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*Reviewed*

Witness Name: Juliet Batten

Statement No.: WITN0343001

Exhibits: WITN0343002

Dated: 26<sup>th</sup> February 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF Juliet Batten

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10<sup>th</sup> December 2018

I, Juliet Batten, will say as follows: -

#### Section 1. Introduction

1. My name is Juliet Batten. My date of birth is GRO-C 1943. My address is known to the Inquiry. I intend to speak about how my adopted daughter, Rosamund, (in future referred to as Ros) was infected with Hepatitis C through blood products or as a result of a blood transfusion that she received for the treatment of her Von Willebrand's disease ('VWD'). In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together. VWD is a genetic disorder similar in nature to Haemophilia and involves the lack of, or defectiveness of an essential clotting protein in the blood.
2. I have been retired for 15 years. I previously worked as a teaching assistant in a school for children with special needs. I am now a full time carer for my

husband John Batten. We have two adopted children, Ros 45, and Paul 43. John and I moved down from Stockport to Kidderminster eleven years ago to be near Ros. I support Ros in a number of ways such as shopping and household chores and moral support. Paul still lives in Stockport.

3. Ros was first made aware of Hepatitis C affecting her in 1993 when undergoing ankle surgery at St Thomas's Hospital. We do not know how or when she was infected or diagnosed because her medical records are missing. However, from 1975 onwards she was continuously treated with a range of blood products. I believe the blood products or blood transfusions used to treat Ros's VWD were contaminated. In my view there is no other explanation as to how our daughter could contract such a disease.

## **Section 2. How Affected**

4. John and I adopted Ros at 12 weeks from the National Children's Home on the Isle of Man. Paul was also born on the Isle of Man, but was adopted separately at 4 years. When Ros was adopted there was no sign of a bleeding disorder, we had adopted a perfect child. I first discovered Ros had a bleeding disorder in January 1975 when she was aged around 8 months. I took her to our General Practitioner ('GP') for a routine inoculation. The GP noticed a small bruise on her forehead and she was referred to Manchester Children's Hospital ('Pendlebury') for further tests. It was at Pendlebury that she was diagnosed with severe VWD, type 3.
5. Around the time she started to walk she had a push along trolley, and she fell into it one day developing a large bump on her head. We had our first trip to the hospital. Sometimes we would be at the hospital every week, or monthly depending on the type of accident Ros was involved in. Throughout her childhood and adolescence she suffered severe and debilitating bleeds. At times the bleeds caused her to be in a wheelchair or on crutches. She was treated with Cryoprecipitate all through those years. When not having bleeds Ros continued to be a

healthy, active child, with a cheerful and positive outlook on life, though she often suffered unexplained bouts of tiredness and minor ailments such as sore throats.

6. Ros was placed under the treatment of Dr David Evans, the specialist in haematology at 'Pendlebury'. She stayed under him and at that centre until around the age of 15. Dr Evans was assisted by a specialist nurse; Alex Susman-Shaw. She was brilliant and very supportive. There was another doctor in the team, Dr Richard Stevens. As a team we trusted them.
7. In some respects Dr Evans was clinical in his approach, but over time he became a personal friend. He arranged parties at Christmas for children who suffered from bleeding disorders. He said the parties were a good opportunity for him to observe his patients in a relaxed environment. I could also speak to other parents with a relaxed state of mind. At the time we thought this was a good thing.
8. Dr Evans' wife was also a GP and on several occasions the parents of the haemophiliac children were invited to their house at Christmas for a social occasion. In later years we knew about the Hepatitis C but I felt unable to bring it up, and I do not recall they ever mentioned it. In 2009 I decided to write a book; 'Funny Blood' which was based around Ros's experience of being a female with VWD, and her ordeal of being infected with Hepatitis C. I sent Dr Evans a copy of my book and he responded with various suggestions which were helpful. One suggestion was that the book ended when he stopped being her haematologist. Of course we are not sure when or how she was infected because the notes Dr Evans kept went missing.
9. One complication of Ros being a female with VWD is when her periods began. At the age of 13, Ros had her first period. It was traumatic. After a week of heavy bleeding Ros was given cryo treatment at Pendlebury.

Her blood count was low and she was booked in for a blood transfusion. Following Ros's third period and many complications with extremely heavy bleeding, which was very frightening for her and us, Dr Evans referred her to a gynaecologist, Professor Elstein at Withington Hospital, Manchester. It was decided that whilst Ros was under the care of Professor Elstein she could be treated at Withington Hospital for both her VWd and the complications that came with her periods. Dr Evans transferred her treatment programme to a haematologist there, Dr Taberner. Dr Taberner treated Ros for her VWd up until she was 19 or 20 years old and on the odd occasion during her time at Huddersfield University.

10. In the early years the treatment was Cryoprecipitate, and Dr Evans was keen to keep her on this treatment as long as he could. I am not sure why, looking back maybe because there was a higher chance of it being more pure. I do not recall ever being told the reasons. Cryoprecipitate was frozen solid, defrosted and thawed out in the sink. It was difficult to administer, and only ever done at 'Pendlebury'. On one occasion Ros had an allergic reaction to Cryoprecipitate and started to go into anaphylactic shock; I may have wondered if that was because the blood product was not pure. Ros needed transfusions on four occasions. Three of these were at Pendlebury in 1987, the fourth in 1995, and I am unsure which hospital that was at. The first three were period related.
11. After Cryoprecipitate, around the mid to late 1980's she was treated at Pendlebury with, I think, a product called 8y. After 8y she went onto Haemate P. Both of these products were Factor VIII. Haemate P was administered at home, it was a bottle of powder, and a bottle of water, we would have to combine the two and Ros would inject herself with a syringe.
12. Ros is a very positive, determined and independent person. She refuses to let her VWD get in the way of her independence. Despite

setbacks with her bleeding problems in her last year at school she secured a place at Huddersfield University to study Communication Arts and Theatre. When she was 21 she spent five weeks with a friend in South America.

13. It was not until 1993, and Ros 19, that we learned she had Hepatitis C. She needed an operation on her ankle, we asked for her to be transferred to St Thomas's hospital. We had done our research and St Thomas's seemed to be very thorough. I was not with Ros when she was told she had Hepatitis C. It was about 30 minutes before she went into theatre when the Doctor, Dr Savidge came to ask some pre – op questions. He talked to her with the assumption that she knew of her Hepatitis C status, it was on her medical records, but she did not have a clue what he was talking about. From my knowledge he did not provide any further information on it. A chance remark to a teenager about to undergo an operation, is not the best time to tell them they have Hepatitis C. Maybe Dr Savidge thought she knew, nonetheless, it was not the right time.
14. Ros must have been informed of her Hepatitis C when I went to visit her at St Thomas's that evening. We could not understand why no-one had informed Ros of this before. Our relationship with the doctors, nurses and other staff at Pendlebury had always been good. But, at no point had anybody mentioned the fact that Ros had contracted Hepatitis C. I did not know what Hepatitis C was, so I do not think it had that much of an impact at first. We were given no information, it was downplayed, and the Doctors did not seem to be concerned. We were too focused on her post- op recovery that it got pushed out of our minds
15. When we went back to Manchester we spoke to Dr Evans about the diagnosis. We were told it was a strange virus and it could take up to 20 years to have any effect. We did not know how long she had been infected for. When Ros asked Alex Suzaman-Shaw, the clinical nurse specialist from Pendlebury, for a copy of her medical records she was

told 'they had gone down a black hole'. We, as her parents, wondered whether she had been infected as a child. In which case, we as her parents should have absolutely, without doubt, been informed as soon as the doctors were aware.

16. The worry did not arise until much later. We were starting to learn the impact Hepatitis C could have. There were people in the Haemophiliac community who were dying from this disease. The concerning thing was the lack of information. Ros was never told she could pass the virus on. There was no information to us about being possible contacts. Advice such as 'not to share a toothbrush', were things we just picked up along the way.
17. In the summer of 1985 there were two meetings at Pendelbury that called for the attendance of parents of children with bleeding disorders. We attended the two meetings, and I remember because I had to come back from a holiday. The meetings were about AIDS and the HIV virus. HIV was coming in and I suppose we were being warned. However, we have no memory of being advised or provided with information about Hepatitis C.
18. It was in the mid 1980's that Ros and I went to Manchester dental hospital for her routine dental appointment. When we arrived there was a separate section for Ros to sit in. Everything was covered in white plastic. Then the dentist, Dr [GRO-D] came out wearing an all-plastic overcoat, masks, gloves etc. and I was confused. It all seemed incredibly protective for a child who at that point was not diagnosed with any virus. We understand that Dr [GRO-D] was in regular communication with Dr Evans regarding his patients, and she was also on the team of specialists for Ros's annual review.

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

19. As far as I am aware, Ros did not receive any infection other than Hepatitis C from the blood products and / or the transfusions she received. Ros did receive a letter from the Birmingham Haemophilia Centre telling her that she had been given a batch of treatment which had been identified as containing vCJd. However it could be that there are other viruses or diseases but they have not yet made themselves known.

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

20. As a parent I gave consent for Ros's treatment for her VWD. However, as far as I recall I did not give consent for her to be tested for Hepatitis C. Nor do I have knowledge of her being tested for any research purposes, though it is possible that, in the interests of medical science and new treatments, samples might have been sent by doctors from time to time. See 22 below.
21. There was a review clinic every year and blood samples were taken to monitor her VWD factor and her blood platelets. We thought these extra blood tests were to help get the balance right for her future treatment. I suppose, looking back, it was possible these tests were used to find Hepatitis C or other diseases.

#### **Section 5. Impact**

22. As far as I can recall we were never told of the potential risks of having the blood products or undergoing the blood transfusions. The first news of Ros having Hepatitis C did not hit home. Soon, the more I learned the more horrified I became. My husband John and I started attending the Manor House Group, a North and West Cheshire group on campaigning. We went to these meetings where everyone was sad and angry. All these emotions of shock, horror, worry and confusion came along as we discovered more. I became very worried as to what would

happen to the health of our lovely daughter. Seeing someone so young and ambitious being infected and facing a very uncertain future, has been very difficult. It has strongly impacted on me over the years.

23. Despite Ros's vWd she has always been determined to be independent. After graduating from University she moved into a flat with five friends, and she got a job as a sales assistant at John Lewis. Ros loved the work and was good at her job, but standing all day was very bad for her joints and she became more and more affected by severe pain. She was earning and able to pay her own rent and bills. However, because of the impact of her Hepatitis C she needed treatment, and that's when I felt I needed to support her even more.
  
24. Around 1998 whilst under the care of the Manchester Royal Infirmary the haematologist (possibly Dr Charlie Hay) had been doing regular liver function tests on Ros's blood and recommended treatment. She started Interferon. She self-injected into the fatty tissues in her stomach and thigh three times a week for three months. These injections were debilitating in the extreme. The initial treatment failed and she was told to continue with the interferon for a further 9 months. The side effects from the treatment meant she had headaches, she was groggy, depressed, and she suffered from joint pain. She had flu like symptoms for a whole year. I remember clearly at the end of our first consultation I was shocked and horrified to find Ros was handed a prescription for the Interferon and was told to go to the pharmacy for it. She had to pay for this Interferon. For me, personally, this was totally horrifying. If as we believe, Hepatitis C was given to Ros through contaminated blood products / transfusion, the very least the NHS could do was pay for her treatment.
  
25. Ros always made arrangements to meet me when she needed support and comfort. The lowest day we both had was when I came out of work, and was surprised to see her waiting for me. Her spirits were very low; she is a very resilient lady but she had just given up. We went for a



coffee and we kept looking at each other and crying. She felt terrible and so did I. At this stage she was working as the Social Secretary at John Lewis, she would sit at her desk and try not to fall asleep. She finally accepted she could not work whilst on the treatment and was off sick for the remainder of the twelve months. Because she was unable to return to work she lost her job. After three months of the treatment Ros was pronounced PCR negative, which was encouraging but at the end of the twelve months on Interferon she was back to being PCR positive.

26. At the time she was living with a friend in South Manchester. Her friend was mostly out at work and Ros was alone at home in bed. I was available to provide physical support such as cleaning, and household chores but it was difficult when I was working. Trying to be independent with VWD and Hepatitis C was a struggle. Eventually she went on to benefits, and due to being on benefits she could not find anywhere to live because no landlord would take her on. She moved in with friends for a while, still determined to be as independent as possible. We had to support her at a time when John was semi – retired and I had stopped working.
27. During this time we were having personal difficulties with our adopted son Paul. The attention we needed to give Ros, during her Hepatitis treatment, meant we were unable to provide Paul with the support he should have had. This has caused some issues down the line.
28. In January 2001 the Haematologist at Birmingham Hospital wanted to carry out tests to monitor the virus. The tests she was having, such as Ultrasound, were good to a certain point, but could not tell them everything about the state of her liver. Most haematologists do not recommend a liver biopsy because of the risks of bleeding. At the time Ros had met her future husband, Adrian, and she had to think about the future with him. Knowing that the biopsy would provide the clearest

indication of the state of her liver, she pushed the specialists and they performed the procedure.

29. During the biopsy they hit her portal vein and caused a massive bleed. The bleed was not apparent until later on in the evening. By the time she realised something was wrong, she was in intensive care having six pints of blood drained from her abdomen. This was the worst day of my life as we were woken at 1.30 am and told to come to the hospital in Birmingham. As we drove down the M6 we discussed the possibility that Ros might be dying and neither of us could remember what hymns she wanted for her funeral. If it was not for the Hepatitis C, this procedure did not need to happen. When the results of the biopsy came back, they reported her liver was in a good state. However, she spent weeks in hospital as a result of the complication.
  
30. Her second course of treatment started in 2002 and continued for six months. This was pegylated interferon with Ribavirin, again with terrible side effects. After this treatment, in June 2003, she was told she was (PCR) negative (not guaranteed virus free) and had to go back every six months for a couple of years. Then she was signed off, even though the treatment and/or the virus has left Ros with prolonged bouts of chronic fatigue, which continue to this day. Ros has not had any paid employment since 2007.
  
31. This whole experience has brought both John and I much heartache and sadness. Having a bleeding disorder as severe as our daughter's is an agony in itself. Having Hepatitis C on top of all of that has drained us of physical and emotional resources as we have struggled to acknowledge what has happened. We have spent much energy and time helping Ros face these challenges in her life. It is really hard to see such a talented ambitious young woman unable to work, or even do the most basic of tasks. The whole time she was undergoing treatment I was worried for her, I could not feel or imagine how she felt and that was difficult. She was not living a normal life. She had to give

up her job and thought because of the virus, nobody would want to be with her. That thought still hurts.

### **Section 6. Treatment/Care/Support**

32 Some years ago Ros asked for counselling through her GP and was referred for six weeks. At the end of six weeks the counsellor seemed pleased with what he thought she had achieved, but Ros knew that he had not even touched the surface of her problems. Many years later in a desperate state Ros discovered she could access a psychotherapist through her haemophilia unit. This lady was excellent but sadly only had 6 months with Ros before she retired. Ros had not been made aware of this option until she was on her knees. At no time was I offered any counselling for myself. I believe counselling would have helped then and now. I was so anxious and suffered a lot with worry.

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

32. The details of the financial assistance I am not aware of. I think Ros received some form of payment from the Skipton fund. I believe it was a very lengthy and difficult process. The reputation of the fund was not good either. There was news that someone who worked for the trust went off with some of the funds. During the time she was on benefits she was able to secure a small amount of money from a Quaker trust. The amount was nothing large, just enough to pay a month's rent, but again I am not clear on the financial assistance Ros received.

### **Section 8. Other Issues**

33. The whole impact of the infection has consumed our lives. Although being a part of a campaign group, Manor House, kept us in touch with similarly affected and infected people, back at home we felt isolated. It is not something you talk to your neighbours about, you cannot discuss this with the general public. In the early days I felt somewhat isolated

from other adopters. Then having a girl bleeder in the family added to my feeling of isolation. The diagnosis of Hepatitis C brought me further feelings of isolation.

34. We are constantly worried about Ros's future. Our experience of having a family member with Hepatitis C, through no fault of her own, has brought much sadness to our lives. We feel and carry this sadness for all the people with haemophilia and other bleeding conditions who have been placed in similar situations, many of whom have become friends.
35. Successive governments could have resolved this situation sooner. Even after a couple of inquiries we are still being ignored. As much as we are able to demonstrate our situation, nobody has been listening, so I am angry with that. A lot of time and energy has been spent on this campaign, when it could have been spent doing something more interesting. A huge part of our lives has been taken away. I have hated being told to go away and not to bother. We have written to the Department of Health on a massive number of occasions, but they just reply with the same letter in a different format. The frustration is with not knowing what went wrong and why. Twelve years on from the first inquiry and I still have unanswered questions.

### **Statement of Truth**

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

Signed

**GRO-C**

Dated *March 2nd 2019*