Witness Name: Rebekah Wintle
Statement No.: WITN1058001
Exhibits: None
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF REBEKAH WINTLE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 January 2020.

I, Rebekah Wintle, will say as follows: -

Introduction

1. My name is Rebekah Wintle. My date of birth and address are known to the Inquiry. I am the daughter of Colette Wintle, and I have inherited Haemophilia A. I intend to speak about my Mother. In particular, the nature of if her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

2. I am aware I come from a family with a lengthy and complex Haemophilia history. Many of the female members have been severely affected by Haemophilia. I am also aware that sadly, many of my family members were infected by contaminated blood products during the 1970's and 80's.

How Affected

3. My mother who is considered a mild Haemophiliac, was first treated with commercial imported Factor VIII blood products in 1976 at Glasgow Royal Infirmary. I now know this is when she became infected with Hepatitis C.

4. She was infected with Hepatitis B in 1982 at Kent and Sussex Hospital and exposed to a further infection of Hepatitis C in 1985 at the Royal Free Hospital.

5. Mum was also exposed to new variant Creuzfeldt Jakob Disease in 1993.

6. All of these infections happened during the course of Haemophilia treatment with Factor VIII blood products provided by the NHS. My mother was infected by three different hospitals across two countries within the UK.

7. I believe my Mum was first informed of her Hepatitis B infection in 1983 when it was discovered she was suffering an attack of Hepatitis. This occurred as a result of having been treated in December 1982 with Factor VIII treatment, following a spinal stretch under general anaesthetic.

8. Neither my mother's GP nor the Haematologist from Pembury Hospital, diagnosed her with this condition. In fact, it was a senior registrar who my mother knew and worked alongside on a surgical ward when she was training to be a nurse in 1982 who made the discovery.

9. The registrar noticed that my mum was severely jaundiced whilst on duty one day and offered to take a sample of her blood to send to Kings Hospital London. My Mum told me she had repeatedly been seen by two GP's and told she was imagining her symptoms of rapid weight loss, dark urine, abdominal pains and jaundice.

10. Without this intervention by the registrar my mother would have continued to struggle with symptoms of ill health but no diagnosis. She would not have realised how serious her condition was. This would have been down to the failures of her GP surgery and haematologist to recognise the connection between her symptoms and treatment with Factor VIII products.

11. I understand she was never given adequate information to manage or come to terms with the consequences of Hepatitis B infection. She was living with my

Aunt at the time, a fellow infected haemophiliac and they did their best to look after each other.

12. Very little information was offered to my mother or father about the risks of passing on Hepatitis C infection even though at the time of her diagnosis I was a newborn baby. She was actively encouraged to breast feed me despite a diagnosis of chronic Hepatitis C. The risk of transmission through breast milk is low but regardless, the risk existed and should have been communicated to my Mum.

Other Infections

13. With regard to additional exposure to infected blood products, it is my understanding that my mother, whilst an inpatient at the Royal Free London in 1993 was also exposed to new variant Creutzfeldt-Jakob disease (nVCJD) during a three month stay in hospital. She made enquiries about possible exposure in the late 1990's when fears over this disease were being reported in the media but was rebuffed by the haematologists at the Haemophilia centre and told to "stop panicking". It took until 2004 before my mum discovered the truth about her exposure to this horrible disease which was nearly a decade after her exposure through Factor 8 treatment.

Consent

14. My understanding from discussions with my mother is that at no point throughout her young adult life was she ever informed of the high risks infection from treatment with Factor VIII products. My mother has been very clear that no doctor had ever advised her about the known risks of hepatic virus transmission from treatment with FVIII products.

15. She was unable to give informed consent as she was not aware of any of the facts relating to Factor VIII products at the time she was being given them. Even though consent to be treated may have been received, consent to treatment

with virally infected products was not. These risks were never communicated so informed consent could never be given.

16. I fully believe that my mother was used as a guinea pig when they were using mild Haemophiliacs to test rising levels of Hepatitis levels with what they knew to be a dangerous blood products. My mum has shown me evidence of what the doctors knew.

Impact

17. The impact of infection on my mother mentally and physically has been extremely stark. It has caused huge pain, upset and depression from not only feeling unwell all of the time but having lost everything she had worked for, such as her career and a 'normal' family life.

18. I remember many times where I have seen my mum extremely upset and on one occasion she did not want to carry on living any more. On this occasion the family were all at home one evening, and an hour had gone by, and we had not seen Mum. We discovered she was not in the house. It was dark and the middle of winter. We searched for her and found her down a dark lane close to a large, deep pond near our home. She was in a terrible state and totally suicidal. The crippling pain I felt seeing her on the edge was indescribable. I was young but all I wanted to do was run up to mum and grab her. No child should ever have to see that, and nobody should have to go through feeling like their life is not worth living.

19. Seeing my mother in that state has had a big impact on me. I was diagnosed with depression myself at one stage which meant I was on medication and undergoing counselling.

20. Physically Hepatitis C has also had a big impact on my Mum in day to day life. She suffered with severe fatigue and sometimes had to stay in bed all day which affected me as a child. Mum would have loved to watch me play sports and participate in out of school activities but sometimes she was not able to. Even

now she has days where she has no energy and can't be as active as she would like.

21. I found Mum's inability to share in my achievements challenging and as much as I knew she loved me, it was tough when she wasn't able to be there. Her constant pain meant that sometimes when she could be there for me, she was not quite herself. This was difficult to understand as a child as she could get aggressive or angry for what seemed like no reason at all.

22. My mother's illness has affected me from the day I was born. She always sought to protect me from the upset of knowing about her infections and the affect they had on her.

23. I first became aware of my mother's infection when I was 10 years old. We were on a family holiday in America, when my mother became unwell and her condition deteriorated rapidly. My father had to call 911 for an immediate transfer to hospital. I have vivid memories of this experience and found it very scary and it is something I will never forget. My Mum was screaming in pain and was hospitalised for the majority of the holiday as a result of an internal bleed which required treatment with Factor VIII

24. I am shocked and upset by how my mother learned of her Hepatitis B diagnosis. The risks of treatment with Factor VIII and risk of transmitting the infection were not explained to my family members. I feel that the doctors knowingly infected my mother and other members of my family. In doing so they ruined my mother's future as a young woman and her life as a whole.

25. Communication to my mother about results of tests for Hepatitis C infection has been equally poor, coming years after the infections occurred. In my view this shows a deliberate lack of care and suggests that doctors were deliberately withholding vital information on the life-threatening illnesses she had been infected with.

26. 1985 was the last exposure to Hepatitis C. By this time the NHS could have chosen to treat everyone with safer blood products but chose to continue to use commercial FVIII products which they knew were contaminated. This leaves the impression that patient safety was certainly not a priority in the treatment of my mother or other infected haemophiliacs.

27. Mum's infection had a massive knock on effect on me throughout my childhood. My relationship with her has been severely strained at times and the bond I have with my mother is not as strong as it should be. It sickens me that my mother has been knowingly infected with hepatitis viruses by medical practitioners who were supposed to care for her. The whole episode is entirely immoral.

28. In respect of vCJD I know my mum had to fight to get her hospital records. To refuse access to a person's own medical records is illegal. I also think it makes the hospitals look like they were trying to hide the harm which they had inflicted on my mother.

29. To know this has happened to my mother is painful and deeply upsetting and it causes me to question whether I can trust doctors with my own treatment and medical records. I am also concerned about whether they have my best interests in mind.

30. Due to my mother having had Hepatitis C she was often left to the end of the day when having operations done. This practice reinforced that stigma existed around her diagnosis and made her feel like she was a danger to medical professionals.

31. This scandal has touched my wider family as well as my Mum. My aunt and GRO-C had also been infected over the time period which this Inquiry is investigating. I was shocked when I learned of this; treatment that was supposed to improve the lives of my family members ended up doing them serious harm.

32. My Mum has always been a great advocate of openness and honesty so she was not shy about discussing her infection and how she came to be infected, with the people she knows but she should have never been put in this position in the first place. She does sometimes get tired of having to explain her history and why she is not able to work now or why she had to retire very early. Infection through contaminated blood really has changed her entire life.

33. I really admire my Mum's openness about her infection, but I have often struggled to explain to my peers why my Mum was absent from various important events in my life. Now I compete in international equestrian events and my Mum cannot always accompany my Dad to support me and explaining this to my friends is hard.

34. Mum being medically retired at a young age also put an additional strain on my Dad. He has always felt like he had to fill the role of both parents and has expressed to me that he felt like a single parent at times.

35. Haemophilia stigma was difficult enough back when my Mum was working without the additional difficulty that Hepatitis C infection brought. She lost a career with an airline solely on the basis that she was a haemophiliac even though it had never affected her employment before.

36. Her Hepatitis B diagnosis ended her attempt to return to a nursing career. In fact, when she was diagnosed, she was told that she was not allowed to complete her nursing training. She did begin working with the NHS in a different role many years later, but she was encouraged to retire aged 38 because she was having lots of Hepatitis C related sickness absences. I think she felt entirely unsupported in any of her attempts at working as a result of either her haemophilia or Hepatitis C infection.

37. Even though my Mum is now allegedly cleared of Hepatitis C my worries about her have not stopped. I live in fear that because of the Cirrhosis caused by Mum's chronic Hepatitis C she will die of liver cancer. This worry will never go

away and it has been caused as a result of treatment provided by the NHS which was supposed to help my Mum manage her haemophilia symptoms.

Treatment/Care/Support

38. My mum was referred to a hepatologist after she was diagnosed with Hepatitis C in 1991. Prior to this she had no support for Hepatitis B or any information prior to her diagnosis.

39. Mum underwent two courses of treatment for her Hepatitis C which she often compared to chemotherapy. These treatments came with terrible side effects which persist to this day. The main difficulty my mother has as a result of these treatments is inflammatory conditions which cause further pain.

40. Mum's first offer of treatment came in 1999. It was a treatment with antiviral drugs and the side effects were so pronounced that she was unable to complete the full 6-month course. She completed 4 and half months of the treatment but this had no impact on her viral load.

41. Mum underwent a further course of treatment in 2015 with anti-viral drugs. This was a difficult time for me as I was just beginning a course to study equine management and Dad GRO-C GRO-C was trying to get back to full health. The stress I was dealing with at the time made seeing Mum struggle even more difficult, she was glowing yellow, her hair was falling out and she was unable to function normally. It was a time I felt I really needed my parents support and both were struggling with their own health.

42. No psychological support or counselling was ever made available to any of the family at that time. I think that the absence of help and support available for me and my Mum was very poor. Some form of psychological support could have helped me understand what was wrong with Mum and how her infection or treatment was affecting her.

43. Treatment for Hepatitis C also came with side effects of severe fatigue, hair loss, jaundice, sickness, muscle and bone aches and itchy skin. Mentally it left her feeling very low and limited her ability to go out and socialise while she was on the treatment.

44. I think more assistance should have been given to my mother when she went through the treatment which had serious physical and psychological side effects. If any alternative treatments were available at the time, I think they should have been considered over the antiviral, chemotherapy style treatment due to the severe side effects and long-term damage it can cause to the body.

45. As a result of chronic Hepatitis C infection my mother has been diagnosed with cirrhosis of the liver. This affects her day to day living as it causes severe fatigue. She receives 6 monthly MRI scans on her liver to monitor for cancerous growths. Waiting for the results of these scans is always a challenging time for the family as it is impossible not to fear that the worst has happened.

Financial Assistance

46. I understand that my mother received no financial assistance until 2005 when it was announced in 2004 by the then health minister John Reid that the Skipton Fund was due to be set up to offer ex-gratia payments. I believe that she was given stage one and two payments owing to the fact that she had been diagnosed with advanced Cirrhosis of the liver in 2004. My mum was aware that the fund was going to be set up and communicated with government in 2004. At the time, as she had been infected first in Scotland, she made an application to the Scottish government but was referred to the English scheme.

47. In more recent times having obtained her Scottish health records showing she was infected for the first time with Hepatitis C at the Glasgow Royal, she made an application to the Scottish scheme but was denied access to it. Despite showing clear records evidencing treatment with US commercial blood products known to be 100% infected with Hepatitis C she was still denied the right to claim from the Scottish scheme because she was domiciled in England.

48. As far as I am aware the preconditions imposed on the making of an application for this financial assistance was dependant on the person being able to prove chronic infection through their medical records, test results, and letters from consultants in haematology and hepatology. All of these requirements had been met through the hard efforts of my Mum and her claim was still denied

49. I think that the ex-gratia payments that my mother has received so far are shockingly low, and do not at all reflect the level of harm and extreme suffering she has gone through and the impact it's had on me and my dad. In my eyes what the government has offered her doesn't even cover the loss of her health and the income she has lost from not being able to work. The financial pressure has meant that at a time in her life when she should be looking toward retirement, she is stressed about not being able to pay off the mortgage on our home and worries about how my dad will cope if she dies.

50. I think it is disgraceful that if mum dies under the current rules of the EIBBS Scheme, my dad receives no compensation for her loss of life. I know how unhappy mum has been about all these different trust funds and has often described them as begging bowls.

51. What makes it worse is that we have GRO-C in Ireland who are treated very differently by their government. Our GRO-C had the same imported factor 8 but their government decided to recognise their extreme pain and suffering and paid them a fair level of compensation years ago. My mum has had to fight and campaign year after year for 25 years. She was unable to take legal action back in 1991 because she couldn't get legal aid and Hepatitis C was not recognised in the litigation. This restriction was in place despite the government knowing haemophiliacs were infected with Hepatitis B and C long before HIV was emerging.

52. Not one UK government has been willing to listen and accept that what happened to my mum was negligent and avoidable. There was safer treatment that mum could have had at the time she needed it. My mum has never been

able to get legal redress and I feel frustrated that the government don't care about the haemophiliacs who were harmed by their NHS treatment.

53. Why is my mum's life worth less than that of our GRO-C in Ireland who were paid compensation well in advance of any inquiry? Why was I denied the right to enjoy a normal life with her? Our family has been denied justice and I hope that this inquiry will tell the truth and do the right thing by my Mum and all the other haemophiliacs in the UK.

Other Issues

54. As a haemophiliac born after the contaminated blood scandal I am certainly in a safer position than my Mum was growing up but stigma around haemophilia still exists as a current issue. When I was at school my Mum was always very conscious about telling members of staff that I was a haemophiliac but should still participate in sports as much as possible, with the exception of hockey. Despite this there were still times where I felt singled out by my teachers. I recall one instance where I was forced to remove my Medical Alert bracelet by a PE teacher who thought it could injure another student. This was humiliating and exacerbated the difference between me and other pupils in my school.

55. I have only been hospitalised as a result of bleeds twice in my life so I understand that I have been more fortunate than my Mum and I know that because of her campaigning for safer recombinant Factor VIII treatment I have been protected from the high risk of blood borne viruses which have destroyed the lives of so many of my family members.

56. I would like the Chair Sir Brian Langstaff to look at and put in place the fair recommendations made by Lord Peter Archer in his Independent inquiry which my mum and dad were witnesses to. I attended this with my mum when I was 12 and I know my mum had hoped that she would never have to carry on campaigning again, but the government refused to follow these recommendations.

57. Lord Archer quite rightly looked at the impact of this blood disaster and the affect it had on victims, partners of victims and their families. As a child I missed out on so much time with Mum and it damaged our relationship. That time is irreplaceable. I want this to be recognised by the Inquiry. The time I have left with my Mum should be eased by financial compensation which will ensure she gets the best possible care and we as a family are not left with the struggle and stress of financial losses caused by the state.

Statement of Truth

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

Signed GRO-C

Dated 02/02/2020