Witness Name: Miss Christine Forbes
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INFECTED BLOOD INQUIRY
WRITTEN STATEMENT OF MISS CHRISTINE FORBES

Section 1: Introduction

1. My name is Miss Christine Forbes. My date of birth is the GRO-C 1964; my address details are known to the Inquiry. I am making this statement in memory of my mum, May Elizabeth Forbes. I am one of seven children, and the youngest daughter. I have two children, a daughter who is 29 and a son who is 24. I am making this statement because of my close relationship with my mum and because my mum brought my children up and they shared a very close bond with her; my son in particular has been quite badly affected by her passing away.

Section 2: How Affected

2. I make this statement in memory of my mum, May Elizabeth Forbes, who was born on GRO-C 1939. My mum was a very hard-working, loving and caring woman. She worked as a chambermaid for many years. She looked after my children for me so that I could go out to work and was a brilliant babysitter. She loved her grandchildren to bits. In total my mum had 15 grandchildren.

3. I was very close to my mum, when I got married my husband and I stayed at home with my mum and dad. My dad passed away so my husband and I remained living with my mum. Mum was always there; always present in my life. I lived with her all my life, until she passed away on 1 June 2011 from hepatocellular carcinoma and hepatitis C infection. Before she passed away the wider family knew nothing about her condition other than that she was carrying the hepatitis C infection and that it had progressed to liver cancer. The receipt of my mum's records tells a much more detailed story which has caused some confusion and shock. There are many things referenced which we did not know about and some which appear to be obviously wrong.

4. I understand that my mum was infected with hepatitis C as a result of a blood transfusion or blood transfusions that she received. There is reference in her records to a number of blood transfusions in the 1960s, 1970s and 1980s. On 29 May 1963 mum suffered considerable bleeding from her pregnancy and following a spontaneous abortion was transfused with two pints of blood. The records reference very vaguely that mum received six units of blood in 1960 as a result of anaemia secondary to menorrhagia and another transfusion in 1967 for anaemia and that her main risk factor to the diagnosis of hepatitis C was the blood transfusion she had in 1979. There are no records to suggest that she did. I assume that this is incorrect. It seems that she received a two unit blood transfusion on 10 August 1983. She was given the blood on admission for a D & C as her haemoglobin level was 8g. There is reference in mum's notes to the medical teams believing that her hepatitis C infection **likely** came about as a result of the transfusion that she received in 1985 for her hysterectomy. This can be seen in a record dated 24 July 1997, and this record can be made available to the Inquiry should it be helpful. However, there is a record in the notes which is dated 22 November 2004 which was written by my mum's GP for her application to the Skipton Fund. This letter seeks to summarise the position in relation to the blood transfusions as Skipton had asked for further information to clarify potential transmission factors for mum's hepatitis C. It

reads '*... I enclose herewith a letter from the Western General Hospital dated 10th August 1983 with respect to Mrs Forbes. As you can see from this letter as the result of investigation of her menorrhagia she underwent a D & C and was transfused two pints of blood because of haemoglobin of 8 on admission. Further to that on the 10th of September 1983 she then underwent an abdominal hysterectomy and bilateral salpingo-oophorectomy. We have a note from the surgeon of the 12th of September listing his operative findings abut there is no specific comment in the records that she underwent a blood transfusion at that stage either peri-operatively or post-operatively. With respect to blood transfusions in 1963 when pregnant I enclose herewith a letter from Stobhill General Hospital dated 4th June 1963. As you can see it states that as a result of spontaneous abortion with considerable bleeding she was transfused two pints of compatible whole blood.*' I have not seen the surgeon note dated 12th September 1963. It is clear that the medical records I have for mum are inconsistent, potentially incorrect and very confusing.

5. My mum did not have a bleeding disorder.

6. It appears that my mum was infected by way of a blood transfusion. I do not know for sure which transfusion carried the infection to her but I think that it could be one of two that she received. She was transfused two units of blood on the 29 May 1963 at Stobhill General Hospital in Glasgow as a result of bleeding from a '*spontaneous abortion*' and she was transfused two pints of blood on 10 August 1983 prior to a D & C operation on 10 August 1983. This operation took place at the Western General Hospital in Edinburgh.

7. I was not given any information or advice about the risk of mum being exposed to infection as a result of receiving blood, and mum never mentioned anything about her being given information or advice about the risk of her being exposed to infection as a result of receiving blood.

8. Mum was infected with hepatitis C. The records indicate that at the same time that she was diagnosed with hepatitis C, she was diagnosed with a condition

called polycythaemia. I understand now that this condition is a slow-growing blood cancer in which your bone marrow makes too many red blood cells. These excess cells thicken your blood, slowing its flow and can make you more susceptible to complication such as blood clots which can then cause heart attack and stroke. The records give conflicting information in relation to this condition. In one instance in 1997 it is said that the she has polycythaemia with '*unknown aetiology*' and in another it is said that she had polycythaemia rubra vera. As I understand it, the rubra vera kind occurs because of a fault in a gene called JAK2 or TET2. There is a letter in mum's records dated August 2007 and written by a professor of haematology, which states that although mum's red cell mass was slightly elevated her condition was considered to be more in keeping with spurious polycythaemia, rather than true polycythaemia. There is another letter written by the same professor and dated December 2007 which indicates that he considered mum to be JAK2 negative and extremely unlikely to have PRV (which I assume is polycythaemia rubra vera) and she never had a convincingly raised red cell mass. He considered her high Hb to be at the high end of normal because of hypoxia associated with smoking and also due to a proportion of carboxyhaemoglobin in her red cells. I understand that it is possible that polycythaemia can be caused by an abnormal production of erythropoietin which can occur as a result of by hepatocellular carcinoma. I assume that this was accepted by the medical teams treating mum as the cause does not seem to have been set out. It is important to note that mum had regular venesection treatment for years.

9. I am guessing by reference to my mum's notes that she was diagnosed in 1997, this is because in June 1997 her records refer to the fact that she had '*probable chronic liver disease*', which changed to diagnoses of hepatitis C and true polycythaemia on 24 July 1997.

10. From the records it seems as though my mum's specialist registrar at the Royal Infirmary in Edinburgh discussed the virus with my mum on 24 July 1997. This person recorded the following details '*we had a long chat today about hepatitis C particularly in terms of risk of long term liver damage and the risks of*

transmission of the virus to other people and possible treatment options. I explained to Mrs Forbes that it is likely that she contracted the virus from a blood transfusion. She was remarkably stoical about all the situation having never heard of hepatitis before. She is due to see Dr Hayes on 8 August 1997 and I am sure that he will go into further discussions with her.' I am unable to confirm whether or not this happened as mum never discussed this with me. I note the polycythaemia diagnosis was not mentioned as part of the discussion.

11. I am unable to say whether the information that she was provided with was adequate to help her understand and manage the infection but I do not think that it was because it seems that she refused treatment for it while desperately wanting treatment; including surgery, for the liver tumours when she was eventually informed about them.

12. I believe mum found out in 1997. I cannot be sure. There is a record dated June 2005 which is incorrect in other respects and states that she was first diagnosed in 1987. I think that this is incorrect because the majority of the other records refer to 1997. The first that I (and the family) knew that she was unwell was in around 1997 when I think she was attending her GP and the hospital in order to establish what was wrong. As I mention above, it was in 1997 that she was also diagnosed with polycythaemia. It seems odd to me that both of these conditions were diagnosed at the same time. I think that my mum should have been told as soon it was known that there were problems with blood transfusions at the relevant time. By 1997, mum will have been carrying the infection for either 14 or 34 years, depending on which blood transfusion infected her. I consider that the system could have traced my mum; she could have found out earlier, suffered less and lived longer.

13. I think that delivering news of something so serious should have been done in a way that would have been as supportive as possible to the infected person. This would be to ensure that the infected person understands what they are being told and can understand and manage the situation in the best way possible. If they choose to not have someone present, then this should be

formally discussed with a medic and recorded. I think that this is particularly important because of the risk of infection to others. I believe that somehow or in some way I (or the family) should have been advised about the risk of infection to me and my family. I should have been given the opportunity to help mum understand what the infection was and to help her decide upon the treatments to have. There should have been more done to support the infected person through this.

14. As far as I know, mum was told that if she cut herself she had to deal with it herself or we had to use gloves to help her, we knew that any small cut carried a risk of infection of her hepatitis C to others. This is all we knew. We did not really know what having hepatitis C meant.

Section 3: Other infections

15. I think that my mum was infected with hepatitis C only; however, as I have mentioned above, she was also diagnosed with polycythaemia in 1997 and I am beginning to think that perhaps this came from the transfusion too. My understanding of the condition is limited but I understand that a version of it can come about as a result of hepatocellular carcinoma which mum developed. In 1997 she had been carrying the infection for either 14 or 34 years so I expect there was the possibility that the hepatitis C could have deteriorated to liver cancer, but I do not know for sure. I do know that a record dated 9 June 2005 states that mum's hyaluronic acid is elevated 400. Further it states '*...There is a question as to whether this might relate to bone marrow fibrosis secondary to her polycythaemia. This lady certainly has multiple spider naevi to suggest that she has chronic liver disease but her platelet count is currently normal...*'

Section 4: Consent

16. My mum always went to the hospital herself with these things and she kept most things to herself. She never mentioned anything about being treated or tested without her knowledge or consent, or without being given adequate or

full information. So I am unable to answer this question. I do not think that she was treated or tested for the purposes of research but I do not know for sure.

Section 5: Impact

17. The impact on my mum was significant. Ultimately it cost her, her life but in the years running up to her death, from her diagnosis she was suffering from various symptoms. Her symptoms included, tongue stomach, oesophageal and duodenal ulcers, itching, pain in her back, arm and abdomen. She also suffered from general unexplained malaise, weak and collapsing legs, chronic fatigue, lethargy, diarrhoea and anorexia. Mum also suffered from arthritis in her knee and from a frozen shoulder. I saw my mum becoming very depressed over time and towards the end she just wanted to sleep at of time, she was tired all the time and lost interest in everything. It was in 2008 that her condition deteriorated significantly, she lost all of her strength and when she fell out of bed she could no longer get up. She sometimes lay on the floor for hours before someone arrived to help her. It was in 2008 that she was diagnosed with hepatocellular carcinoma even though her hyaluronic acid levels were so raised and suggestive of chronic liver disease from as early as 2005. It seems that despite the hepatitis C diagnosis focus was on the hyaluronic acid levels being attributed to the polycythaemia rather than to chronic liver disease or hepatocellular carcinoma. I do not know why this is, especially since the liver cancer is a risk once you are diagnosed with hepatitis C.

18. I query now whether the polycythaemia was caused by the transfusion or the hepatitis C. My mum's condition progressed to hepatocellular carcinoma in 2008 and caused numerous other symptoms that she had to deal with.

19. Mum passed away in June 2011.

20. As far as I know, Mum was not given any treatment for her hepatitis C. This meant that the infection was allowed to progress to hepatocellular carcinoma which cost her, her life. I cannot understand why this was. There is mention in her notes to treatment being discussed, but, it appears as though she rejected the possibility of treatment. I recall mum telling me that she would not have the treatment as she was told that it would have no effect; that it would be pointless. In 2010 mum was taken into hospital very urgently as she was suffering from severe stomach pain. Her GP had told her that the cancer could not have caused her problems with her stomach, and so was effectively not dealing with the problem. I do not understand this. At this point, mum's cancer was at a really advanced stage. The problem became so bad and mum was in so much pain that we had to fight to get her admitted to hospital, this eventually happened in April 2010. When she was admitted we had to fight to have her scanned to find out what the problem was. It was then that they found that she had numerous ulcers. They did not say what had caused this; they thought it was as a result of her taking ibuprofen. I do not believe that mum took ibuprofen that often. It seemed the medics wanted to totally ignore the massive elephant that was in the room; her advanced cancer which desperately needed treatment. A decision was made to not treat her cancer or the hepatitis C until her ulcers were dealt with. At that point; June 20`0, it seemed possible that mum might be able to have surgery. Mum wanted to have the option of surgery. It seems that mum's first MRI was conducted in July 2010 which confirmed that she had multifocal hepatocellular carcinoma, with at least four lesions, and unlikely to be cured by a resection. She was not considered to be a candidate for transplantation. In the end mum was given chemo-embolization in August 2010, which delivered a laser beam to the tumours and while it reduced the size of the tumours, by October she had developed further hepatic spread of her disease with at least two further malignant lymph nodes found. Mum suffered a stroke during this treatment, I wonder if this might related to the polycythaemia and the risks that this carried if not treated properly. I do not understand why my mum's condition was allowed to deteriorate like this. She was diagnosed in 1997; she had multiple haematology, hepatology, and

gastroenterology appointments at the hospital. Even when there was the possibility of surgery, they decided to wait until her ulcers were treated before looking properly at the underlying problem of the cancer which was threatening her life. How and why did she die of liver cancer?

21. Mum was diagnosed in 1997. This was 14 or 34 years after she received the blood that carried the infection to her. The possibility of interferon treatment was discussed with mum with her gastroenterologist in February 1998 who referred her to the hepatitis C clinic. The referral appointment seems to have taken place in June 1998. The letter states '*...I have discussed this lady with Dr Hayes and, given that her illness is well-compensated, I will make an appointment to see her again in one year's time. I did broach the subject of treatment with Interferon at this visit but Mrs Forbes is quite adamant she wishes no form of treatment in the meantime.*' There is another record dated 18 June 1998 written by haematology which states '*I saw May in clinic today... She tells me her recent scan was satisfactory and is adamant that she wouldn't want interferon treatment...*' I cannot help but feel that they did not want to treat her with it. I recall that Mum told my brother and me that she was told by the haematologist that the treatment would not do anything for her, that it would only serve to buy her a couple of months. I do not know why this was the case particularly because there is another record written by haematology which is dated 16 June 2006 and which states '*...If she is genotype 3 she would have a 75% chance of cure with 6 months of treatment and it might well be worth it. Is she was genotype 1 she has 50% chance of cure with a years treatment. She had a serum hyaluronic acid of 400 and I will get this rechecked as there is no other evidence of cirrhosis and I am not sure whether her haematological disorder could affect this result*'. Written in handwriting below is '*genotype 1*'. Mum decided off the back of what she was told that she would not have the treatment. Mum was not diagnosed with the cancer until 2008 so I am unsure why the haematologist felt then that the interferon would only serve to prolong her life by a couple of months. I do not know why 11 years were allowed to pass by without her being given any treatment for the hepatitis C. It was almost

inevitable that her condition was going to deteriorate further and that she would develop liver cancer. I cannot see that any attempts were made by her medical team to encourage her to have treatment or to discuss with her fully the options that were available to her, this is not detailed anywhere in the records that I have. I do not think my mum ever knew the full extent of what the hepatitis C was or what it was going to be.

22. I do not whether there were any treatments that could have been made available to mum.

23. As mum did not have any treatment, there were no side effects experienced.

24. I do not believe that my mum's infected status impacted upon her treatment for other conditions but I do not know for sure.

25. Mum was not someone who went out a lot; she used to go out maybe once per week to visit her sisters and she would have a few drinks there. She stopped going there in around 2004 because she had been told to stop drinking. So her social life became non-existent. My mum did not have a private life, my father passed away when my mum was in her early 40s. She never met anyone else. My mum enjoyed her time with her family very much and I do not think that there was a difference in the family life she had with me and my family because of the infection but I do believe that her family life with her sisters and brothers changed and with her own children changed. I know that they stopped coming to visit as often as they used to and mum definitely noticed this. I think that mum suffered effects to her private, family and her social life as a result of the infection. There is reference in her records in March 2010, to her being in a depressed mood and lacking enjoyment in life.

26. In the beginning there was no impact as we did not know. Really this did not impact on my life until around 2008 when she was diagnosed with the cancer. Mum gave us no signals. Sometimes I noticed her in pain, but she would never let on what it was. From then I was aware of doing things to prepare myself for her leaving us. Her being sick really deeply worried me. I used to think about

her all the time. Physically I had to keep going, I had to be strong for us. Mum's life was bound up with mine. We shared everything including our finances; we were life a married couple. I had to reduce my hours and work part time to take care of her. This involved me doing the housework and shopping for her. I noticed mum becoming sicker and I had to take her to more appointments. For example, she woke up one night where her tongue was bleeding and it would not stop. No-one could figure out what it was. She had to go for a biopsy on her tongue, in March 2010. I started going to all her appointment so I could try to find out more information about what was going on. I tried to carry on as normal. I still have not grieved for her and I will not until all of this is over. It has been very difficult to watch her go from a very strong woman to a lifeless woman. After mum had the chemo mobilisation she could not go out anywhere. So from the October to the June when she passed away she went nowhere other than to the hospital and the hospice.

27. The impact on other family members has been significant. I think that the infection scared the family, for they stopped coming to see her. Mum lost touch with her brothers and sisters and with her children, apart from me. I know that mum's illness affected my children too. My son started to skip school. We found out last year that my son has GRO-A and I know that mum not being here is responsible in part for this. Mum used to do a lot for him, she was a main care giver to him; she spoiled him.

28. I believe that there work and financial-related effects of the infection. I know that my mum had to stop work in around 1994 as she could not take it physically any more. She was totally exhausted and could not cope. This obviously had an impact financially. Mum was only 55 at the time. Mum helped me out at home with my children and I started working full-time to try to compensate for the loss of salary to the household. The effect on me was that I left my children at home with mum while I went out to work. I expect that mum actually needed to rest but instead she was taking care of the children. This situation carried on until I had to take part-time work in 2010 to help mum with her illness. This impacted on things like my mortgage and my general ability to

make ends meet. We had accrued debt which has effectively taken much longer to clear.

Section 6: Treatment/ Care/ Support

29. Yes my mum faced difficulties and obstacles in obtaining treatment, care and support in consequence of being infected with hepatitis C. Mum received no treatment whatsoever for her hepatitis C. I do not understand this. In my view she did not know the seriousness of the infection and as a result it seems that she decided to not receive treatment. The records don't show that the treatment was explored fully with her, or that her medics explained her condition could deteriorate as a result; they seem to accept very easily that mum was deciding not to have treatment. I understand there were three attempts to discuss the treatment with her; there is no detail around this in the records. The notes merely say the treatment was discussed. I recall my mum telling me that her consultant had told her it would not do anything for her. It seems she made the decision to not have it based on incorrect information. As a result the virus was allowed to progress to cirrhosis and cancer.

30. As far as I am aware, there was not psychological support or counselling made available to my mum or to me in consequence of what happened.

Section 7: Financial Assistance

31. Mum received financial assistance from the Skipton Fund only.

32. It was in 2004 and through a consultant liver specialist that she found out about the Skipton Fund. This consultant encouraged mum to make an application.

33. Mum received £20,000 in October 2004 from the Skipton Fund. Then in May or June time 2009 she received £25,000, this was when he condition had developed to Stage 2.

34. As far as I remember, Stage 1 application was not a problem. For Stage 2, mum had been told in 2008 to apply for Stage 2, but she was refused it because her blood levels were not quite where the Fund wanted them to be. I understand that all of her other symptoms were there for the payment including cirrhosis but the payment was refused on the basis of the blood results. Mum had to apply again in 2009 and at that point her application was successful. I do not know whether the blood counts did improve for the Fund.

35. The difficulties that mum faced are included above. Apart from this, there were no further difficulties.

36. As far as I know there were no preconditions for the making of an application for or grant of financial assistance. I do recall mum discussing a waiver at one point but I know nothing about the detail of it.

37. I think that the availability of the Funds should have been common knowledge for people. Mum should have received a further £25,000 as a top up payment in 2010. She should also have received the annual payments from the Fund but again she did not. This information was not made available to my mum and as a result she missed out on these payments. I think this is wrong; these payments should have been made available to my mum when she was alive. She was never able to make use of the money when it finally came in 2012; she passed away before it arrived.

38. I have received payments from Skipton only.

39. I received the £25,000 in May 2012; this was the sum that my mum should have received in 2010. I did not receive the annual payments that my mum

should have received. I asked about this, but Skipton said they could not make any back payments as the government had made no provision to do this.

40. I was not informed that mum could have received the £25,000 or the annual payments, I found out by accident when I had a look at the Skipton Fund's website which indicated that there was a top-up payment available to certain people. I emailed the administrator of the Fund, I advised I was my mum's next of kin and emailed the relevant documents across. The payment was made soon after.

41. Apart from never being told about the scheme or the Fund, I did not experience any difficulties or obstacles in applying for and/or obtaining financial assistance; however, I have just found out about there being a bereavement fund which I never knew about. I am currently looking into this.

42. There were no preconditions imposed on the making of an application for, or the grant of financial assistance.

43. As I have said previously the information was never forthcoming and I believe it should have been made available to people and that they should been advised about what they were potentially entitled to in a very open way.

Section 8: Other Issues

44. I would like the Inquiry to find out whether the polycythaemia was connected to the hepatitis C. Did this come from the hepatitis C, or the blood transfusions that mum received.

45. I want the Inquiry to find out the truth about what happened. There are all of these speculations and they need to come to an end finally. Someone needs to hold their hands up and admit that they got it wrong. I want the Inquiry to

deliver justice to people, give them the answers they need to put this to bed and to allow them some comfort in the time that they have left.

46. I would also like the Inquiry to look at providing help for families who lived with and supported the infected person; psychological and financial support for those who do not fall neatly into a bereavement partners/ spouses category but who might have fulfilled that role anyway, from a financial, psychological and emotional support perspective. I have seen support provided to bereaved partners and spouses, yet there has been none available for me. My mum lived with me and my children all through her illness; I cared for her financially, emotionally, psychologically, physically. We have been affected by this and are in need of support. There seems to be nothing for a deceased's family like us.

47. When my mum was diagnosed with Stage 2, my brother and I were taken into a room by a consultant and told that he would fill in the form for my mum for Stage 2. From that point onwards, he had no involvement with my mum. I feel as though because she had progressed to Stage 2, he washed his hands off her. As her consultant, I expected him to be there to see her through until the end. But he was not. I feel like he treated my mum like a leper.

48. The fact that my mum refused treatment for the hepatitis C suggests that she was not properly informed about the risk of the infection to her and what treatment was available to her. The records that I have indicate that she was consulted about treatment in 1998, 2000 and 2007 but that seems to be it. There is no detail in the notes about what was actually discussed with mum. She died from cirrhosis of the liver and liver cancer. Both of these conditions came from the hepatitis C which she contracted from an infected blood transfusion.

49. I have grave concerns about the accuracy and completeness of the records for mum. Throughout the records, there are inaccuracies and inconsistencies; there is even the suggestion that mum might have had a second hysterectomy!

There are 15 years of records missing from mum's files. I found out that the records were missing by going through them and realising that there was a very large gap at the beginning of the records. I can see in the records that my mum's GP has written for results from the Royal Infirmary Hospital which never came. I recall my mum actually going up to the hospital at one point, to try to find her records but this proved pointless.

50. I myself have only managed to get hold of the GP records. I did not have trouble in getting hold of these. The GP printed these off for me very quickly. I noticed the gaps of time in these records and I believe these too are incomplete.

51. Overall I do not think mum was treated badly by anyone in particular. I think that the hospital staff should have listened more attentively to my mum when she presented with the ulcers. She was in severe pain at this time but she was not listened to. I also think that he consultant was not interested in treating mum any more once she hit Stage 2 of the infection.

Statement of Truth

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

Signed: GRO-C

Full Name: Christine Forbes

Date: 8 APRIL 2019