

Witness Name: Stephen Kenneth Roles

Statement No.: WITN3546001

Exhibits: None

Dated: October 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF STEPHEN KENNETH ROLES

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I, **STEPHEN KENNETH ROLES**, will say as follows: -

#### Section 1: Introduction

1. My name is Stephen Kenneth Roles. I was born in  South Wales. My date of birth is  1967 and I reside at   Hertfordshire . I am currently working as a primary school teacher. I have three children; two with my former wife and my current partner, Michelle, has one child.
2. I have mild Haemophilia A.  is a carrier of Haemophilia, which she knows, and she has had gene therapy tests.

#### Section 2: How Affected

##### *Haemophilia*

3. When I was one year old and just starting to walk. I fell on my baby bottle and split my gum. I was taken to Neath and Port Talbot Hospital and they could not stop the bleeding. I lost so much blood that my veins collapsed, and they had to cut my ankle open to get access to a vein. They still could not stop the bleeding,

so I was rushed by ambulance to the Royal Infirmary in Cardiff. At Cardiff Royal Infirmary I received treatment and I was diagnosed with mild haemophilia A (6% clotting).

4. My grandfather had haemophilia. He was in the cavalry in World War I for a year, until he was bed ridden for weeks following a tooth removal. They found out he had haemophilia and he was discharged on medical grounds. At that time there was no treatment for haemophilia. He was in bed for weeks after just a bump. GRO-C  
GRO-C. My brother does not have haemophilia.
5. My mother must have been told about the impact and risks of haemophilia at the time I was diagnosed. At that time, the treatment was with Cryoprecipitate and we were not told of any risks of the treatment. I was treated at the Cardiff Royal Infirmary until a Haemophilia Centre opened at the University Hospital of Wales ("UHW").

*My experience of treatment with blood products*

6. I was treated by Professor Bloom at UHW until around 1979-1980. My parents did not drive, and it was a 70-80 miles round trip by public transport. A Haemophilia Centre then opened at Morriston Hospital (part of Swansea Bay University Health Board) in Swansea, which was closer, and so my mother moved my treatment to that hospital. I moved to Morriston Hospital in approximately 1979-1980 (when I was 12-13 years old) and continued to receive Factor VIII treatment. I continued to receive dental treatment at Cardiff. At Morriston Hospital I was under the treatment of Dr Kurshid.
7. My mother's cousin had two children with haemophilia and their treatment remained at UHW. Unfortunately, they received contaminated blood products, contracted HIV and died.

8. My mother had seen a programme on the television regarding contaminated blood and had spoken to a doctor at UHW about her concerns. The doctor said not to worry and that the treatment in Cardiff was not and would not be affected. It was said as though the treatment in Cardiff was "special". Unfortunately, this was not correct and seven children of members of the South Wales Haemophilia Society died of HIV, two of which were my cousins. UHW must have received a bad batch of blood infected with HIV.
9. My mother always asked the doctors if the product was heat treated, but there were times when my mother was not there. When I was around 12-14 years old, the doctors would come into the room and give me the treatment. I would not ask at that age, but when I got older, I started asking if the product was heat treated myself.
10. I remember around this age (12-14 years old) I had a knee injury and was treated at Morriston Hospital and received Factor VIII. Whilst I was recovering in hospital, I was taught how to self-inject Factor VIII. I was told about the risks of injecting the Factor VIII incorrectly and was told to mix the Factor VIII in a certain way. I was not told about risks of the Factor VIII product itself. I did very well injecting the Factor VIII in hospital and so I started home treatment.
11. I have been on hospital and home treatment with Factor VIII and later in adult life Advate, if I have needed it. If I had a small injury, my mother would phone the hospital, she would be told the amount of Factor VIII to inject and I would inject myself. Whilst I was at school, if I had a bump, I would be off school for a few days or a week depending on the severity. When I started home treatment with Factor VIII, I was not off school so frequently. I did not have any side effects from taking the Factor VIII.
12. I completed my A levels and I went to Caerleon College, Newport from 1988 to 1992. Whilst I was at college, UHW was the closest centre and I transferred back

to that hospital for treatment. I recall having several bleeds, bumps and bruises during college including a broken foot and a severe bleed to the hip.

#### *Testing for HIV*

13. I do not recall and was never told when I was tested for HIV, but it was probably whilst I was at university between 1988 and 1992. Thankfully, the tests proved negative.

#### *Diagnosis with Hepatitis C*

14. I have only had sight of some of my medical records to date and I await copies of the rest of them. Those records I have seen confirm that I tested positive for non A-non B Hepatitis in 1982 in Swansea. They also confirm I received American Factor VIII that year.
15. However, my recollection is that it was not until 1992, the year I finished college, that I received a letter for a regular outpatient review appointment at UHW, where I had some standard blood tests. I had regular reviews every six months, which I attended on my own. I was told at that appointment that I had been tested and had been infected with Hepatitis C. I do not recall the name of the doctor that informed me, but I do not think it was Professor Bloom, my usual doctor.
16. This was the first time I was told my results were abnormal. This was a massive shock to the system. I was given no advice or information during this appointment, except I think I was given a small A5 leaflet either then or at a later appointment. I have often wondered if there was a long gap between discovering that the blood had been contaminated and being informed I had Hepatitis C, and my records suggest there was.
17. I had already had Hepatitis B at the beginning of college (approximately 1988) and I had cleared that virus and received boosters to ensure it did not return. I was not told how I contracted Hepatitis B, but I was tested during routine blood

tests, I think. I was not given much information about Hepatitis C during this appointment, as not much was known at the time. In my mind I thought it must be similar to Hepatitis B. I was not told about any risks of transmission. I became a teacher and I got married, so it was not at the forefront of my mind for a while. I told my mother and my then fiancée, and we took precautions.

### **Section 3: Other Infections**

18. As noted at paragraph 15 above, I did contract Hepatitis B in or around 1988. I was given boosters to keep the virus away,
19. When I was in my late thirties or early forties, at some point between 2005 and 2010, I received a letter confirming I had received blood which had been contaminated with vCJD and I was at risk of contracting that infection. At the time, there were adverts on the television about mad cow's disease; it really shocked me. I was told it could take up to ten years to present with symptoms and there is no test for it. I was informed I was at risk around ten to fifteen years ago now. I later received a letter stating that I had received blood products from a donor who had died of vCJD.

### **Section 4: Consent**

20. I recall being told the doctors would test my blood for HIV. This would have been during one of my regular blood tests. I was never told that my blood was being tested for Hepatitis C.

### **Section 5: Impact**

#### *Treatment for Hepatitis C with Interferon*

21. Soon after being told about my diagnosis in 1992, I was informed that I could go on a trial of treatment with Interferon, which would last six months. I underwent treatment in approximately 1992 or 1993 in the form of injections. I did not know

much about the treatment, but I said I would have a go. I was still working during the treatment, but I regularly had a few days off work following side effects of the injections both physical and mental.

22. I injected myself with Interferon and I was shown how to do so by UHW. The treatment was one of the most horrible experiences of my life. I had a number of side effects including sweats, hot and cold flushes, flu like symptoms and shivering. I had to wrap myself up in bed for a couple of days after several treatments. I would be very, very tired, with aching limbs and quite tearful at times. I developed mood swings. My ex-wife was still at university at the time. I could not get up in the morning because I was so tired. Unfortunately, the treatment did not clear the Hepatitis C; I was still infected.

*Treatment for Hepatitis C with Interferon and Ribavarin*

23. I then moved to GRO-C Hertfordshire in around 1996, as both my then fiancée and I had been offered full time teaching positions there. At the time, teaching positions in Wales were only for one year at a time. During this time, I was treated by Dr Lee at the Royal Free Hospital in London ("Royal Free"), part of the Royal Free London NHS Foundation Trust. GRO-C was an hour from both Addenbrooke's Hospital (part of Cambridge University Hospitals NHS Foundation Trust) and the Royal Free. I then got married in 1997.
24. Whilst at the Royal Free, in around 1996 or 1997 I was informed about a new trial of treatment, which was a combination of two drugs, Interferon (injections) and Ribavarin (tablets). It was a 48-week treatment plan. Dr Lee asked if I wanted to try the treatment. By this time, I knew more about the consequences of Hepatitis C, such as liver cirrhosis and cancer, which meant I had a lower life expectancy. It was because of these potential risks that I said I would go ahead with treatment. I do not recall a doctor telling me about these risks, but it was something I knew from speaking to other people.

25. The effects of the combined treatment were twice as bad as the first round of Interferon alone. I was told by doctors at the Royal Free about some of the possible side effects of the treatment. I was told that I could develop “man breasts”, which I did, that I might experience flu like symptoms, tiredness and periods of highs and lows. It was nothing like I was expecting though, it was a lot more significant than I was told. I used to inject the drug before bed and I would be shaking, have sweats and flu like symptoms. I was tired all the time. I had a pain down the right side of my body, which still flares up now and again, 20 years later. On one occasion, the Head Teacher at my school was so concerned he drove me to the Royal Free. I had to regularly take a few days off work because the treatment left me so tired.
26. I could not last the 48 weeks of treatment and I had to finish at around 45 weeks because of the side effects. Dr Lee told me she thought I had taken enough of the treatment. A couple of months later I was told that I had cleared the virus, which was a big relief.
27. I recall going to Addenbrooke’s Hospital to see a liver specialist after clearing the virus. The doctor examined me and told me I did not need to see them again, and so I have not been back to the liver department since.

#### *Impact on Employment*

28. I have been diagnosed with depression and the “lows” I experience are very low. In 2009, my wife left me. Unfortunately, my mood swings and fatigue contributed to the breakdown of my marriage. In the divorce proceedings, my former wife mentioned the Interferon treatment and, in particular, the mood swings. She said that I did not understand how she felt when I was on Interferon. She did not talk to me about it at the time.
29. I was working throughout this time. My former wife left, and I felt alright for 18 months to two years. I had some time off work now and again. However, over

time, I became increasingly tired. We shared the children, so it may have been partly that, but I felt it was more than just work and family life.

30. In 2011 I was diagnosed with exhaustive depression. I was unable to walk very far or complete the smallest of day to day tasks. I had six months off work, and I tried to go back to work too quickly. I went back to work for three weeks and I had a further breakdown. I was dismissed from my job as a teacher in 2011 on the grounds of ill health, which hit me quite badly.
31. I was off work for around 18 months until I built myself back up to return to work. I have now been teaching again since around 2013. I have been at my present school now for four years, but I am struggling now to do my job again. I feel I am just clinging on and I do not have anything left in the tank anymore.
32. The fatigue is awful. During the day I struggle to keep going and only put on a smiling face for the children and colleagues. I get back from work at around five or six o'clock and I am not able to do anything. I am not able to mark the children's books on an evening, which I need to do, because of the fatigue. In the day time I get "brain fog" and I forget the children's names, or I forget the words I am trying to say. It's an awful feeling and I beat myself up that I am not able to do what I used to be able to do. I am a very good teacher; I have previously been part of the senior management team and I was seconded as a deputy head. The tiredness gets to me every day. It has a significant impact on my day to day life.
33. Generally, the schools I have worked at have been understanding but it gets to a point where they think "*he's off work again*". The parents and other teachers do not understand.

#### *Impact on the Family*

34. My mother was involved with the South Wales Haemophilia Society and went to regular meetings at UHW with Professor Bloom. My mother is now 75 years old



and does not want to provide a statement to the Inquiry herself. However, she wrote a letter to me to pass on, setting out the background information she is aware of and explaining the impact on her, of her son contracting Hepatitis C from contaminated blood products:

*“Stephen received treatment at the Heath Hospital Cardiff from 12 months in 1968. As a small child he had Cryo and then Factor VIII. After seeing a Panorama programme about infected blood at a routine check-up I questioned a doctor who dismissed this as “never happening here” and I pushed for that heat-treated treatment. At this time, I was involved with the South Wales Haemophilia Group on the committee before it was centralised. A meeting was called of all patients.*

*Out of the committee members, seven sons were lost to HIV including two of Stephen’s cousins. This at the time was kept very secret and not discussed because of the fear and stigma for the families.*

*He was moved to Morriston Hospital aged around 12 to 13 years as a centre opened there and it was not so far to travel, as Cardiff was a 70-mile round trip. He later returned to Cardiff when at Caerleon College, he received treatment several times. He was informed he had Hep B and then Hep C, but it was just brushed off. He had Interferon which left him very ill and did not have any effect. After moving to GRO-C to teach he had treatment at the Royal Free Hospital and was put on a gruelling course of Interferon and? [Ribavarin] because of the Hepatitis C, of which only two patients at the time completed the course. He is now treated at Addenbrooke’s Cambridge.*

*This has left Stephen with depression, fatigue and the worry of the future. It cost him his marriage, home and job while looking after his two children. Through the years he is still fighting and is back in work, also knowing what it has cost his parents and brother through years of anxiety, caring and fighting to keep him safe and well.*

*This was a cover from the start when a heartless government tried to evade the responsibility of their actions and take a cowardly act by laying the blame on the victims.*

*What could a mother do but try to protect her son, not known the treatment could harm her son. Our hope is that those responsible will be named and shamed, and the victims can then have peace”.*

35. During their childhood, my children knew that I had haemophilia, but they did not know about the Hepatitis C diagnosis. I kept it away from them. They saw me have highs and lows, and I would get angry sometimes. Sometimes I could not do anything with them because I was so tired and drained. But they knew that I loved them and supported them.
36. It was hardest for my son, we went through a rough patch. The children decided to move in with my former wife around four or five years ago. They were aged 14 and 16 at the time. They still visit and stay with me and my partner. I have a good relationship with my children, and my partner's child. My children have never gotten into trouble and they are now in university.

#### *Psychological Impact*

37. I still go to Addenbrooke's Hospital for regular reviews for my haemophilia. On the last occasion, in June 2019, I was very low, and the doctor has confirmed he will do a HIV and Hepatitis C test again to reassure me. The doctor is 99% sure they will be negative, but they will check again. I had understood that all the tests I had received since completing my Hepatitis C treatment in 1997 had been negative. However, in the medical records I have received, it is confirmed that in 2003 I was "Hepatitis C antibody positive" and it was recommended that a doctor speak to me about this. I was not contacted at the time, and I do not know what "Hepatitis C antibody positive" means.

38. My two cousins had died from HIV before I cleared the Hepatitis C virus. One died in 1994 aged 32 and the other died in 1995 aged 31. It has been a battle ever since that. I have been getting worse over the last five to ten years. The tiredness is getting worse, sometimes it is hard to get out of bed, and even raising my arms is tiring. I am also forgetful. I do not believe this is due to age, as I am only 52 years old. I struggle to make decisions and I do not feel like I am the same person as I was in my teenage years or twenties. Sometimes I do not feel like "Stephen Roles".
39. These symptoms appear to be getting worse and I have contemplated suicide in the last few months. This is not the first time I have thought about it. I do not think I would commit suicide, but I would welcome the feeling of peace, not having to go through the tiredness, but to go somewhere I do not feel it. I have been to regular counselling for this recently.
40. I have three lovely children that keep me going. I recognise there are lots of people who are worse off than me; people that have died through no fault of their own.

#### *Financial Impact*

41. During periods of sick leave from work due to the effects of haemophilia or Hepatitis, I have still been paid due to the nature of my job, so I have not experienced a big difference. However, when my former wife left me and I lost my job, I had to take on her debt of £32,000. In 2011-2012 I had to claim benefits for 18 months whilst I was not working. Because I lost my job, I had to declare myself bankrupt in February 2012. At the time I was working with Christians against Poverty to try to pay back the debt I owed, however, Christians against Poverty recommended me that I should declare bankruptcy. The bankruptcy still currently appears on my credit score, but it will no longer appear after February 2020.

### *Stigma*

42. I told the Head Teachers at the schools I worked at about my Hepatitis C diagnosis as I thought it was important. I also told two Head Teachers about my depression associated with this. They were generally understanding.
43. I remember on one occasion in around 2011 or 2012 I needed an endoscopy procedure, as I had a bleed in my stomach with an unknown cause. The doctor saw reference to a risk of vCJD in my medical records. He said he needed to leave me until last in the list and he asked the nurse to go and get the old equipment. He did not say why this was, but he did complete the procedure. I also used to have a large label on my file that said something like "chance of infection" or "contaminated blood". I cannot remember exactly what it said.
44. I have avoided having dental treatment for the last 10 years. I did have a tooth out at Addenbrooke's Hospital, I cannot recall when. I was told I can have dental treatment at a "normal" practice, but I would need treatment with blood products before and afterwards. I was worried that if I go and say that I have had Hepatitis C, but it was cleared, and I am at risk of vCJD, they would refuse to treat me. I am now registered with a dental practice, but I have not been there yet.

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

45. I was treated by Professor Bloom at UHW until around 1979-1980, before moving to Morrision Hospital from 1980-1988. From 1988 to 1996 I was treated again at UHW. From 1996 to 2001 I was treated at the Royal Free. Since 2001 I have been treated at Addenbrooke's Hospital and I still go to Addenbrooke's Hospital for regular reviews for my haemophilia.

### *Psychological support*

46. I was not offered any counselling following my diagnosis nor during my treatment. I have arranged counselling myself on and off for eight or nine years. I had some

counselling through the GP which was a six-week course in 2011. I have had a couple of blocks of six-week sessions through the GP. The counsellor did not link exhaustive depression to the Hepatitis C at that stage. I have also had private counselling.

47. Around two years ago, at a regular appointment at Addenbrooke's Hospital, I explained to them that I was low all the time. I was told that haemophiliacs are known to have low feelings due to treatments they experience. I do not know if this meant treatment for Hepatitis (Interferon and Ribavarin) or treatment for haemophilia. This helped me, as I thought *"it's not me then, it's the treatment that has made me like it"*. It was not until I sent the form to England Infected Blood Support Scheme ("EIBSS"), as I refer to below in paragraph 50, that it has really sunk in that it could all be linked to treatment. Before the treatment I was fine during my teenage years and university years.
48. I have had to restart private counselling recently as I was feeling so low. Now I am going to counselling once a week. I was off work for five weeks and I have just recently, at the beginning of July 2019, returned to work on a phased return.

## **Section 7: Financial Assistance**

49. I was a member of The Haemophilia Society and my mother was on the committee of the South Wales Haemophilia Group from when I was around nine years old. My mother told me about the Skipton Fund and that they were available to provide financial assistance. I applied in around 2007. I received a £20,000 ex gratia payment. I cannot remember much about the application process, but I recall filling the forms in and being told I was entitled to £20,000. I was told this was a one-off payment. I am not sure whether I was asked to sign anything.
50. I did not receive any further payments, until a nurse at Addenbrooke's Hospital mentioned EIBSS to me. She encouraged me to apply. I filled in the form and

sent it to the nurse for her to complete with a doctor. She then sent it back to me, and I sent it to EIBSS. I recall there were sections on the form to explain how I had been affected. Dr Emily Symington, Consultant Haematologist, completed the form on 22 May 2018 and confirmed that:

*“Mr Roles has a documented history of depression and has been on medication for this. This along with anxiety has affected both his work and family life. I think it is very likely that Hepatitis C and its treatment has contributed to his mental health problems and it certainly something that is well documented within our haemophilia patients who have been diagnosed with Hepatitis C.*

*Mr Roles describes chronic fatigue that has limited activities of daily living. It is very likely that these symptoms have been contributed to by the Hepatitis C infection and its treatment. This is a common symptom reported by our haemophilia patients with Hepatitis C.*

*Mr Roles reports significant mental health issues and chronic fatigue which are ongoing and are affecting his activities of daily living on at least a weekly basis. I think it is very likely that the Hepatitis C is contributing to these symptoms.”*

51. I received a letter confirming I was eligible, and they backdated the payment to 2016. I received around £9,000 and then from September 2018 I began receiving regular payments of £1,500 a month. This helps me to fund the private counselling at £300 a month. Recently the payment has risen to £2,300.

## **Section 8: Other Issues**

52. I have been informed by Morriston Hospital that my medical records have already been destroyed. This concerns me, particularly as I was a patient at the hospital for a number of years. I believe hospitals should contact patients when they are

about to destroy their medical records, so that they can request a copy before they are destroyed.

53. I think living with Hepatitis C, you become a prisoner. You do not want to go places, you do not want to be involved and you do not want to be around lots of people. You become numb. I often need reassurance and encouragement when I am doing something new. I have been through hell and I am still going through it. I am very concerned about my future and my new family's future, however, to some extent, I am one of the lucky ones.

**Statement of Truth**

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

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

Dated: ..... 16/10/19 .....