Witness Name: Frances Joy
Statement No.: WITN3098001
Exhibits: WITN3098002-003
Dated: 15th August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF FRANCES JOY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 25th June 2019.

I, Frances Joy, will say as follows: -

Section 1. Introduction

1. My name is Frances Joy. My date of birth is the GRO-C 1950. My address is known to the Inquiry. Before I retired, I helped my husband with his retail business doing bookkeeping. I am currently living with my husband Michael Joy, who I have two children with, Laura Moore and Ian Joy. I intend to speak about my son, Ian Joy, who was born on the GRO-C 1975 and his infection with hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together as a family.

2. I have appointed Thompsons Solicitors to represent me for this matter. I do not wish to be anonymous for this statement.

Section 2. How Affected

3. Ian was diagnosed with mild Von Willebrands when he was very young, when GRO-C GRO-C during which Michael and I were questioned about his bleeding. We had not noticed any problems with his bleeding prior to this, however the doctors could see that something was not quite right, so they took blood samples from him and ultimately he was diagnosed with Von Willebrands disease. They also tested GRO-C I at the same time, and GRO-C I also received the same Von Willebrands diagnosis. GRO-C GRO-C We were all told that if we had any sort of operations in the future, that we would be required to take a blood product.

4. Ian received prophylactic Factor VIII in 1984 prior to an operation. He may have received blood products at other points but I am unclear on when this would have been and it appears from what we have been told by the hospital, that it was the prophylactic Factor VIII that was infected with hepatitis C.

5. Ian was treated at Dundee Royal Infirmary which is now closed and Ninewells Hospital, Dundee, where he was diagnosed with hepatitis C in 1996. I cannot recall the names of all the GP surgeries where Ian has been registered. After he left school, Ian attended Robert Gordon University in 1992/1993 and then attended Dundee University from 1994-1997 until he graduated. He then moved to GRO-C in 1997 where he had his first graduate job. Since then he has moved back to GRO-C and has finally settled in GRO-C with his wife Nicola Joy and their three children.

6. Ian had a hernia operation in 1984 and received prophylactic Factor VIII as a precaution. This operation was uneventful and everything continued on for him normally, until he was attending Dundee University, where he attended from 1994 - 1997. He began to feel quite tired and went to his doctor, where I understand they did a liver function test. The results were such that the nurse commented to him that he must be drinking a lot of alcohol because the levels

were too high. Ian remembers feeling confused by this comment as he did not feel he was drinking an excessive amount then, nothing at this point was followed up on though.

7. GRO-C went on to give birth to GRO-C at Ninewells Hospital in 1996 while Ian was at university. She was questioned at the hospital if she had any other family members with Von Willebrands disease. She advised yes and we were then contacted and asked if we had received any operations/blood products in the past. We were then asked to go into hospital for tests which Ian and I did. GRO-C GRO-C We were accordingly contacted after we attended the hospital and asked to return, where we were informed by Dr Porter-Boveri that I had not been infected with hepatitis C, but unfortunately Ian had contracted the virus.

8. I had no idea what hepatitis C was at that point. Fortunately Ian did not have the HIV virus. I realised very quickly during the conversation with Ninewells Hospital though that this was something that was quite serious. As well as seeing Dr Porter-Boveri, we also saw a haemophilia nurse, June Ward, who was very nice and supportive of Ian. She explained all about the infection and I recall her showing us a chart and setting out how hepatitis C could affect Ian in the future. June has been an excellent support all the way through Ian's treatment and as I understand it, she only recently retired. We always knew we could contact her if we had any questions or concerns.

9. The other information we were given at the point Ian was diagnosed was that they were not sure about what treatment would be available and that it was very expensive. As a result, only certain people were being given it. We found out later on that Ian was genotype 1A.

10. Ian and I were absolutely gobsmacked with the diagnosis. We couldn't believe something like this had happened at all. The doctors were clear with us from the beginning that the infection had come from the blood products. I felt bad because I realised that I must have signed something in 1984 so Ian could receive this treatment, but I had no idea there was any sort of risk associated

with receiving it, it was a complete shock finding out there were these risks, all these years later. I had no idea that some products had come from America for example, I was under the impression that the products were either man-made products or it was like having a blood transfusion from one person to another. I had no idea that one treatment was a batch comprised of hundreds of donations.

11. Thirteen years passed from the point he was infected until his diagnosis. Information should have been given to him, much earlier. He was just a child in 1984 and as his parents, we should have been fully informed of all possibilities and risks.

12. We were given practical information about how to prevent the spread of infection. Things like what to do if Ian had a cut, and advice around toothbrushes and hygiene was provided. Ian was also given advice about relationships.

Section 3. Other Infections

13. Ian hasn't contracted any other infections from the blood products that I am aware of. I am unclear if he has ever received a letter about Variant CJD though. This would have to be clarified in his own statement. I believe he would have been notified if he was impacted by this, because Ninewells Hospital have been excellent at keeping him informed since his diagnosis.

14. I did receive a letter advising me that there was no risk of me contracting Variant CJD in 2004. I am not aware of having ever received a blood product. I had a hysterectomy many years ago, however I did not receive a blood product during this procedure. It could be that I received this notification because I am registered as having Von Willebrands and the letter was automatically generated, but this would be a guess. I exhibit this letter dated the 15th September 2004 as **WITN3098002.**

Section 4. Consent

15. As far as I know, they just tested Ian when they pulled us into hospital after the birth of my niece. They did tell us they were testing for a viral infection but there was no more information then. It wasn't until the test came back confirming the infection, did I realise how serious it was. We were told the results quite quickly. I think there has been such a delay with all the years between his infection and diagnosis, I have no idea what difference that would have made to his health now. Perhaps Ian wasn't as well as we thought growing up. He didn't have any obvious things wrong with him, but then I don't know how he was feeling fully, I don't know what he would have been like if he had never contracted hepatitis C.

16. Certainly at the point Ian was being treated in 1984, Michael and I were not given any information about the products he was receiving and the risks it posed to him.

17. If Ian has given permission to be part of research at any point, this would be something he would cover in his statement. I am not aware of anything.

Section 5. Impact

18. Ian's health was fine up until the point he was diagnosed in 1996. **GRO-C**

    GRO-C

19. Ian was eligible for treatment and received interferon and ribavirin. He had two lots of treatment and was very unwell with it both times. During the first treatment, he was living in GRO-C He was about twenty three or twenty four years old, so it took place around 1998/1999. The first time he had treatment, he was clear for about six months, but then the virus came back.

20. He was very unwell when he had treatment, which he did twice. GRO-C GRO-C GRO-C It was really quite a nasty treatment. He was inclined to be quite GRO-C prone to mood swings while he was on it as well. After the virus came back, he had no further treatment until about six or seven years ago, which by this time he was married and had children. He continued to work throughout the second course of treatment, but he was incredibly tired on it, really fatigued. I don't know how he managed to remain working. GRO-C GRO-C GRO-C he was too tired to make the journey back to hospital so I had to run him back to Dundee, as he just didn't have the energy. The second course of treatment was also for six months.

21. It was just very upsetting learning that the first course of treatment had failed. We had hoped that he was clear and that was the end of it. It was very distressing particularly seeing what he put up with. It is an awful treatment, and then for it not to have worked, emotionally it left a heavy impact. He wasn't keen to have treatment again at all, and he told me he would wait until they came up with something which was not as difficult. He was offered treatment quickly after the first one failed, but he declined and waited for many years before attempting it again.

22. When he did accept a second course of treatment, he still found it very invasive. He wasn't well on it at all, he was fatigued, tired and had terrible mood swings. Since then he seems to have cleared the virus though and the doctors say he is totally clear now. I would say, I have my doubts because nobody has been clear of it long enough to say, you are clear from it forever. We just have to wait and see but my understanding is, if it did come back, there are better treatments available now, which is a bit of a comfort. Ian was relieved when he finally cleared the virus. He has a wife and three children, so he was happy and relieved it was over and wanted to get on with his life. The hospital did monitor him afterwards for a little while, but they discharged him after a period of time, and as far as I know, unless he has any problems he does not need to return.

23. Ian doesn't want to talk about the infection. With the Inquiry coming up, it has brought a lot of it back again for him emotionally. I feel the same myself to be honest, it brings back memories about how awful it was. I can imagine Ian's feelings will be described in his own statement.

24. When I found out that he was no longer getting follow-up appointments, I told him if he ever felt unwell again, in any shape or form, he must go straight back and ask to be tested. Unfortunately I have an acquaintance that I knew about four or five years ago who had a liver transplant because they had been infected with hepatitis C. This acquaintance went to the doctors and said to them that they believed that the hepatitis C had returned after the transplant, and they were dismissed. The doctors spent so long telling him that he was clear, that when it got to the point where everybody realised that the virus had indeed come back, it was too late, he had deteriorated to the point of no return and passed away. That is why I have the anxiety about everything, it could in fact emerge again.

25. Ian didn't have any obstacles for treatment, he has always been offered what was available. Originally when he was first diagnosed, they were mentioning to Ian that treatment was quite expensive and that they were having to look at individuals lifestyles and assess who they thought was going to be the best candidate to clear the virus. With him being younger, perhaps there was a better chance of him clearing than someone who was older and had more health complications or liver damage. I can remember we looked at options about what we would do if he did not qualify for treatment, if we could raise the money ourselves somehow. This would have not been easy but it was definitely something we considered. It turned out though that he was one of the successful candidates.

26. Ian had quite a bit of bother at university with hepatitis C. When he graduated he told us that he would have given all of it up, if he could have not contracted this illness. He told me a story about an incident where he wasn't even allowed into a party one night. He went to someone's house and was met at the door with "*You are the one with that funny blood disease. We don't want you here*".

He had several incidents like this with people who didn't want to know. He told girlfriends about the infection and they seemed to be ok and understood. I think there was possibly some that weren't ok with it as well, but he has not shared that with us.

27. Some of Ian's friends were supportive, and other people were inclined not to mix with him for that reason. I think when there were all those adverts on the television, the AIDS adverts, a lot of people were very scared. That was a Government campaign, but I think people got a fright and thought they didn't want to mix with anyone or with anything like that. You see the tombstone on the television and it just leaves you feeling awful. He carried on though, he lived his life as best he could. He met his wife, Nicola about nineteen or twenty years ago when he was working in GRO-C and told her about the infection straight away. That was a fear he always had, before he met Nicola. He was worried he was never going to have children, as maybe no one would want him, but fortunately this has not been the case.

28. Sometimes I think it has been hard on his wife, because he still gets these mood swings and gets very uptight. I have read these can be side effects but because he has been so young when he was infected, we just don't know what he would have been like now if he had never contracted it. Now, he watches his drinking and really only has a drink very occasionally.

29. Generally Ian has had an acceptable experience with dentistry and treatment with other medical conditions. He did however find it upsetting when he was told he would always have to be the last appointment of day when going to the dentist because of the instruments. At one point he had to go in to Ninewells Hospital GRO-C He was in a ward with a sharps container by his bed, he was aware of the other patients there, who were looking at him and asking him questions about if he was a drug addict. In reality the hospital were keeping everything separate because of the hepatitis C, but these other people didn't know that. Maybe he would have been better in a private room to respect what was going on for him, but then of course I think that would have made it look even more like something

dodgy was going on for him.

30. As his mother, I have been absolutely devastated by this and have written to anyone who would listen. I have asked them to sign petitions and demanded answers. Ian being infected has left me incredibly sad, upset and distressed. I feel very guilty because I signed some piece of paper in 1984 and had inadvertently given him a dangerous virus. If I had known there was any sort of risk, I would have asked more about it and asked if he had to have the treatment. He received prophylactic Factor VIII as a precaution only, perhaps he wouldn't have needed it at all if it had been kept on standby. The doctors must have known where the blood was coming from, we didn't, but someone knew. They can't possibly say blood was being imported from America and nobody knew about the risks it posed; that makes me very angry.

31. I have campaigned for years and written to anyone with any sort of interest at all, whether it has been Westminster or the Scottish Government, anyone I thought who would be supportive of our cause. There are a lot of people who have had a worse experience than us though, there is definitely a stigma attached to the virus. He was a young man when he was diagnosed, people presumed it was his own fault and that the hepatitis C had come about from something he had done. I exhibit a letter I wrote to the Scottish Government on the 9th December 1999 under **WITN3098003.**

32. Michael, my husband, was very much like myself, he was just really devastated and distressed. As parents, we were as supportive as we possibly could be. We were open with our family and told them everything. We are lucky with our friends and relations, they are supportive and have signed petitions and things on Ian's behalf.

33. If I ever require treatment for the Von Willebrands myself, I would definitely ask about things now. My daughter is a nursing director in Derbyshire so she is knowledgeable on the medical side of things and she most certainly would ask for information. I wouldn't take anything without being fully aware of what it was that I was taking now and I know Ian would ask as well.

34. Ian hasn't had any problems with jobs. When he was younger, we got Dr Porter-Boveri to write a letter on his behalf to show any future potential employers about the source of his infection, in case it did become an issue as he had to declare it on job applications. He is a computer programmer by trade and worked at the same time as having all the treatments, which left him absolutely exhausted. He is very conscientious and I think he was worried that people would think he was skiving off because he was on some sort of treatment, I am not sure how much he told people at work about it. His employer in GRO-C was very good; the treatment was done in Dundee and they allowed him to move back home to be closer to Dundee for six months. He only had to go through to GRO-C to do a report once a week, which allowed him to get his full treatment and work at home.

Section 6. Treatment/Care/Support

35. Ian didn't need outside support, he had proper family support all the way through his illness. He attended regularly at hospital and I think at one point he did have counselling which he arranged privately. I think it would have helped if the NHS had offered psychological support right at the very beginning of his diagnosis. I went to the Haemophilia Scotland meetings over time and found that it certainly did me a lot of good, listening to some of the other patients who had been infected. Ian at the beginning wouldn't go along to anything like that. When he did move back to GRO-C I did manage to persuade him to go and he met some people with similar issues to himself. From that point of view, that was a support that made us realise that he was not the only one in this situation. Latterly once Ian was involved, I stopped going though because it was making me quite depressed. I still had a lot of sympathy for everyone there, but it was affecting my own health.

Section 7. Financial Assistance

36. I am not sure when he found out about the financial help that was available. It is possible that it was the Haemophilia Society that we obtained information from, they were very good about sending information about what was available.

37. Ian hasn't required to look for any monetary financial backup from the benefits system fortunately. I think some people have had a hard time getting even that and trouble with applying to the various funds and trusts. His insurance has skyrocketed and the premiums he has to pay are much higher. I don't think he has life insurance, I think he looked into it, but it was going to be so expensive it was just not worth it.

38. Ian received £20,000 but I am not sure which Trust it would have come from. This information would be contained in his statement. He then received another £30,000 later on. He was asked to sign a piece of paper, stating that he wouldn't ask for any more compensation if he received this money. I don't know who it was that said don't do this, but someone advised him not to sign this document because if anything came up in the future, he would have signed away his chance to get compensation. The Haemophilia Society came on board and also advised everyone not to sign the form as well. I am not aware of anyone advising him he is entitled to apply for a monthly payment with SIBSS.

39. He completed all the forms issued by the Trusts himself, he didn't really mention it to me.

40. I think it is good that the illness is being recognised and people are able to receive financial help if they require it through having hepatitis C or any of these blood viruses.

Section 8. Other Issues

41. I don't have any other issues to raise for the Inquiry's attention. I hope that in the future, anyone dealing with anything like this, is very careful about what they are doing and not ever bring in anything, or use anything, that would cause such a disaster in the health service again. So many people have been affected and there are a lot of people who have not yet been diagnosed and don't even know that they fall into this category.

Statement of Truth

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

Signed GRO-C

Dated 11/2/2020