

Witness Name: Janet Morgan
Statement No: WITN2515001
Exhibits: WITN2515002- WITN2515006
Dated: 17th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JANET MORGAN

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Janet Morgan will say as follows:-

1. Introduction

1. My name is Janet Morgan. My date of birth is GRO-C 1954 and my address is known to the Inquiry.
2. I am a widow of a haemophiliac who contracted Hepatitis C ('Hep C') from contaminated blood products.

2. How Affected

1. My husband was classed as a mild haemophiliac and his medical records confirm that he had haemophilia A.

2. My husband did not suffer from spontaneous bleeds and therefore only had treatment as a result of an accident. I recall that my husband told me that he only experienced spontaneous bleeds after he had received Factor VIII.
3. We married in 1989 but met one another in 1986. My husband told me when we met that he was a haemophiliac and that as a result of receiving Factor VIII he became very ill and contracted hepatitis non A non B which resulted in him suffering with stomach problems.
4. My husband was a very private man who took his family responsibilities very seriously. His attitude was that he suffered with haemophilia but it was not who he was and that it was nobody's business. This is why he didn't tell people that he suffered with haemophilia. My husband loved mountaineering and was an active healthy man. He also rallied cars was an avid reader and loved politics and as a member of Plaid Cymru he stood as a candidate in the local elections. He engaged in caravanning, playing golf, freemasonry, walking his dog and keeping Koi Carp. He started his working life in a 5 year apprenticeship as a brick layer and later attended college to become a chartered building surveyor in 1981. It was whilst he worked in the building trade he became site manager and managed multi million pound contracts.
5. It was when my husband was building an extension on our house I recall that he hurt himself a number of times. However I would like to add that my husband was a very careful person and when he experienced a bleed this would be a rare occurrence.
6. I recall my husband attending the dental hospital at University Hospital Wales ('UHW') he would receive cryoprecipitate or blood products before treatment as a precaution. Prior to us meeting one another, my husband informed me he hurt his ankle on a weekend and that the haemophilia clinic was closed so he had to receive treatment on a ward and that was when he received his one and only treatment of Factor VIII.

7. My husband discussed with me how he felt sick when he received the Factor VIII treatment. He became so ill and was having spontaneous bleeds throughout his body so he called an ambulance and was admitted to the UHW where he was diagnosed and treated for liver failure.
8. It was in 1994 that my husband was told he had contracted Hep C. My husband received a letter from the UHW requesting he attend the Haemophilia Centre so he went down to the Haemophilia Centre at UHW for what he thought was a standard check up when they then informed him he had Hep C from contaminated blood products. They told my husband there and then that he had Hep C. However from viewing my husband's medical notes I can see that it is noted he developed 'hepatitis C with liver failure in 1981'. I refer you to Exhibit WITN2515002. The Exhibit is a 'physiotherapy haemophilia musculoskeletal assessment form' dated 19th February 1999. The Exhibit provides a brief overview of my husband's health at the time and shockingly shows that my husband had hepatitis C along with liver failure as far back as 1981.
9. My husband was asked by medical professionals at the time how he felt. Medical professionals at UHW kept emphasising during that period that my husband was a sick man. They told him at the hospital during that time that he had contracted Hep C from Factor VIII blood products, there was no treatment available to him and that he had 3 to 5 years to live.

3. Other infections

1. My husband contracted cirrhosis of the liver and chronic liver disease. I am unsure on what exact year my husband was informed that he had liver cirrhosis. When I viewed my husband's medical records I discovered a letter dated 19th August 1998. The letter was from Dr Dasani at University Hospital Wales Haemophilia Centre addressed to my husband's GP Dr Phadke. I refer to Exhibit WITN2515003. The letter states that an abnormal ultrasound test result was "suggestive of cirrhosis of the liver".

4. Consent

1. My husband did not agree with being given the Factor VIII but was told by the doctor at the time that this was the treatment my husband had to receive. From the many discussions we had my husband was adamant that there was a heated exchange between the doctor and himself. With my husband insisting that he did not need Factor VIII as he had always responded to Cryoprecipitate. My husband told me that the doctor's response was "well on this occasion as I am the doctor you will have Factor VIII". Factor VIII is what he received.
2. It was at a recent Public Inquiry meeting that I became aware of the term PUP and found out that my husband fell into a category that labels individuals who were used for testing as PUPs. At the same meeting I was also made aware that my husband was the only previously untreated person who worked in the whole county of GRO-C to have been given Factor VIII. Hearing this information came as a shock to me and I felt angry and devastated to learn that my husband had been abused this way.
3. My husband was the Chairman of Haemophilia Wales years ago. I firmly believe that my husband had no knowledge that he was a PUP. I don't believe he was ever aware of the term PUP as he never ever mentioned it and it was too important for him not to tell me.
4. My husband never told anyone that he was a haemophiliac as I have stated earlier in my statement he was a very private person and it was not in his nature to share information like that about himself with others.

5. Impact

1. My husband knew that he had not received Factor VIII prior to 1981. My husband developed a very low mood upon hearing this news of his Hep C diagnosis.

2. I would say my husband did become quite depressed. This was not in his nature prior to his diagnosis. It later came to my knowledge that there is a link between Hep C and low mood.
3. At the time of his diagnosis my husband was informed that he had three to five years to live. When my husband gave me the news it was in such a matter of fact unemotional manner even though it was not his way to behave like that. I thought he was winding me up as I could not believe what he was telling me.
4. My husband had two children from his first marriage and he went onto adopt my youngest daughter from my first marriage. At the time of diagnosis it was just my husband, myself and Felicity, our youngest daughter, who was 12 at the time living at home. We were all devastated by the news and Felicity became afraid, angry and very upset at the thought of losing her father.
5. I recall during the time that my husband received his Hep C diagnosis, there was not a lot of information about what it meant to have Hep C. We did not receive any information as to how Hep C could be transmitted other than through blood products. Therefore it came as a bit of a shock to see posters in the hospital which stated that Hep C was a sexually transmitted disease.
6. Dr Dasani informed myself and my husband that a lot of research had been carried out regarding Hep C and the majority of those who had contracted Hep C from their partners were found to be intravenous drug users and shared needles.
7. During the clinical trials which involved Interferon, my husband suffered such chronic fatigue that he would sit in the chair and just stare into space. He also suffered with severe insomnia and couldn't sleep for 4-5 days at a time and

his sleeping pattern changed drastically. After the trials his sleep was never the same again, his sleeping pattern was very disruptive. Dr Dasani informed us that this was one of the side effects of the Interferon and that he should try and change his sleeping pattern back to prior to the trial but that my husband should keep going with the trial.

8. My husband would think that he was having heart attacks at times. I believe that the Interferon definitely induced feelings of anxiety and paranoia in my husband.
9. Eventually my husband became too unwell to continue working. He would sit at the dining room table to sort out the bills and I recall him being extremely stressed and distressed. When my husband could no longer work he became more concerned about money when his health deteriorated.
10. I recall on one occasion finding my husband rocking back and forth on the floor extremely distressed over a utility bill he had received, he said "look at what we owe!" On inspection of the bill I noted that we were in credit to the sum of £250. I found this very distressing and disturbing behaviour as he always dealt with the household finances and was so sharp and on the ball with money and numbers that he never wanted to owe any money.
11. My husband was the head of a professional office for the second largest local authority in Wales. He was an intelligent, articulate and successful man. It was awful seeing him deteriorate so quickly. I recall on one occasion he accused me of stealing money from our joint bank account even though he had possession of my card for the account as I didn't need it as I had my own account. I would attribute my husband's change in behaviour with the Interferon he had been receiving. My husband's character changed completely after the clinical trials.

12. My husband liked routine and administering Interferon involved routine. When he took the Interferon, his behaviour would become quite predictable. When I say predictable for instance my husband would administer the Interferon on Tuesdays, Thursdays and Saturdays at 7pm sharp. Therefore we knew that Monday would be a good day. The reason I say this is that when there had been a break for a few days after the medication it was as if the Interferon would leave his system and he would feel more like himself again. The cycle was very upsetting, I could see my husband becoming anxious on a Tuesday as this was the day he would have to administer the Interferon again.

13. Whilst on the trials my husband's thighs would be black and blue, this was a result of having to inject the Interferon into his legs 3 times a week for between 6-12 months at a time.

14. Whilst on a visit to the hospital for a check up and to collect more Interferon and Ribavirin it had become a practise for a nurse to come out and talk to me about any issues that my husband was experiencing on the trials. This was due to the fact that my husband would not tell the doctor how he was really feeling on the trials. However I note from the medical records that I wasted time as what is recorded is that which my husband had told them. Unfortunately the information he gave them was so far from the reality of what he was experiencing as he wasn't aware of how bad the situation had become. He also didn't tell the doctor as he felt that the medical profession didn't care as the response was always the same to all his complaints and that was he was experiencing the side effects of the drugs.

15. The side effects of the drugs on my husband are demonstrated in his Disability Living Allowance application form. I refer you to Exhibit WITN2515004 this is a copy of my husband's application form dated 13th July 1998. The form my husband submitted indicates the true reality of what he was experiencing. There is such a huge difference between what he said to the Doctor and what he wrote on the application form. His style of writing indicated to me how much he was aware of the situation and how poorly he

had become as it wasn't in his usual articulate manner. I know that when he filled in the form it greatly distressed him.

16. My husband was first placed on an interferon trial in 1995, he was on this trial for around 6 months. My husband was then put onto another trial of Interferon with Ribavirin not long after the first trial. Whilst on that trial his behaviour became so bad it caused a lot of arguments which really upset and distressed our young daughter. I trusted my husband implicitly and I know he hated violence and it was not him to behave in this manner. He became a completely different person on the clinical trials.
17. The following day my husband received a telephone call from Dr Dasani telling my husband to stop the trial as the side effects were so bad and the trial was not working. My husband reacted very badly towards me and demanded that I tell him what I had discussed with the nurse because he felt that whatever I said resulted in the stopping of the trial. Out of loyalty and love to my husband I could not tell him how bad his behaviour had become as this was something that I know would have deeply hurt him. This became a real problem between us until just a couple of weeks before he died he still felt annoyed with me about this issue. I feel happy with the fact that my husband died not knowing how bad he had become, it wasn't his fault it was the effect of the drugs.
18. My husband was so angry and upset with me for, as he saw it, revealing to others personal information about himself. I believe that Dr Dasani could have handled the situation more sensitively than he did. To prevent causing my husband anymore stress and further anymore arguments I stopped attending the clinic with my husband.
19. During one of the medical trials after a few months my husband felt so ill that he just stopped the treatment without informing Dr Dasani. Some weeks later Dr Dasani phoned my husband and my husband agreed to go back on another trial. My husband also told me that Dr Dasani was very annoyed with him for not informing him that he had stopped the trial. When I saw the note on my husband's medical records which referred to that telephone

conversation and the comments made by Dr Dasani stating that my husband felt guilty and ashamed. I found this very upsetting and disturbing as my husband did not feel guilty about having Hep C and if he was ashamed he would not have told a doctor that.

20. Medical professionals knew what was happening with my husband but I still wonder why they covered up certain things. For instance on investigation of my husband's medical records I note that on 30th September 1999 one of the blood samples were stored as requested! I refer you to Exhibit WITN2515005. This Exhibit is a note from Cardiff Laboratory that demonstrates the point I make above. I have no idea what is meant by that comment. I requested and paid for my husband's medical records and after a number of months waiting they couldn't find many of my husband's records. There was no record of him receiving Factor VIII and no record of him being admitted to hospital within a few weeks of receiving the lethal dose of Factor VIII. Although in 2003 my husband requested and received the records in relation to the batch number of the Factor VIII he had received in 1981 which now appear to be missing. I also noted that my husband had in 1991 tested positive for Hep C but was not told he had Hep C until 1994. I discovered this upon viewing my husband's medical records.

21. I am sure that he was not aware of this test as until he was told in 1994 he was still convinced he had Hepatitis non A non B. He was also tested for HIV in 1991 and I'm sure he wasn't aware of that test. He was also exposed to CJD prions. In a letter dated 20th September 2004 from Professor Collins at University Hospital Wales addressed to my husband, it is stated that the Welsh Assembly instructed Cardiff and Vale NHS trust to contact everyone who has a bleeding disorder and attends University Hospital Wales. I refer to Exhibit WITN2515006. The letter also states that any person who was treated with plasma products between 1980 and 2001 should inform any surgeon or dentist if they are to undergo any operations. When my husband died in 2010 we believed that he was to have a post mortem. I was pleased with this as my husband and I often discussed this issue and it was his wish that he had a

post mortem. It was my husband's belief that a post mortem would reveal everything that he had been exposed to by the NHS. However the following day after his death we received a telephone call asking us to go to UHW where we were told that a post mortem was not going to be carried out on my husband's body.

22. When we asked why we were told that the pathologists had refused to carry out the post mortem as my husband had contracted Hep C and had had a massive intracerebral bleed and posed a very high risk to the pathologists. Despite the fact that I made it clear that I wasn't happy about this and that it was my husband's wish to have a post mortem the doctors remained resolute in their decision not to carry out a post mortem. When we went to register the death of my husband with the registrar, she asked us if we were happy with the diagnosis and I informed her that I wasn't and also informed her of the doctor's decision not to carry out the post mortem. I believe that post mortem would have revealed the full extent of damage done to his body due to the factor VIII.

23. We had been married 5 years when we discovered my husband had Hep C which completely destroyed our lives and I feel robbed of a happy life with my husband. Before we had a chance of a happy life together the clinical trials started a life of an unbearable existence together. Taking care of my husband was very difficult as he became totally dependant on me for everything even cleaning his teeth and bathing him. His skin became very sore as he had severe itching. Often he scratched whilst asleep which would wake me up. During his sleep I would wake to find that his breathing was very slow and sometimes I thought that he had stopped breathing altogether. I wouldn't sleep the rest of the night as I believed he might die. There were many occasions during the trials that my daughter and I went to bed fearing that we would wake and find him dead as he was so ill. When my husband was unable to work it became financially difficult for us so I had to go back out to work whilst caring for him.

24. Life became very difficult and even more so for our daughter who was still young and as much as I tried to shield her from the problems relating to the trials she was very aware of many aspects and felt very distressed and frightened for the future. We felt isolated and alone which was partly due to the fact that my husband was a private and proud man who didn't wish for his personal predicament to be revealed to anyone.

25. I also felt isolated and alone as I knew no one who was enduring the same issues as we were experiencing. When I went to the hospital with my husband I never saw anyone there who I felt I could talk to. I remember wondering if we were being deliberately segregated from other patients who had Hep C. Physically, things began to take a toll on me as I also as I had to work nights, take care of the family and a very sick husband. To watch my husband so sick was absolutely devastating and very stressful. I watched him transform into a different person. It was very difficult trying to keep a balance when we were all so stressed and distressed.

26. Whilst I took care of my husband, I tried to be understanding about the situation which was very difficult as my husband became very belligerent and we argued a lot. Whilst he was on the trials my life became a horrible existence. When my husband's health deteriorated we did not have a social life. I think it destroyed our lives for around 15 years.

27. I recall a specific time after one of the clinical trials, I spoke to my husband. In the conversation I said to him that if he died at this point in time we would only have bad memories to remember our lives with him. The conversation was very difficult as I had to take care that I didn't reveal the extent of the issues as my husband would have been distraught knowing how bad the situation was. To my husband taking care of his family was paramount and prior to the trials and he took care of us very well. It was difficult getting him to allow me to take on his responsibilities whilst he was ill.

6. Treatment/Care Support

1. My husband received the vast majority of his treatment at the Arthur Bloom Haemophilia Centre at UHW. Prior to this my husband received the majority of his treatment at Cardiff Royal Infirmary ('CRI').
2. My husband was primarily under the care of Professor Bloom at both CRI and UHW. I recall my husband telling me that he often had disagreements with Professor Bloom.
3. From 1994 onwards my husband was placed on clinical trials. My husband was on clinical trials starting in 1994 but I am not sure of the date of the last time he received Interferon and Ribavirin. However my husband continued to suffer ill health and just weeks before his death he believed that the Hep C was back although the doctors have recorded otherwise.
4. For the Hep C, my husband was placed on Interferon at first. I would say he was first placed on the Interferon treatment in 1995.
5. After trialling the interferon, my husband was then given a combination therapy which comprised of Interferon and Ribavirin, he also had a combination of Interferon and Amantadine.
6. I will say that when I applied for my husband's records and when I viewed my husband's medical notes it became apparent that most of them comprised of his treatment in the 2000s and that a lot of notes were missing from the date of my husband's diagnosis and through his Interferon trial. I also noted that records were missing prior to 1985 and those that were available were few. I noted that there were no records of when he attended the hospital due to an injury and was given Factor VIII and when as result of the Factor VIII he was admitted to hospital with liver failure. There was a later record which referred to the fact that he had received Factor VIII and had been admitted to hospital with liver failure. This was previously shown in Exhibit WITN2515002 which I referenced earlier in my statement.

7. When my husband found out that he had cirrhosis as a result of his Hep C I am not sure if he was given a biopsy. My husband thought he was on a liver transplant list when his health began to deteriorate. When his health became gradually worse he began having problems with his joints. My husband was given the option to have a fusion when he began to have issues with his joints. My husband refused to have his joints fused as he had spoken to others who had regretted having this treatment.

8. I recall that during one of my husband's clinical trials he was referred to a clinical psychiatrist. During one of the clinical trials which involved Interferon I asked my husband to go to the hospital and tell them what was happening with his mental health and how he was feeling psychologically. He returned home absolutely livid to have been offered psychiatric support. He felt resentful over the fact that his mental health was beginning to deteriorate. This left him feeling that the medical profession believed that the issues he was experiencing was all in his mind.

9. My husband would experience terrible headaches when he was on this Interferon. When he told the doctor about his headaches he was told to take paracetamol. My husband was quite stubborn and would only take one paracetamol for a headache believing that he didn't need anymore. Other than taking tablets for flu I didn't see my husband taking medication other than when he had chemical treatment for injuries and the clinical trials.

7. Financial Assistance

1. I have received financial assistance. In the past 8 years I received £34,000 from the Skipton fund. I receive monthly payments from Wales Infected Blood Support Scheme also.

2. My husband received payments of £20,000 and £25,000 which equated to just over two years of his previous salary. My husband was robbed of a healthy and happy life.

3. My husband received welfare benefits. I remember in 2010 before his passing he was scared that if the benefits we were receiving were stopped we wouldn't be able to pay the bills. He was so concerned about our financial position that he was constantly telling me he would have to go out and work. The Interferon and Ribavirin left him easily stressed and rendering him incapable of returning to his previous type of work. He was so stressed by the possible lack of income that he even spoke about getting a job collecting the trolleys at the stores.
4. My husband's work ethic was amazing. He hated that he had to retire at a young age. He always wanted to be active and doing something.
5. I applied for the Caxton fund and experienced problems receiving financial support from them. I remember I had to provide 2-3 quotes. I applied for a widow's allowance. They refused the application on the grounds that my husband's death certificate did not state that he died of Hep C. They told me that if I could send them medical evidence proving a causal link to Hep C then I could apply again so they would consider the application. Fortunately, due to Haemophilia Wales' Lynne Kelly's hard work and pursuing this issue with the Welsh Government, they announced that the funding would be provided and that we didn't need to provide a causal link.
6. I spoke with Lynne Kelly who contacted Dr Collins and arranged an appointment in the hope that he would provide the medical evidence that I needed. I left that appointment without any help from Dr Collins. I became very distressed with his questioning and left the appointment.
7. I must say that I found the whole process of applying for financial assistance embarrassing and belittling.

8. In relation to the Caxton fund, I had to provide proof of there being a causal link between my husband being unwell and the Hep C. Dr Collins invited me to UHW and asked if I could recall the events leading up to my husband's death. This question caused me a great deal of distress and I fell apart and became a babbling idiot. Even now I feel that it was a cruel thing to have asked me. Dr Collins then told me that there was no causal link. However we found out afterwards that one of the side effects of using Interferon long term is that it can make you susceptible to brain haemorrhaging. I did not know this initially.
9. I had an email from the social worker who also attended the meeting with Dr Collins at the time that I was applying for the Caxton Fund. She asked me how I felt about my meeting with Dr Collins. I told her that I felt humiliated in how I had been treated and the fact I felt as though I had to beg for money. I also told her that it was a complete waste of everyone's time as it appeared that Dr Collins had already made a decision not to help.
10. As a result of my experience in trying to obtain money from the Caxton Fund, I was offered counselling by the social worker. I politely refused as I had already tried counselling a few times but I soon realised that it wasn't for me.
11. Lynne Kelly appealed to Health Minister at the time Vaughan Gething. The appeal was successful and I eventually received the money.
12. I would like to add that Lynne Kelly has been so supportive throughout this situation and is the person who keeps me in the loop with everything that goes on in regards to the Inquiry and Haemophilia Wales.

8. Other Issues

1. I would like for there to be some kind of accountability. I would like recompense on those who destroyed these innocent individuals' lives.

2. I want systems implemented where medical professionals have to be upfront and have accountability in order to prevent this from happening again.
3. I believe the doctors who gave my husband and thousands of other people contaminated blood are on par with those who commit atrocities.
4. What happened to my husband turned our lives upside down and quite frankly the Hep C and cirrhosis ruined our lives for a good 15 years. However saying that, we were lucky compared to some families. I know that some families really struggled financially, we didn't experience losing our home we never had this problem. We were able to pay our mortgage. I feel lucky that I did not experience any stigma that I know a lot of individuals have unfortunately experienced.
5. I feel as though the doctors treated people as experiments. I would like it so that this can never happen again.
6. When I returned home from work in October 2010, I found my husband collapsed on the kitchen floor. I then telephoned for an ambulance. Even though the Paramedic told me that he believed my husband had a cardiac arrest I knew from the signs that it was an intercerebral bleed and that it was imperative that he got to the UHW to receive bleeding disorder treatment as soon as possible. I explained this to the Paramedic but he insisted that my husband be taken to the nearest hospital which was a couple of miles closer to our home than the UHW. I repeatedly told him that if my husband was to have a chance of survival he needed to get to the UHW where they could give him the life saving products he needed.
7. Eventually I telephoned my step daughter and asked her to contact the Haemophilia Centre at UHW and ask the doctor to phone my home and speak

to the paramedic. The doctor did speak to the Paramedic and he was taken to the UHW where he received the treatment.

8. Unfortunately it was too late for my husband and he died the following morning on 4th October 2010. I underwent a very distressful experience getting my husband to a hospital that would increase his chances of survival. I shouldn't have had to battle with the Paramedic in this way. I would like to see a system put into place where either all hospitals have access to the treatment for haemophiliacs or that the Ambulance Service are made aware of the need to get the patient to the hospital that caters for the specialist needs of haemophiliacs.

Statement of Truth

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

Signed.....

GRO-C

Dated.....

17-04-2019