and thought that the virus would come back. The first three months of the second treatment were awful; I became really aggressive, depressed and grumpy. I refused to take time off work because I did not want to be treated differently by my employer. Therefore, I kept my illness a secret at my workplace and took holidays when required instead of sick days for my treatment.

27. I think that there is a stigma attached to a diagnosis of hepatitis C. I feel like the initial romantic relationships that I had were affected by the HIV scare that was going on at the time, even though I only had hepatitis C. People did not really see a difference between hepatitis C and HIV. Some people were really concerned about it and treated me differently as a result. Even I treated myself differently as a result. Things like the dentist not treating me and not being able to get life insurance make you think that you are different. The way I thought about myself was affected and this in turn affected my socialising and sports. I did not tell anyone that I was infected after a while; I decided to keep it a secret and even asked my family not to tell anyone. I kept it a secret at work. My hepatitis C made travelling to India for work quite challenging, as I had to take supplies with me.

28. I do not think that the hepatitis C affected my education, as I managed to finish my degree. However, I feel like it affected my work because, as I mentioned, travelling became difficult and I had to work from home

for the duration of the first and the second treatments. I took holidays instead of sick days so that no one would notice that I was infected. I had to refuse certain customer visits in India where if an accident happened, I would not be able to have the medical support required to treat me.

29. It is hard to tell whether becoming infected with hepatitis C had any financial effects for me. I do not know as I have been with the same company for 18 years. When I left university, I had previously thought of moving to other countries and working abroad. After I found out that I had hepatitis C, I was told that this would be an issue with immigration and I would not be able to do it. I remember that even changing jobs was difficult. I knew that I was not going to be able to leave the country. I also did not want anyone finding out that I had hepatitis C. It changed my life and my plans that I had made for my life two or three years prior to finding out that I was infected.

30. I do not really think that hepatitis C had any effect on my education, but I would say that it made my remaining period at university more anxious, especially when doing exams. It constituted an additional element of stress. I still managed to obtain good results, so I do not Tknow if the effect was that noticeable. I was already in my third year at university when I was diagnosed with hepatitis C. I think the illness made it harder but I was still able to do what I needed.

31. The effect on my family life, that is, on my children and wife was more to do with the effects of the treatment, which caused mood swings and depression.

32. My mum and dad felt responsible for allowing blood products to be administered. I know that my mother feels guilty about this.

Section 6. Treatment/Care/Support

33. I was offered counselling a long time ago in order to deal with anger management issues. There are letters in my medical notes that refer to my anger management issues due to having being given contaminated blood and getting hepatitis C. I produce a copy of these letters in evidence and refer to them as **WITN2175007** and **WITN2175008**. It was offered to me at hospital and it was limited to five or six sessions as it was very hard to organise. This counselling took place in 2002 in Dundee. It was not very successful as I was told that I had every right to be angry instead of being shown how to channel my anger. My wife was not offered any counselling or psychological support. They knew that the second treatment would be bad and, in fact, it almost broke our marriage, so I think that more counselling should have been offered.

34. **GRO-C**

Section 7. Financial Assistance

35. I received a £20,000 payment from the Skipton Fund and then the most recent payment of £30,000 from the Scottish Government.

36. I found out that I was entitled to financial assistance through Ninewells Hospital and the Haemophilia Society. I was made aware of this through message groups and mailing lists. The Skipton Fund sent me notifications regarding the second payment and Thompsons provided a lot of information to me as well.

37. I cannot remember a lot about the process of applying for financial assistance. I just remember that I only received a payment once the funds checked with the hospital that I was actually telling the truth. For the second payment, I was not required to do anything. The first time, I obtained all the information from my nurse and doctor.

38. I do not think that there were any obstacles for me in applying and obtaining financial assistance. The main obstacle for me has been not being able to have life insurance as a result of becoming infected.

39. I cannot remember the details of any preconditions imposed on the making of an application for, or the grant of financial assistance, but there was a suggestion that you could never bring up a case against the NHS if you applied for financial assistance, although I cannot remember if this 100% accurate.

40. I have no observations to make about any of the trusts or funds because I think that they are fairly well organised.

Section 8. Other Issues

41. I think that there seemed to be knowledge in Canada, the USA and Germany of what was going on and there were people taking precautions that were not taken in the UK, such as screenings. It appeared from the Penrose Inquiry that these things were not known in the UK, but other countries had an awareness of the risk and to me it seems odd and raises a lot of questions and concerns. I believe that financial matters came before any concerns about where the blood was coming from and what the risks were. I do not think that there was due diligence. Also, I do not think that the Penrose Inquiry was particularly investigative and I think that more questions could have been asked.

42. I gave a statement for the Penrose Inquiry, but I did not attend the hearings.

43. I have not been involved in any campaigning or litigation, as I never had the time.

44. I think that my medical records seem complete.

45. I do not wish to be anonymous.

Statement of Truth

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

Signed GRO-C

Dated 14th Feb 2020