



Witness Name: Rosemary Wright

Statement No.: WITN2286001

Exhibits: NIL

Dated: 16th November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROSEMARY WRIGHT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Rosemary Wright, will say as follows: -

Section 1. Introduction

1. My name is Rosemary Wright. My date of birth is **GRO-C** 1959. My address is known to the Inquiry. I am William (Bill) Wright's wife. I intend to speak about my husband's experience of being infected with hepatitis C. In particular, the nature of if his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.
2. I married Bill 32 years ago, in August 1986.

Section 2. How Affected

3. In May 1986, Bill stumbled on a rock and hurt his leg. This happened in the Peak District in Derbyshire. I was not there, Bill was there with friends. He phoned me on a Sunday to tell me about the incident and came back to Scotland by tea-time on Monday. His thigh was swollen. He went to the GP and was told to rest for a few days. Then the swelling moved down to his knee. Bill went back to the GP who sent him to A&E at the Edinburgh Royal Infirmary. He had an X-ray. Nothing was broken, and Bill left with a diagnosis of water on the knee and was instructed to continue to rest. I didn't go the hospital with him because I was at work and we didn't see the injury as anything other than a soft tissue injury. There is no medical record of that visit to hospital. However, in his medical notes, there is later reference to the fact that he went to A&E on this occasion. Bill must have told the doctor who noted this down when he attended the next time and it was never questioned. After attending A&E, he came back home and carried on resting. The swelling did subside. He felt well enough to go back to work. Shortly after, he was standing at the sink at home washing up one evening and got a terrible pain. I was not present as I worked at a care home in Perth and slept over as the senior in charge, so I could not leave. There was no indication that what Bill had was anything other than a soft tissue injury. I phoned the next morning and spoke to him. He said he was at hospital, he had been given something and was feeling more comfortable. I was still on duty when we spoke by telephone, but when I finished my shift, I went to see him. He had already seen Dr Ludlam by the time I got there. Dr Ludlam had told him that he probably had haemophilia and that he had been given Factor 8. Dr Ludlam also advised that there was a 50% chance that he might have contracted non A/non B hepatitis as a result of receiving Factor 8. The risk of contracting Aids was thought to have been eradicated by improved heat treatments. This was on 14th May 1986. Subsequently, Bill had vaccinations for hepatitis B. About 6 weeks later, Bill was feeling ill and his blood tests showed that he had raised ALT levels. He was then told that he had contracted non A/ non B hepatitis from the Factor 8. This was clear and was presented to us as a fact. I wasn't there for most of Bill's discussions with Dr Ludlam but I was for some. Bill was in hospital for about 10 days. Once he was given a diagnosis of NonANonB Hepatitis, he was told to stay off alcohol for a while, but that non A/non B hepatitis should be self-limiting and should resolve itself over time.

4. We found out that Bill had mild haemophilia A. The figure was 31% clotting level at his lowest and sometimes near 40%. As a child, Bill had bleeding problems and his parents understood that he had haemophilia. He carried a card regarding his haemophilia. However, this didn't really present any problems and in 1974, Bill went to the Glasgow Royal Infirmary for tests because he wanted to apply for the Police Force so he needed to be clear as to what his medical condition was. At the end of that, he was told that he didn't have haemophilia and stopped carrying his card. He lived a completely normal life. We went hillwalking and rock-climbing. He never had any particular issues with bumps and bruises. At that time he didn't think that he had haemophilia, although from his GP notes in Edinburgh, when he registered he did mention to the GP that he had bleeding problems and maybe haemophilia as a child. This is on his GP notes and over the years this has been a source of anger because when he injured himself in 1986, the GP should have realised that Bill could have bleeding problems and taken a different approach to the situation straight away.

5. Regarding the blood products Bill received, there is nothing that he or his parents ever remembered and nothing documented of him receiving any blood products as a child. He only received Factor 8 at the Royal Infirmary in Edinburgh. They have never tried to deny that it was this dose that caused Bill to become infected with non A/non B hepatitis. However, the doctors on duty on the night when Bill received Factor 8 had a miscommunication and the senior doctor suggested that they didn't give the go ahead for Factor 8, but the junior doctor understood that she had agreed to the treatment and so proceeded to administer the Factor 8. Since they knew of the risks, the fact that Bill ended up with a Factor 8 dose suggests that there was no effective process or system in place to highlight unusual patients. Factor 8 was administered without checking his clotting factor. It should only have been given as a last resort and the fact that it was given to him in an emergency situation after 3 previous medical consultations indicates a lack of awareness among doctors. The doctor who administered the Factor 8 should have been more aware of the risks. Bill received DDAVP, another blood product, in 1993 as a treatment for hepatitis C when he needed a liver biopsy, in order to reduce any bleeding and this worked very successfully.

6. Bill was treated at the Edinburgh Royal infirmary between May 1986 and April 1987. He was treated by Dr Ludlam, Dr GRO-D and Dr GRO-D Between November 1987 and June

1996, Bill was treated at the Manchester Royal Infirmary by Dr **GRO-D** and Dr **GRO-D** (hepatologist). Between 1996 and the present date, Bill has been treated at the Edinburgh Royal Infirmary. He was treated by Dr Ludlam until he retired in 2010 and since then by Dr Rosie Dennis and Dr Peter Hayes, who is a hepatologist.

7. Bill received infected Factor 8 on 14th May 1986.
8. It was only after Bill had already received the Factor 8 that he was told that there was a 50% chance of contracting hepatitis C.
9. Bill only contracted hepatitis C. **GRO-C**
GRO-C He had vaccinations for hepatitis B. He has been told that there is a low risk for CJD. He was told about this much later, this is a low risk and he hasn't shown any symptoms.
10. Bill was informed about the risk for hepatitis C the morning after he received Factor 8. He was told that he had hepatitis C six weeks later, when he was not feeling well and they did more blood tests, which confirmed raised ALT levels.
11. We were led to believe that the hepatitis C was self-limiting. He could not drink any alcohol on the day of our wedding 9th August 1986. After that initial period of feeling quite ill, Bill did seem to get better. We were told about the Hep C by Dr Ludlam and he was upfront about the fact that Bill had hepatitis C, but we were led to believe that it would eventually disappear. In early 1987 Bill applied for and got a job in Manchester, which he started in May 1987. We bought a house in October 1987. In the meantime, we stayed at my dad's caravan and rented a flat. We only registered with a GP when we bought the house. The GP referred Bill to the Haemophilia Centre in Manchester. He didn't have any appointments with any doctors until then. The illness wasn't an issue to us because he was feeling well and we thought it was over. He saw no urgency to register with the Haemophilia Centre. We were not made to feel concerned and thought that Bill didn't need monitoring.
12. I can remember that Bill was told not to drink alcohol initially but started drinking in autumn 1986 when he felt better. I can't remember anything else being said at that

point, and we were not planning to have any children at that point, so we were using barrier methods of contraception anyway. In Spring 1988, when Bill went to the Haemophilia Centre in Manchester, they took blood tests and told him that he still had hepatitis C. Dr Warnes told Bill that he may only have 10 years to live. This was a complete shock to us. At the next appointment, I was present and Dr Warnes said that there was a risk to me through sexual transmission, although this was low and if we wanted to have children, we should go ahead and do that. We were also made aware at that point of the risk of transmission through toothbrushes and razors, or blood left anywhere as a result of an accident. We were only made aware of these issues in Manchester. Dr Ludlam never mentioned this.

13. I believe that we should have been given more information earlier on. I think that Dr Ludlam was not prepared to be open and transparent. There was no internet back then or any other easy ways to be informed. I understand now there was still debate at the time about what non A/non B hepatitis meant and how serious it was but the possible implications should have been explained to us.
14. My view about how the results of tests and/or information about the infection were communicated to us is that if you are told that something is expected to resolve itself like we were, then you don't think you need to worry about this. I don't think Dr Ludlam was open with us, but by spring 1988 when we saw Dr Warnes, he was upfront. We then had to make a decision about whether to have children, which we did. I think Dr Ludlam was scared of criticism about the issues and played down the implications, I think he was particularly aware of Bill's circumstances knowing it was the only transfusion Bill had and it had such consequences.
15. We were not given any information about the risks of others being infected as a result of Bill's infection at the time when he was told that he had hepatitis C. It was only a year later, when we attended the Haemophilia Centre in Manchester that we were warned about the risks of sexual transmission and transmission through toothbrushes and razors, or through blood left anywhere as a result of an accident.

Section 3. Other Infections

16. Bill was only infected with hepatitis C as a result of being given Factor 8 on 14th May 1986. He hasn't shown any symptoms for CJD and this is not something that worries us just now.

Section 4. Consent

17. I believe that Bill wasn't treated without his knowledge, because he remembers being given something. I cannot really comment about his actual consent, because I wasn't there. It is very worrying that the doctors miscommunicated and the use of Factor 8 was not a properly considered decision. As regards whether Bill was tested without his knowledge, I do not know.
18. As to whether or not Bill was treated or tested for the purposes of research, I am aware of information passed between the two doctors that night. I am aware that at the time doctors were trying to find out which treatments would work and having someone with no previous treatment would be a useful basis for research. But I don't think this is the reason why his haemophilia wasn't picked up on by the GP, or on his first visit to accident and emergency at Edinburgh Royal Infirmary. The fact that it was administered in the context of an emergency situation probably means that it wasn't planned. However, I believe there was a lack of adequate systems in place at the Edinburgh Royal Infirmary to determine when or not to administer Factor 8; there was a lack of awareness.

Section 5. Impact

19. Bill becoming infected with hepatitis C has had a huge impact on our lives.
20. Psychologically, Bill and I have had to deal with the likelihood of a shortened life, the feeling of dirty blood, financial insecurity, anger because of the circumstances and depression. Physically, during the eighties and the nineties, Bill suffered from fatigue when he became overtired. He did manage a normal lifestyle and we went hillwalking.

rock-climbing and skiing. But he would get more tired than me and he would get very nauseous and sometimes be sick. Apart from the period when he had treatments and up to 2007, he had these symptoms but he could lead a normal life on a day-to-day basis. Since 2007, when he had his fourth attempt at Interferon, although he didn't complete the full course, his health went off a cliff and he never recovered from having that treatment. In April 2007, the weekend before the treatment commenced, we had a full day rock-climbing and hillwalking and he was fine. Then he was on treatment for a number of weeks, but he couldn't tolerate it and had to stop. He has never again been able to do such an active day. He has recovered a bit since completing the new treatment in 2015, but he has never fully returned to the way that he was before. That is a result of the interferon treatment in 2007.

21. As a result of his hepatitis C, Bill has cirrhosis of the liver. There have been no other particular clinical complications. He has also experienced depression and fatigue, and daily sickness. He was previously a healthy person. [REDACTED] **GRO-C**
[REDACTED] **GRO-C** He remains at risk of liver cancer. This risk has probably reduced now he has a sustained viral response but for a period of time, 2 or 3 years ago, his blood tests were very worrying.

22. The course of Bill's illness is that he became infected in 1986 and had symptoms for a few months. From then until 2007, other than the periods of treatment, he had symptoms but they were manageable. As long as he didn't do too much, he was okay and led a normal life. From June 2007 onwards he was increasingly fatigued. By 2013/2014, he was vomiting most mornings and sleeping most afternoons. He spent whole days feeling nauseous, sick, achy all over or washed out. He experienced brain fog; couldn't find words and forgot things, and still does, he feels more than simply getting older. He was diagnosed with cirrhosis in 2011. By then, he was having more of those symptoms more often and they continued until the end of 2015 when the new treatment was successful. From June to December 2015, he received the new treatment. He undertook this treatment as he was advised time was running out. The treatment didn't fix the cirrhosis, but the virus is no longer acting on his liver on an ongoing basis and the cirrhosis should not get any worse. Over the last couple of years, Bill has been feeling slightly better. He has more energy, is only sick when he is really

tired and can manage 2-3 days at a time without sleeping during the day. However, he still has to pace his activities and if he does too much has to take time out to recover.

23. The first treatment that Bill had in 1993 was Interferon and Ribavirin. It was awful and not successful. He was ill for months, and still trying to work although he felt like he had the flu. His second treatment was in 1997. He was given Pegylated Interferon. He was only on that for a short period of time because we received a call from Dr Rosie Dennis advising that Bill's liver was reacting badly to this treatment and he should stop. His third treatment was in August 2000. He received Pegylated Interferon and Ribavirin until April 2001. The virus was reduced. We were hoping that it might be successful but within a month of stopping, the virus was back. This was a really hard course of treatment which caused Bill to have to reduce his working hours, and so his earnings were reduced too. He was exhausted all the time and found it really hard. He had serious mood swings, unpredictable behaviour and suicidal thoughts. His fourth treatment started in May 2007. This was Interferon and Ribavirin and lasted a matter of weeks. It was again really hard. He reduced his working hours, but it was still more than he could cope with and he agreed with the medics that he couldn't tolerate it. He only did it for a few weeks but never recovered. His fifth treatment was June to August 2015. I cannot exactly remember what the name of the treatment was, something like Harvoni but it was just tablets, no injections, and it was successful. He was told in December 2015 that the treatment had been successful.
24. Bill experienced no real obstacles or difficulties in having access to treatment. In Cheshire, there was a question of obtaining the financial resources but it did go ahead. In 2015, there were issues about whether the treatment would be funded for longer than 3 months. At that point, either Bill took the treatment, or his health was likely to seriously deteriorate at any time, so we didn't want to risk him being on the treatment for a period shorter than was optimal. Ultimately, Bill was on the treatment for three months and it was successful, so we did not have to fight for longer. So, I do not think that Bill has ever been deprived of adequate treatment since initially being infected with Hep C.
25. I do not think that there were any other treatments which Bill should have been offered but were not made available to him. In fact, because of his problems with Interferon, Bill

was anxious about having new treatments and understandably reticent about trying new products.

26. The treatments were all really hard except for the last one and Bill had to make arrangements to reduce his work hours beforehand. The first four treatments were horrible. Two of them, he didn't stay on for long. On his first treatment, he felt ill and had to inject himself. He would feel really bad after the injections, then he would pick up slightly until it was time for the next injection. We had our daughter at that point and all he could do was work and look after himself. He didn't stay on the second treatment for long. The third treatment was really difficult too. He experienced fatigue and flu-like symptoms, serious mood-swings, unpredictable behaviour and suicidal thoughts. We had been warned of the risk of depression, but he did not present as consistently depressed, so we didn't seek advice about it and at the time I didn't equate the mood-swings to the Interferon. We continued despite the side effects because of the blood tests were promising and we hoped that the treatment might be successful. When it wasn't, it was really, really hard on us. We realised all the ways in which the illness had impacted our lives and the hope of being free was destroyed. We continued to have so many worries hanging over us. Bill's mental health really deteriorated after that. Years 2001 to 2005 were a really difficult time. Bill developed depression, an alcohol problem and suicidal thoughts that were sometimes more than just thoughts. We know now that Interferon can have a severe impact on the mind. Bill felt a lot of anger and money was always a worry, added to the stress of family life, and worrying about his future physical health. I do not really want to say anything more about this time, the whole period is too painful. By the spring of 2006, Bill had turned things around and apart from one or two blips early on has drunk no alcohol since. However, there was always the knowledge that if he didn't attempt treatment again, ultimately time would run out, but it was unclear when this would be. We were aware that people were dying all the time and the virus had been attacking his liver for almost 20 years. He was encouraged by Dr Hayes to attempt treatment again and began this in May 2007. He was on it only for a few weeks and then said that he didn't want Interferon again because he was completely floored by it. In preparation for this treatment, he had negotiated a reduction in his working hours, but he had no assistance, so really he had to do the same work in fewer hours, which made him more stressed. The treatment was halted after a few weeks but then he didn't recover from the treatment and was a further huge blow to us. He never went back to

work after July and his contract was ended in December 2007. The fifth treatment was okay compared to all this, it did not have such a big impact, there were no significant side effects and the result was successful.

27. Bill's infected status has impacted upon his medical treatment but not substantially. In Cheshire, Bill was refused as a patient by a dentist due to his hepatitis C. More recently for a while, always had to have the last appointment of the day because of the worry of CJD or HepC cross infection. It is not happening anymore.

28. The impact that hepatitis C had on our lives has been in many different ways which means you are never be free of it. As a family, we have lived with the uncertainty that Bill might have quite poor health at any time, continual financial insecurity and the impact of his fatigue on our family life, particularly when the children were growing up. From 2007, our children's normal was to come back from school and their father was in bed. The fatigue was such that it could be difficult to plan activities because he never knew how he'd feel. During the periods of treatment he was just ill. There were many things that our children have missed out on because their dad couldn't do all the things that he wanted to do with them. He lost his ability to do the outdoor activities he loved and we used to do together, creating an additional strain on our relationship and emotional health. His circumstances have had an impact on social situations; we cannot enjoy a bottle of wine together and he gets very tired when standing up at social situations, so we have to leave early. If he gets overtired, he can become short-tempered. Over the years we have not had the same opportunities and quality of life as we might have expected and we have seen in our long term friends. We lived with the risk of cross-infection until 2015. We knew that there was a risk that the children might get it. Luckily, I got pregnant quickly both times, so that particular route of risk was reduced. Until 2011, I was too scared to be tested because of the financial complications that might arise if I turned out to be infected and because of how it might affect Bill's (and my) emotional health. I felt so embattled for years. GRO-C

GRO-C I was tested in 2012 and thankfully was negative. GRO-C

GRO-C Although I always knew that I could ask for a test at any time, I was never offered support to talk about it and discuss the implications before making a decision, GRO-C

GRO-C I decided to get tested because Bill was diagnosed with cirrhosis and we qualified for stage 2 Skipton money and for the first time I felt financially secure enough that I could deal with the implications if I tested positive. When I decided I was going to be tested and I asked at the Edinburgh Royal Infirmary whether I could speak with somebody about the possibility of a positive result, I was not offered any advice or support and was told to ask my GP. When I asked my GP, I was told that they wouldn't normally arrange tests and that they didn't have any counselling available and I should ask the hospital. In the end my GP agreed to do the blood test and gave me the good news but if the result had been positive I am not sure how I would have coped.

29. There is a stigma attached to a diagnosis of hepatitis C but Bill bravely made the decision not to keep it a secret from the start. So we haven't really experienced any stigma from family and friends as they understood the circumstances. We believe that keeping it a secret is something that leaves you with an additional burden, but not everyone feels they can be so open.
30. Hepatitis C had a devastating effect on Bill's career. Knowing that you've got a serious illness, you are always thinking about when treatment will be needed again and since 2007 Bill has been affected badly with fatigue. Bill gave up full-time work in 2007 and before this he had not always worked full time and felt restricted in applying for jobs because he would be due more treatment in the future. In 2007, when he gave up his job on medical grounds, he tried to be self-employed, but was just exhausted. He then applied for and received incapacity benefit. From 2007 to 2011, we only had my income plus his incapacity benefit and we had a mortgage and two teenagers. I am not saying we didn't eat, but we were struggling more and more, so ironically being diagnosed with cirrhosis in 2011 and the Skipton Fund changing at that point, gave us the financial relief to keep us afloat, although of course it was still bad news for Bill to be diagnosed with cirrhosis. I never had to give up my work, but I was restricted in applying for promotions because although we needed more money, I couldn't deal with the additional pressure of a promoted post and didn't want to be so stressed that I couldn't put my children first, or care for Bill if he became more ill. Bill worked reduced hours on and off from 1994 to 2007. He also looked after the children, as I had become the main earner, although this is not the way we would have chosen to do things as a couple. That is another way in which the Hep C has affected us. He has lost his ability to have

a career and I the opportunity to work part time and spend more time with the children. He was self-employed for some of this time so if he didn't work then he didn't earn. By 2007, he was an employee with a permanent contract but then was medically retired. Without the Hep C, he would be now in a completely different situation. I have been the main earner and have needed to work full time most of those years to support the family, and couldn't afford to get ill. Being ill was a constant worry for me, not only that but also potentially having to take time off work to care for Bill if his health deteriorated, which would also mean a loss of income.

Section 6. Treatment/Care/Support

31. We did have some counselling. Briefly in Cheshire and then in Edinburgh, we both saw a counsellor to help us deal with what life had thrown at us. In 2011, I felt pretty let down that there was no help available with the possibility of a positive diagnosis, when I decided to get tested. Whenever we had counselling this was because we knew that it was available, so we asked for it.

Section 7. Financial Assistance

32. We have received financial assistance from the Skipton Fund.
33. We knew about the Skipton Fund because Bill has been active in terms of campaigning for justice. There were never any difficulties finding out or knowing about this. Dr Hayes told us about stage 2 Skipton payments when Bill was diagnosed with cirrhosis and completed the necessary medical information.
34. We received £20,000 in 2004. In 2011, when Bill was diagnosed with stage 2 cirrhosis, he qualified for £50,000 and a yearly payment of around £14,000 payment. Then it changed to the Scottish Scheme last year and he now receives £27,000 a year. This has made a huge difference to our lives.

35. The process of applying for financial assistance was fine because Bill moved to stage 2 in 2011, and this is a clear-cut position. He was aware of the arrangements because he was involved in pushing for justice. Filling in all the forms was not a problem for us.
36. We never faced any difficulties or obstacles in applying or obtaining financial assistance from the schemes.
37. There were no preconditions imposed on the making of an application for financial assistance.
38. I don't really have any observations to make about the Skipton Fund, but the Scottish Scheme has made a huge difference and has had a real impact on our life. It is just another example of how this Inquiry has been long overdue, as I am aware that the same support is not available in England. I am now not constantly worrying about money for the first time in my life since we had children. It is very debilitating when you are not financially secure.
39. I have personally never received any financial assistance. I have always been in employment

Section 8. Other Issues

40. We were involved in the Penrose Inquiry. We did start litigation in 1999 that has not come to a conclusion and Bill has always been involved in campaigning. Our litigation is on the basis that Bill should not have received Factor 8. There was already a better product in England, meaning that new patients like Bill could receive a product free from hepatitis C. In June or July 1986, Dr Ludlum wrote to England to see if he could get some of the English product and he described in his letter a situation that looked a lot like Bill's.
41. As concerns key documents, I think these would be in Bill's medical records. We already have Bills medical records, as do Thompsons and I am not aware of anything

significant being missing. I don't know if there is any document that would be particularly relevant, these are with Bill's information.

Statement of Truth

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

Signed GRO-C

Dated 1/3/19.