

Witness Name: K BERTENSHAW

Statement No: WITN3001001

Exhibits: 0

Dated: May 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF KATHARINE BERTENSHAW

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I, Katharine Bertenshaw will say as follows:-

#### Section 1. Introduction

1. My name is Katharine Bertenshaw of GRO-C  
GRO-C My date of birth is GRO-C 1974. I am divorced and have two children, aged 11 and 2. I GRO-C in June 2018 and I have not returned to work.
2. I make this statement in relation to my late mother, Patricia Ronan, who was born on GRO-C 1949 and passed away on 21 January 2014 at the age of 64. She was infected with Hepatitis C and Creutzfeldt-Jacob disease (CJD) as a result of receiving contaminated blood products. On my mother's death certificate the cause of death is listed at Bronchopneumonia due to Creutzfeldt - Jakob disease, sporadic type (MM1 sub-type).

3. This witness statement has been prepared without the benefit of access to my late mother's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

## **Section 2. How infected**

4. My mother was diagnosed with severe Von Willebrand Disease (VWD) as a child. This disease meant that when my mother had a bleed it took longer for her blood to clot and for the bleed to stop.
5. My mother was only ever treated for her condition at the Manchester Royal Infirmary (MRI), apart from an isolated visit to Blackpool Victoria Hospital during a family holiday. I believe she was infected with Hepatitis C and CJD at the MRI. I am unaware of the names of doctors that treated my mother throughout her early years, I only have knowledge she was under the care of Dr Hay, the head of the Haematology Department and then transferred under the care of Dr Bolton, from around the 1980s. As far as I am aware, my mother had a good relationship with the Haematology department and particularly with the nurses.
6. My mother was also under the care of Dr Campbell at the MRI whom treated her for her bowel lesions He was revolutionary in helping her to reduce her number of bleeds from the bowel and providing her with treatment which would help to prevent bleeds by using new technology he brought to the MRI which could detect the lesions and laser them. He also agreed to give her regular check ups, and put in place a process that if she was admitted to hospital with a bleed he was to be informed immediately so that he could investigate and laser the lesion to stop the bleeding. Prior to Dr Campbell being at the MRI my mother would just have to keep having endless transfusions, Factor VIII Concentrate and platelets until it stopped naturally and healed itself. I truly believe that Dr Campbell and his approach really

helped my mother to cope with her VWD mentally and practically.

7. My mother was very good at dealing with her VWD and the effects. She suffered from lesions on her bowels which would lead to internal bleeding. I do not believe that my mother was ever offered any sort of regular home treatment, although I do remember that she kept tranexamic acid in the cupboard at home.
8. All of her treatment would take place in hospital. Whenever she went to hospital she was treated with Factor VIII concentrate, and she referred to have platelets and blood transfusions. I am unable to recall the frequency of her admissions into hospital however as I got older her visits became much more frequent. I do not know the number of times that she received Factor VIII concentrate or how many blood transfusions she received.
9. I do not know whether any information or advice was given to my mother beforehand about the risk of being exposed to infection from blood products. I cannot imagine that she would have known about it.
10. I am not sure of the exact date but I believe it to be sometime in the 1990s that my mother found out she had been infected with Hepatitis C. I believe it was first brought to her attention during a conversation with Dr Hay and it is possible that Dr Bolton may also have been present. I do know that my mother was by herself at the time and as far as I am aware it was one of her regular check up appointments with her consultant, as she generally attended those alone. I am not sure why at this appointment it was revealed that she had Hepatitis C. I can only assume it was due to the development of the Interferon treatment, which they wanted her to try.
11. My mother was shocked and horrified with the diagnosis. I am sure that had she known she was expecting test results she would have ensured she was not alone and would have taken someone with her. This also leads me to believe she was

tested without her knowledge or consent.

### **Section 3. Other Infections**

12. I am aware that my mother received a letter in the post which stated that she may have been at risk of CJD and this was definitely after her Hepatitis C diagnosis.
  
13. Following my mother's diagnosis of CJD the hospital conducted a post-mortem and it was later confirmed that my mother suffered from the condition known as Sporadic Creutzfeldt-Jakob disease. We were told that, because my mother had multiple blood product and blood transfusions over many years, the Edinburgh surveillance unit would call for her medical records. Following my mother's death, it was concluded that she had died from Sporadic CJD and that my mother was just extremely unlucky in developing sporadic CJD and that it had nothing to do with the blood transfusions that she had in the past. However, I would also question the ability to accurately check my mother's medical records and the treatments she has been given, as I am aware of many people that have requested their records for the purpose of the inquiry, only to find that they are not complete. I would therefore fully expect that my mother's records are not intact and would be unable to provide the full information required.
  
14. I am highly sceptical about this. There was supposed to be an inquest into her death, but when Dr Patrick Urwin, Research Registrar at the National Creutzfeldt-Jakob Disease Research & Surveillance Unit at the University of Edinburgh said it was not variant CJD, the coroner cancelled the inquest. The coroner was very rude to my father as we tried to request an inquest, on the grounds that following all the transfusions and blood products she had received this would have put her in an exceptionally high risk category for vCJD and then to suddenly develop a condition that is, as we were told, had a "million to one chance" of catching, which is a random mutation and according to the consultant

at Salford Royal where my mother passed away was "a matter of extreme bad luck" seemed strangely "unfortunate." My method of coping with this as a diagnosis at the time is that I believed that the doctors didn't really know enough about CJD and stayed hopeful that in time we will get our answers.

15. In October 2016 or thereabouts Dr Patrick Urwin contacted me, explaining that they had had a similar case to my mother's, although they had confirmed Sporadic CJD, other instances in my mother's case had mirrored the symptoms of vCJD in that she had been exposed to potentially contaminated blood products, and the speed in which the disease had taken hold and then passed away. He informed us that another lady had died from similar circumstances to my mother. He told me about Professor Will, from the University of Edinburgh who was writing an article for publication for healthcare professionals to be aware of the existence of cases of sporadic CJD where patients had received blood plasma products and blood transmissions. My father provided his consent to include a description of my mother's illness. This was subsequently published worldwide to see if anyone else had experienced the same thing. NOT RELEVANT  
NOT RELEVANT This suggested to me that my mother may have died from the variant type of CJD as opposed to the sporadic kind. We also briefly discussed the disease and I expressed that I felt at this time they didn't know enough about the condition and he agreed, hence the article to try and get more information worldwide.

#### **Section 4. Consent**

16. I believe my mother was tested without her knowledge, consent and without being given adequate or full information. She did not know she had been tested for HIV or Hepatitis. I would not be at all surprised if she had been tested for other conditions too.

**Section 5. Impact of the Infection**

17. From our point of view, my mother appeared very good at coping with her condition and she carried on with her life as normally as she could. However, in hindsight I believe she had developed a type of paranoia regarding her blood, as she had to ensure that she took adequate measures to prevent transmitting the infection to anyone else. If she bled she would not let us go near her. Her toothbrush was stored in a different part of the bathroom and she was so conscious of passing on the infection. However, I know in my mother's mind Hepatitis C was not as serious as HIV and she knew there were many patients who had contracted HIV and my mother counted herself lucky that she had not, I think this carried her through.

18. GRO-C  
GRO-C Thankfully, GRO-C  
GRO-C my parents had a very good relationship. My father was absolutely amazing at handling the situation. He saw my mother struggle and in so much pain and I imagine it was very difficult for him. We are eternally grateful for the love they had for each other which kept our family together.

19. I found out my mother had received a letter stating she maybe at risk of vCJD. She never discussed this possibility with me or the implications. I am sure this would have caused an immense amount of stress and worry. I cannot imagine how it must have felt to open a letter containing a potential death sentence, and I wonder who sanctioned a letter as a good way of informing patients of the risk. I believe my mother did not discuss this with me or my brother, as she had always protected us from her health condition and the implications and therefore continued to do so.

20. I am aware that my mother received Interferon treatment in or around 1990. She would inject herself and because of the VWD she bruised easily. After receiving

the Interferon injections my mother felt unwell and experienced extreme flu like symptoms. The Interferon treatment did not seem to agree with her. She suggested to her doctors that she would like to stop, but they asked her to continue as they felt it was having a positive effect, which she did, but things did not get any better with the side effects and she called a halt to it. I believe, following the treatment, her general health was never the same as she felt very lethargic and didn't do the things she used to be able to do. She could not physically manage housework and the house was never as clean or tidy as it once was. I would help out, but over time my mother needed me to do more and more as she just didn't seem to be able to keep on top of things. I would take her shopping and when we came home, she would make an excuse of having to pop to a neighbour's, or something to that effect, as she knew that I would put the shopping away, I used to get very frustrated with her 'disappearing' which now upsets me as I realise it was one of her ways of coping without wanting to tell me she couldn't manage.

21. My mother was unable to obtain travel insurance and she was too afraid to go on holiday, and what it may implicate, as she felt safe in her home environment. There were a couple of exceptions, as my brother married in Lanzarote, and she went on a girls holiday to Florida and New York which she really wanted to go on, and we rallied and insisted she went. Instead of foreign holidays we stuck to domestic destinations and had lots of camping holidays, as my parents bought a caravan, which gave my mother a safe place. My mother always protected herself and stayed away from things that could harm her. Any travel for her was a major consideration. My father is Irish and they were rarely able to go home to Ireland because of my mother's health.

22. Looking back and after talking to my father I can now see that the Hepatitis C infection really had an impact on the relationship that my mother wanted to have with my son. She wanted to spend time with her grandchild, but she was so frightened that she would infect him that she didn't feel confident enough to have

him stay with her alone or overnight. I became very upset about this as I was worried that she was unable to bond with him, which I didn't understand as she was so excited about having grandchildren, and would talk about him with great pride and love, but it appeared to me that she put up a barrier, which I now realise was probably due to her worry of something happening that could lead to infecting him. Eventually, as my son got older, the situation improved. She would chat with fellow grandmothers at the park and discussed raising children with them like she was an expert. This boosted her confidence.

GRO-C

GRO-C

I cannot begin to imagine how badly this infection had affected her that she felt the need to keep a barrier up with her own grandchildren, and to still keep how she was feeling from us, as a form of protecting us, as a mother does.

23. My mother's infection was never made common knowledge and only some of our really close relatives knew. She hardly ever discussed it with us. I am sure she went through a lot of anxiety stress and worry, along with sleepless nights. If there was any reference to Hepatitis C in the media my father said the TV would be switched over, as her way of coping was not to delve into what might happen, and to manage each day as it came.

24. My mother worked as a seamstress. Her workplace was very close to our home and she worked alongside two of my aunts, which she introduced. She was very good at what she did but I feel that she deliberately chose that profession in that location due to her infection, and the other employees were family members, so she felt safe. She surrounded herself with people who were family and who understood her situation. The designer who my mother worked for knew about her VVD, but not about the Hepatitis C. I am sure that she could have had a much better job. She had trained to be my father's operations manager for which she passed a tough set of exams including courses on accountancy and bookkeeping. In addition to this my father has told me that prior to working as a seamstress, she worked in a local pub making lunches which she loved, however when they found out about the Hepatitis C they said she could no longer work



there due to the possibility of infection. This was very upsetting, as she really enjoyed the work and the people she worked with. This then lead her back to being a seamstress.

25. In November 2013 my mother went to the doctors as she felt she had severe catarrh that she had tried to treat at home. The doctor gave her antibiotics. This then seemed to affect her balance and the doctor diagnosed an ear infection and again gave her antibiotics. By the end of the month my mother no longer felt safe to drive as she felt the car was wandering, and asked my father to check the tires, but they were fine. I then took my mother to the walk-in centre as she had pain in her neck and it seemed to be swollen. They said she had vertigo.

26. I am not sure of the exact timings of the following course of events, but my father eventually took her to A&E in December as my mother was beginning to become uncertain on her feet. They referred her to a consultant for vertigo, he saw her and said it was just a severe case, and would take some time to clear up. He suggested she have a scan. We waited for the appointment, and my father called the hospital many times, as she was getting worse. I think they went back to A&E but no further treatment was given. By this time her movements were affected and she could not get down the steps at the front of the house so she had to use the back door. She was very unbalanced. In the night she would go to the toilet but became disorientated, so my father would have to go with her. It seemed to me like a type of dementia, as she sometimes would say strange things that made no sense, and then she would be alright again. We got through Christmas, but on New Years Eve my father took her to the MRI haematology department, as we thought perhaps her blood count was down. They conducted the tests and sure enough, it was low, but we were told to bring her back in the new year as it was probably low due to the ear infection.

27. My father took her back to the MRI Haematology department in the New Year but by this time we could only get her round in a wheel chair. They decided to give

her a transfusion as an out patient. Luckily one of the nurses saw my mother and immediately realised something very serious was wrong, as this was not how she usually was. After having a word with the doctor, they admitted my mother. Later that day my mother underwent a scan, and we were told nothing had showed up. Thereafter, my mother was just left in the hospital bed unattended to. She couldn't feed herself, and couldn't really speak as it was as if she had had a stroke. It was horrendous to witness her health deteriorate so rapidly. We had thought it was supposed to be vertigo. My father went to the hospital every morning and stayed all day to ensure she ate, and had her medication, as the nurses did not. Eventually they decided to move my mother to the SRH. She was admitted and had a nurse sitting with her, as she was thrashing in the bed.

28. The following day she seemed to be much improved and was eating herself, although we still had no diagnosis and had not been seen by a doctor. I remember frantically telling every nurse that came into the room that that was not how my mother was and that she was usually very fit and healthy. I tried to ask them what was wrong.

29. Eventually the following week the consultant came to see us, and told us the diagnosis. I was completely shocked, and knew what the impact of that diagnosis would be. My mother had a moment of clarity and following this I believe she was then sedated, as she never spoke or really awoke again. The CJD surveillance team came and took over her care. They conducted some test, but told us ultimately they would only find out what was wrong through a post mortem.

30. Once my mother had passed away, we were not able to bury her until 14th February due to the impending inquest and the tests they wanted to do. Around ten days after she passed away, my father was called upon to go and identify her body, which I felt was very unkind and traumatic for us all, we are still unsure why he had to do this. Eventually they released my mother's body, but wanted to

keep a part of her brain for some more tests to which we agreed. They then got in touch to say they wanted to use the tissue to grow samples on a mouse. We refused, as we just wanted all of my mother to rest in peace.

31. I am unable to put in words how this all felt at the time. It has been the biggest shock I have ever had in my life, as we thought she had an ear infection, and we were in no way expecting the diagnosis we got. I was physically retching in the corner of her room when the doctor told us, as I watched my father fall apart. In addition to this we were not able to be with my mother when she actually passed away. We were on our way to the hospital when we received a phone call requesting us to come to the hospital. We were there within minutes. My auntie had been sat with my mother when two doctors had gone in and asked her to leave. We waited outside for about ten minutes when they came out they told us she had passed away. I still have a lot of confusion as to what they were doing in those ten minutes and why we were not allowed in. No amount of tears has healed or helped us to come to terms with what happened, or the subsequent events whilst waiting for her body to be released.

32. In terms of my other family members, they were equally as traumatised. My father had planned on retiring, but instead he found himself having to continue working so that he had an income and also to keep his mind engaged. My father lost his life long partner and he never got to enjoy his days in retirement with her.

33. My mother was never able to get life insurance, or certainly none my parents could afford, so following her death my father had to sell our family home which is something he never wanted to do. I helped sort the mortgage out for him. He had wanted us to inherit the house but we were concerned financially for our father and the property was sold. He gave some of the proceeds to me and my brother.

34. The loss of my mother has affected me terribly. I GRO-C job after 17 years of employment as an account manager. My job entailed getting

disabled customers into employment and I was very good at it. I found it easy to do and before my mother was ill I was at the top of my game. I had to take a lot of time off work following my mother's passing and thankfully I had a very good manager. I have never been the same since she died. After my mother passed away, I found it difficult to return to work. I was assigned special projects which gave me more flexibility. However my performance dropped as I couldn't get over what had happened, and have been unable to concentrate on work. GRO-C

GRO-C Luckily, my partner earns enough to provide for us.

### **Section 6. Treatment/care/support**

35. I am not sure if we were ever tested for Hepatitis C. I recall GRO-C tested for Von Willebrand's Disease in the 1990s and to see how quickly our blood clotted. At that point, we may have been tested for other things.

36. No counselling or psychological support was ever made available to me in consequence of what happened. I did get in touch with a counselling service linked to the Caxton fund, they told me they were waiting on more funding and would be in touch once this was in place, we are still waiting. Although I did have some counselling through my GP but I really could do with some more.

### **Section 7. Financial Assistance**

37. My mother received £20,000 from the Skipton Fund. I do not believe she knew anything about top up payments. The Caxton Fund paid for my mother's funeral and paid off one of my mother's personal loans. My father now receives monthly top up payments of £200.

38. There is a compensation fund that my father could apply to in regards to my mother's CJD, however because on her death certificate the CJD was described

as the sporadic kind rather than the variant kind he did not qualify.

### Section 8. Other Issues

39. I believe that the Inquiry should meticulously investigate how on earth this was allowed to happen. It would be nice if Professor Will who wrote the report on CJD could provide expert evidence. That way I can be better informed on the disease which we still know very little about and this may give us clarification on the origins of my mother's condition. Along with this if the findings of sCJD are inconclusive can/ should the death certificate be reissued?

40. I hope that nothing like this will happen again and that our children will not have to live through such a harrowing experience. I also would like informed consent to be put in place regarding the receiving of blood products.

**Anonymity**

I do not wish to remain anonymous and I want to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed... GRO-C .....

Dated... 22/5/19 .....