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Witness Name:

Statement No: WITN0047001

Exhibits WITN0047002 – WITN0047007

Dated: 16th May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

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, will say as follows:-

1. Introduction

1. My full name is My date of birth is 1943 and my address is known to the Inquiry. I am a widow. I have two children and also have two grandchildren.
2. I make this statement because I was previously contacted 'out of the blue' by a representative of the Inquiry in August 2018. The representative made an appointment to visit my home and take my witness statement. My statement was finalised over a period of 3 days. I mistakenly assumed that the person had contacted me on behalf of my solicitor, as I was already registered as a client of Watkins & Gunn at that time.

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3. I wish to make a further statement, as I believe the representative from the Inquiry did not allow me enough time to fully consider the contents of my witness statement, neither did I have time to properly consider the implications of whether I wished to submit my witness statement, with or without anonymity.
4. When giving my previous witness statement to the Inquiry my husband's medical records had not been sourced and were not available at that time. These records have since been sourced by my solicitors and I am now able to add relevant exhibits to my statement and therefore provide a more accurate witness statement.
5. My husband [GRO-B: H] was born in [GRO-B] London on the [GRO-B] 1935. [H] was a severe haemophiliac (type A) with 0% Factor VIII in his blood.
6. We first met around 1962 when I was a Student Nurse in [GRO-B] Hospital. [H] was in hospital for a long period of time due to complications with his haemophilia. At this time and for much of his life, [H] needed crutches and/or callipers to walk.
7. [H] had very little school education due to his constant visits to hospital with his severe haemophilia, but he was an avid reader of books, which became his education. He went on to complete a teacher's training course later in his life and obtained a Degree in Philosophy at the University of Cardiff.
8. [H] had a lot of interests some of which were literature, art, natural history and a love of classical music. He had many friends with the same interests and enjoyed collecting beetles and other bug type creatures to place under a microscope. He and his friends spent many hours at the Museum in Cardiff. It was a way of taking his mind off his illnesses. [H] always had a positive outlook on life.

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9. We married in 1963 and moved to [GRO-B] so that [H] could do his teacher training course. [H] was still very ill at this time. In 1965 he spent a week in Exeter Hospital where he had a bleed in his stomach and pressure on his lungs. This led to him getting pneumonia. He also began to hallucinate. The hospital contacted me and said I should get there urgently as they thought he was going to die. Unfortunately I was unable to drive at that time, so I had to take my daughter to my mother's house, then I hitched a lift with the aid of a police officer who stopped a lorry and asked the driver to take me to hospital.

10. As a Student Nurse, I was aware of a new treatment for haemophilia, called AHG (Anti Haemophilic Globin). I mentioned this to Harry Hall a Senior Consultant at Exeter Hospital. He established that AHG was only available in London or Oxford. He considered sending [H] by helicopter to one of these locations but [H] was too ill and it was considered unsafe, so instead the AHG was transported to Exeter Hospital. This was in 1965. [H] was then sent to Oxford General Hospital under the care of Dr. MacFarlane

2. How Infected

1. In 1966 we moved to Cardiff as some of our friends had moved there and [H] got himself a teaching job. Then [H] came under the care of Professor Arthur Bloom at the University Hospital of Wales (UHW) in Cardiff. Professor Bloom was the Consultant Haematologist dealing with haemophiliacs at the hospital.

2. Despite his regular treatments for haemophilia and having very poor knee joints, which were effectively smashed by the regular bleeding, requiring him to use callipers, he managed to continue to work as a teacher. The school where he worked at the time were very supportive and allocated him a classroom on the ground floor.

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3. In the early 1970's Professor Bloom suggested to [H] that he start an independent support group. He did this [GRO-B] [GRO-B] [H] was the Secretary and [GRO-B] was the Treasurer. This group still continues to this day [GRO-B] [GRO-B] The group is a charitable research and support group.
4. At this time, if [H] had any problems blood wise, he would go straight to the UHW as a day patient to the unit run by Professor Bloom. He would usually be given Cryoprecipitate (freeze dried Factor VIII) or blood transfusions. Exhibited at WITN0047002 is a letter dated 10th February 1975 from Professor Bloom at the UHW to Dr. [GRO-B] [GRO-B] Cardiff advising that [H] has been selected for home treatment of Factor VIII concentrate. It advises that 'a small percentage of the freeze dried preparations contain, unavoidably, the virus of serum hepatitis and therefore is potentially dangerous to the patient and his relatives etc'.
5. In 1976 [H] injured his hip and went to the UHW. It was initially thought that it was just another haemophiliac bleed, but we insisted that he was x-rayed because [H] suspected that it was something more serious. The x-ray confirmed a fracture of his hip. [H] underwent an operation and a 'Gardner screw' was fitted. Again, he was given Cryoprecipitate and blood transfusions. A routine blood test carried out at this time, showed that he had Hepatitis B (Australian Antigen). The hospital staff were horrified, as they were unaware of this and had to sterilise the operating theatre. Exhibited at WITN0047003 is a letter dated 21st January 1976 from Professor Bloom to [H]'s GP Dr. [GRO-B] advising that [H]'s last blood test showed that he was positive for hepatitis associated antigen and suggesting that this was picked up from the Factor VIII concentrates.
6. I was eventually taught to give the Factor VIII given to [H] by the hospital at home. He was unable to administer this himself because of a haemophilia related injury to his left elbow. It made it awkward for

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him to self-administer. The Factor VIII was a powder that we mixed with sterilised water and I could give this to [H] when required to save him having to go to hospital.

7. In the late 1970's hospitals were 'cavalier' with their approach towards blood; spills would often not be wiped up straight away. On one occasion we saw a nurse almost swallow another patient's blood whilst using an oral pipette.
8. In the early 1980's the media started to report that homosexuals in America were dying from an immune disorder (it was not referred to as AIDS at this time). Then we became aware that haemophiliacs had also started to become infected with this disease. The UHW did not say anything to us about this at this time and no information was provided to us. Exhibited at WITN0047004 is a letter dated 28th January 1983 from the Registrar in Haematology, M.B. Liddell at the UHW to [H]'s GP Dr. [GRO-B]. In this letter he expresses [H]'s concerns about the 'possibility of acquiring the acquired immunodeficiency syndrome', however Dr. Liddell suggests there is no grounds for suspecting the diagnosis in him and advises he will see him again in six month's time.
9. I recall whilst I was giving [H] an injection one day of the hospital Factor VIII, [H] saying "of course, you know this comes from American drug addicts and prisoners". I said to him, "could you go back on the British treatment?" I and I believe [H] felt this wasn't right. At [H]'s next routine appointment with Dr. [GRO-D] at the UHW, he asked Dr. [GRO-D] if he could go back on the treatment that he had received previously before the Factor VIII, which I believe was Cryoprecipitate. He was told it was not possible as to provide this treatment to [H] would be more difficult. I believe that the American treatment was much simpler to administer. I don't believe there was much discussion about this with Dr. [GRO-D]. [H] was just told no.

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10. We failed to understand why they were using 'American' blood which people were being paid to give, when in the UK the donations were being given voluntarily.
11. At around this time in the early 1980's the UK Government said they were going to build a centre in Edinburgh to produce safe Factor VIII for use in the UK. David Owen MP was the Health Secretary at this time and was advocating this process should happen. I understand David Owen then moved departments and unfortunately his successor never followed through with it.
12. We heard from a Scottish female MP (who had previously worked as an Orthopaedic Surgeon), when we were in London to listen to a debate on haemophiliacs with HIV in 2014/15 that apparently there was an Orthopaedic Surgeon based in Scotland who would only give blood transfusions that came from British donors because she knew that American blood was contaminated.
13. Around this time, MPs began to make comments on the situation. I remember that Gerald Kauffmann spoke out, saying that people were dying every day from the diseases as a result of the American blood and blood products. Virginia and Peter Bottomly also made comments. In particular, that the money being awarded to victims was not enough. The debate was whether or not it needed to come out of the NHS budget.
14. In early 1983 Professor Bloom told H "it is likely you have this disease relating to an immune deficiency" (which later became known as HIV/AIDS) and he was put back onto British Factor VIII.
15. There were GRO-B other haemophiliacs at UHW in the same position as H. It was suggested that they form a self-help group. They originally met at the Birchgrove Public House, which is near to the UHW. The members called themselves the 'Birchgrove Group'. Other

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members of this group were [GRO-B]
[GRO-B] Initially, the members of the group were purely the 'infected' men. Later their families were also included.

16. The Birchgrove Group met up with other haemophiliacs with HIV from around the UK and Ireland, then later linked with HIV groups from the gay community. The Haemophilia Society of London was also involved, but they (the Haemophilia Society of London) did not mention in any of their literature, HIV, which annoyed some members of the Birchgrove Group. The members thought that they were blind to HIV, even at the height of the news.

17. The Reverend Tanner [GRO-C] was heavily involved in the Haemophilia Society of London. He was not thought very highly of by the Birchgrove Group. Reverend Tanner went on to become part of the MacFarlane Trust which was involved in giving financial assistance to haemophiliacs infected with HIV.

18. The MacFarlane Trust seemed to cause issues with the various HIV groups, involving how they were distributing monies. The groups felt this was being carried out unfairly. It appeared that they would give different amounts to different people, depending on the quality of their application, rather than its merits. This caused anger and despair about the MacFarlane Trust.

19. I recall someone telling me that a parent had applied for money for a bicycle for her young son who was dying, but she was refused the money. However the MacFarlane Trust were paying to keep another little boy in private school. It just did not seem fair.

20. During [H]'s illness, I have been asked if [H] ever had any tattoos or injected himself with recreational drugs, which I find insulting and insensitive. I can say that he never did either of these. He did have

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numerous transfusions of blood and treatments of blood products, which all related to his haemophilia issues from birth.

21. [H] was informed in 1983/84 by Professor Bloom that he had HIV from blood or blood products he had been given. Initially he was told in private and then as part of a group of HIV sufferers from across Wales. I was present at this meeting. There were about 40 patients present in all. They were given very little advice. The majority formed the opinion that even Professor Bloom and his staff did not know very much at this initial stage.
22. The young victims made light of the situation during this meeting, saying things like 'they could be killed walking across the road'. The seriousness of the situation was not pointed out to us and we had no other information or literature to help us.

3. Other Infections

1. [H] was infected with a combination of infections; HIV, hepatitis B and hepatitis C where he had the antibodies but no symptoms.
2. The situation with his hepatitis C was a great worry to the both of us because he received no treatment and we were aware that a great many people in this situation developed full-blown hepatitis C quickly and often died soon after.
3. When Professor Bloom formally told [H] and myself that [H] was infected with AIDS in 1983/84. He also told us that [H] had probably been infected earlier from blood products he had been treated with.
4. The information given to us initially was not adequate. It was described simply as an immune disorder and antibiotics would not work to clear them up for the patients.

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5. There was a lack of information given to all the haemophiliacs who had contracted HIV. There was no literature to give to us and at that time, not like today, we could not look things up on the Internet. There should have been much more information about the transmission of bodily fluids and the possibility of infecting others.
6. I believe that information should have been given earlier to all the victims, to allow them to cope better with the numerous issues they faced.
7. The method of communicating the test results I feel was handled by Professor Bloom as well as he could with the information available to him at that time.
8. Very little information was initially given to us regarding the risks to others close to the victims. For example, during the initial meeting of the group of Welsh HIV victims, we were told that "the ladies do not need to worry, they cannot catch it". There was no warning about sexual transmission between partners. There seemed to be an overall lack of knowledge and information.
9. In October 1998 [H] was tested for prion disease as there was a possibility of prions being transmitted by blood products. A prion is a type of protein that can trigger normal proteins in the brain to fold abnormally. It is a fatal degenerative brain disorder. The most common form of prion disease that affects humans is Creutzfeldt-Jakob disease.
10. In 2001 [H] suffered with recurrent tonsillar pain, this proved to be a retrotonsillar abscess which was HIV related. Exhibited at WITN0047005 is an assessment sheet dated 8th June 2001 from the Arthur Bloom Haemophilia Centre at the UHW indicating this.

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11. In 2003 he underwent an operation to repair a right inguinal hernia at the UHW. He was hepatitis C PCR negative following treatment with Interferon and Ribavirin.

4. Consent

1. I am unable to say whether [H] was ever treated or tested without his knowledge.
2. In relation to consent, over the years [H] had tests for numerous reasons but was not always told what the tests were for. For instance, the blood test after his major hip operation resulted in the Hepatitis B being identified. Therefore, he may not have given consent to specific tests.
3. Information about [H]'s procedures was usually communicated to us.
4. On occasions we were aware that research was going to be carried out on [H]'s blood, and this was done with [H]'s consent but we were not always aware of what type of research.

5. Impact

1. The mental effects of [H]'s infection were very traumatic for both of us. We were aware from the press that numerous people in America were dying from HIV and personal friends were dying very quickly after their diagnosis. [H]'s infection appeared to us to be a death sentence.
2. [H] often worried that I would also become infected with HIV. He worried that our children would be orphaned and what would become of them. Additionally, when he was told he had the antibodies of hepatitis C there was no explanation given about the implications, this again caused [H] great concern.

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3. When [H] was diagnosed in the 1980's we had already had our children and after [H] was diagnosed with HIV, we made, as many others did, a decision to become celibate.
4. The physical effects on [H] got progressively worse as the infection took hold. He was badly constipated and would get coughs that lasted for years, even with antibiotics they would not clear up. [H] found it continually difficult to swallow.
5. In addition, he developed a fluid filled lump on the back of his neck (Lipodystrophy) and had a few minor strokes. Eventually in 2012 [H] had a massive stroke which he never recovered from and died on [GRO-B] [GRO-B] 2012.
6. In addition to the details above, from the time of his infection, which was diagnosed in 1983/84, he got progressively more ill and suffered numerous symptoms synonymous with HIV.
7. In the 1990's [H] was put on a course of AZT tablets (I do not know what the initials stand for). These had to be taken throughout the day and night. This meant that [H] had to set an alarm for 2.00 am so that he could take his medication. This medication had to be taken with food, so he would need to eat a biscuit in the middle of the night.
8. We did not feel that we had any difficulties obtaining the various treatments. Professor Bloom and his staff made treatments available to us.
9. We were not aware of any treatments that were not made available to him.
10. In 1996 [H]'s HIV count was going back up again, so they changed him from AZT to a triple set of drugs, one of which was called Indinavir

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(which is a protease inhibitor). I do not know the dosages that [H] was taking. These drugs had bad side effects on [H]. These side effects included sickness, rashes, itchy skin and painful throat problems, including abscesses which resulted in an admission to the UHW ENT Department but they were unable to identify a specific cause

11. As this treatment of the triple drugs continued, the side effects got worse. [H] lost weight in his body, face and his skin was yellowing. This was the period when the Lipodystrophy was affecting his neck and was getting worse. Consequently, he was unable to wear a tie and he had to wear a cravat. He got progressively more tired.
12. Since being first diagnosed with hepatitis B, [H] had to go to a specialist dentist at the UHW.
13. In relation to the effects on our private lives, it was not too bad. [H]'s parents had both died by the time he was diagnosed with HIV. We did not tell his brother and sister until his illness became much worse. [H] remained enthusiastic about the many interests he had in his life.
14. I never told my parents about his HIV. However, they knew he was a haemophiliac. Both of my parents had also died before [H] got very ill. At one stage my sister asked if [H] was infected, but we lied, telling her no and that he had only been treated with British blood. We only told relatives when he got ill.
15. We did not tell our children about the HIV infection until they were older, probably teenagers. I recall our daughter was away at college. We had received a financial pay out, so decided to tell them, so we could give the news as a "bad news/good news" scenario.
16. We felt there was very much a stigma about HIV. However it was contracted. This included adverse publicity and poor taste jokes within

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- the community. It felt like we had the plague. We didn't know how to deal with handling blood, bodily fluids, washing clothes etc. The children thought it was strange that they were told to use separate toothbrushes and towels.
17. We had also heard of a haemophiliac child aged 6 with HIV in the Welsh valleys whose mother's house was daubed in paint with anti HIV graffiti. Unfortunately the boy died shortly after and the mother was forced to move away because of the stigma and people's ignorance. This was very distressing for the whole affected community.
18. Although [H] had a poor formal education due to his haemophilia, he was able to qualify as a Teacher, but not until he was older. Then due to ill-health, as a result of the HIV, he had to retire at the age of 57, which resulted in a much reduced pension.
19. Due to [H]'s haemophilia, I did not finish my nursing training. I was only able to do part time work to begin with. Later however, I qualified as a Teacher and did full time supply teaching. Eventually, I had to give this up as [H] became progressively more ill due to the HIV.
20. My son was diagnosed with bi-polar disorder prior to [H] becoming aware of his infection with HIV. This appeared to put more strain on [H] as his condition worsened.
21. On reflection, I feel sorry and guilty that was not able to offer enough support to my children when they were teenagers and when they were sitting their GCSE's/O'Level exams. Trying to keep [H] well was always my priority.

6. Treatment/Care/Support

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1. I believe that [H] received good care and service from Professor Bloom and his staff at the UHW. All the doctors and nurses were very good and supportive.
2. When [H] was initially diagnosed in the 1980's, I feel that the counselling and support workers (primarily Social Workers) were completely overwhelmed. They were young people dealing with many deaths, attending funerals and attempting to support the families. They were often young female social workers who were dealing with young males which could possibly be embarrassing. More mature social workers would have been more suitable.
3. They would often call us to say another person had died but we didn't need or want to know this every time. It was very depressing. Once we had a call just as we were to leave for a holiday we had been looking forward to. Consequently after the call our mood was very low. After this we asked them only to contact us if it was a specific friend of ours that had passed away.
4. Support was offered to me individually, by the authorities as well as to [H] but we went through everything together.
5. I do not feel that the support provided was very good initially, but it did improve over time.
6. In 2011 whilst administering [H]'s home treatment I pricked my finger. I did not think anything of it and just washed the blood away with water. [H] was due to attend at the UHW on that day and whilst at his appointment he mentioned to the staff that I had pricked my finger earlier in the day. I then received a call from the UHW for me to go to the hospital where they carried out some tests and prescribed me a cocktail of treatment that I should take in tablet form for about 6 weeks. I am not sure what this treatment was called but I believe it must have been something similar to whatever

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[H] was taking at that time. I commenced this treatment but the side effects were awful. My skin began to go yellow and I constantly felt sick. It was at this time that I fully sympathised with [H] and the awful treatment and side effects that he had to go through. I was tested again after taking the treatment and fortunately had the all clear.

7. Financial Assistance

1. We received financial assistance from the MacFarlane Trust in the late 1980's. This was in the form of payments of £200 and this went towards holidays.
2. The social workers were helpful in helping us to apply for money for holidays and 'special reasons' for money.
3. We later received £60,000 for [H] because we had a dependent son at home. We received a further amount of either £20,000 or £25,000.
4. We were also contacted by an American legal firm called Leiff Cabraser who stated they were representing various UK groups and individuals against US drug companies. We were paid approximately £18,000 in about 2000. As far as I am aware everybody got the same payment of this fund. I have a memory that this was linked to the Skipton Fund, but I cannot be sure of that.
5. In February 2001 Dr. Dasani at the Haemophilia Centre at the UHW discussed the implications of the ex gratia payment announced by the Government for hepatitis C with [H] and unfortunately informed him that in view of [H]'s PCR negative status without treatment he does not qualify for the ex-gratia payment. Exhibited at

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WITN0047006 is a letter dated 5th February 2004 from Dr. Dasani at the UHW to [H]'s GP, Dr [GRO-B]

6. The only difficulties I recall are when the Birchgrove Group identified issues with the MacFarlane Trust's method of making payments.
7. I recall at one point we had to sign a waiver or we would not receive any money. I do not recall exactly when this happened but it was early in the process, therefore I believe this would be in relation to the MacFarlane Trust.
8. I have no other observations about the various trusts and funds.
9. Approximately 2 years before [H] died he suddenly began to worry a lot about how I would survive financially when he wasn't here any longer. He knew that my pension would not amount to much. I don't know whether the hospital had told him something, but he did not tell me as I don't think he wanted to worry me. My concern was for him, I didn't want him worrying about me.
10. When [H] died, it was suggested to me to apply for assistance from the MacFarlane Trust, due to my upset at this time, I do not recall the process. It may have been that someone helped me to make the application.
11. I received £3,000 towards [H]'s funeral costs in 2012 from the MacFarlane Trust. I was later made aware that I was entitled to an allowance, but because of the pressures and upset around [H]'s death, I did not follow this up until later. In 2013 I received a one off payment of £7,000 in lieu of the allowance.
12. I remember it was very difficult to sort out the payment of £7,000 due to the bureaucracy of the MacFarlane Trust at that time. I

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made numerous calls to the Trust but the staff seemed disinterested and did not call me back. Eventually, I did get through to the finance department and they managed to sort it out.

13. I also received £21,000 from the Welsh Government, which was in lieu of any future payments that could have been paid to me. This was following the Scottish Government's decision (which was devolved from Westminster at this time) to pay an allowance to widows of haemophiliacs that had died of HIV. The Welsh Government (also devolved) decided they would stay with the English decision to make a one off payment, rather than pay ongoing regular payments. As I was older, this would have little effect on me but it will have a significant impact on younger widows.

14. I don't think there were any other preconditions set on me in making these later applications relating to me.

15. I have no other observations about the various trusts and funds.

8. Other Issues

1. In 2004 [H] was approached to take part in a project conducted by Brighton University. He agreed to do this and was interviewed at our home. The interview was recorded. I have a transcript of the interview. Exhibited at are six photographs of the most relevant pages. This set of six photographs are referred to as Exhibit WITN0047007. I am also aware that the contents of these audio files are stored at the British Library in London.
2. Other than the matters listed above, there are no other litigation issues we have been involved with.

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3. **H** and I have not been involved in any other investigations or campaigns. **GRO-B**

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Statement of Truth

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

Signed.. GRO-B

Dated *16th May 2019*