

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOHN BARNES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16th April 2020. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, John Barnes, will say as follows: -

1. Introduction

1. My name is John Barnes. My date of birth is [GRO-C] 1946 and my address is known to the Inquiry. I am a retired shopkeeper.

2. How Affected

1. I write this statement as an affected person. My late father was a haemophiliac and a victim of contaminated blood.
2. My father was born on the [GRO-C] 1925. I recall my father suffering with bleeds when I was a child. The type of haemophilia my father suffered from was haemophilia A. I would say my father's haemophilia was mild. It wasn't a regular occurrence for my father to receive treatment for his haemophilia.

3. Before the Haemophilia Centre at the University Hospital Wales ('UHW') opened, my father received treatment at Cardiff Royal Infirmary. When I was child, I remember him having his teeth removed and he received treatment for his haemophilia as a precautionary measure.
4. As I got older, I recall my father suffering from bleeds more regularly. At UHW, my father was treated primarily by Professor Bloom. My father thought a lot of Professor Bloom and the general opinion of Professor Bloom was that he was 'God'.
5. I would say my father attended the haemophilia centre at UHW on average every 2-3 months. I am not sure if my father received cryoprecipitate. I remember him being given factor VIII. I recall my father having a bleed on his elbow and a further severe bleed not long after this. This was in the late 1970s. He also had an operation on his knee in the early 1980s. He received factor VIII to treat these bleeds.
6. One the earliest memories I have of my father's haemophilia was when he went to Majorca in 1978. Whilst he was on the trip, he had a bleed and required factor VIII. I had to get in touch with Professor Bloom to collect a bottle of factor VIII. I then had to take my mother (along with the Factor VIII) to Heathrow Airport. Initially, security wouldn't let my mother through customs as they were suspicious of the factor VIII. However, once Professor Bloom spoke to them on the phone, they let her through. Once my mother arrived in Majorca, she went to see my father and handed the factor VIII to the doctors. The doctors then administered the factor VIII to my father whilst Professor Bloom gave them instructions over the phone. It was unbelievable, within 30 minutes of taking it he was completely out of pain and back to normal.
7. My family has a long history of haemophilia. Two of my uncles suffered with the condition and died as a result of their bleeds. One of my uncles passed away from a perforated stomach. Medical professionals simply couldn't stop the bleed.

8. I would like to add that my mother didn't know my father was a haemophiliac until after I was born. Due to my father's haemophilia, my mother and father chose not to have any more children after me. My parents were concerned about passing the haemophilia on.
9. It was in the early 1990s that my father was told he had tested positive for hepatitis C. My father was told by Professor Collins of UHW Haemophilia Centre that he was positive for hepatitis C.
10. Initially my father told me that he had hepatitis B but a couple of months later, he told me the truth that he had hepatitis C. I think my father was scared of the reality of having hepatitis C.
11. My father never told me any specific details as to whether he was warned of the risks of being exposed to hepatitis when he was given blood products to treat his haemophilia.

3. **Other infections**

1. Following review of my father's medical records from UHW Haemophilia Centre, I am now aware that my father suffered with many other medical conditions as a result of his hepatitis C and haemophilia. Exhibited before me at **WITN4166002** is a copy of a letter from Dr Dasani of UHW Haemophilia Centre to my father's GP, Dr Rogers dated 24th February 1999. The letter states that my father suffered from the following conditions; severe haemophilia A, hepatitis C, chronic haemophilic arthropathy of both ankles, angina, hypertension, heartburn, bilateral lower limb pain and aortic aneurysm.
2. My father always suffered with painful joints. However, I was unaware before viewing my father's records and specifically Exhibit **WITN4166002** that my father suffered with chronic haemophilic arthropathy of both ankles.

3. I was also unaware that my father had aortic aneurysms before viewing his medical records. Discovering these medical conditions came as a surprise to me.
4. My father's death certificate states he died on 16th May 2000 as a result of hypertension, intracerebral bleed and haemophilia A. A copy of the death certificate is exhibited before me at Exhibit **WITN4166003**.

4. Consent

1. I don't believe my father was treated without his knowledge or consent. My father received treatment for his haemophilia with an open mind and never questioned what he was being given. He believed the treatment he received was going to help him.
2. Further, I do not believe my father was tested without his knowledge or consent or without being given full or adequate information.
3. Following review of my father's UHW records I am now aware that my father's haemophilia records were reviewed on 27th January 2005. The reason my father's haemophilia records were reviewed was to assess whether he had been exposed to vCJD. The form concludes "the patient is not at risk of vCJD for public health purposes". A copy of the vCJD exposure risk form dated 27th January 2005 is exhibited before me at Exhibit **WITN4166004**. I would like to add that I did not know my late father's blood samples were being assessed for vCJD and I was not alerted by UHW that such testing was taking place.

5. Impact

1. My father did not have any issues with regards to receiving treatment for his haemophilia. He simply wanted to get better. He wanted to lead a normal life. He worked down the colliery for years. During his time at the colliery he confided in one of his friends about his haemophilia. However, soon after his friend had told one of the managers and my father was moved from

underground and told to work on the surface of the colliery. Not long after this, my father was made redundant.

2. Following his redundancy, my father had various driving jobs. In March 1976, my father bought a baker's shop and café in the centre of Maesteg. He retired in 1989 and I took over the business. My father was not a big drinker and would sometimes go to the local golf club with my mother for evenings out, but this never involved heavy drinking. In terms of what he did with his spare time, my father loved gardening. He also enjoyed making love spoons.
3. I don't believe my father experienced any mental side effects following his hepatitis C diagnosis. I think he was frustrated by his diagnosis in the sense that it was out of his control but besides that I don't think there were any other mental effects on him. Even after my father received his hepatitis diagnosis, he still liked to keep fit and active by walking. The frustration I discuss above was simply part of my father's character, that's who he was.
4. Following his hepatitis C diagnosis in the early 1990s, my father began his treatment at UHW straight away. At this time my father had finished work. I believe my father was mainly prescribed tablets as treatment for his hepatitis. Since requesting my father's records from UHW, we have only been able to retrieve around 100 pages. These pages were my father's haemophilia records and did not include any detail regarding my father's treatment for hepatitis C.
5. I do not believe my father experienced any mental or emotional side effects from the hepatitis C or the treatment he received for it. Physically, however, he often became very fatigued and tired. He would go to bed in the daytime. He was a very private man and only very close family knew of the hepatitis C. When I looked into what hepatitis could do to you and its side effects, I became very upset.
6. My father would experience pain in his liver which would cause him real discomfort. He also experienced symptoms of his haemophilia when he was

elderly with him often having swollen joints. My father would require ankle supports to keep his joints in place. My father's health deteriorated in the late 1990s and he subsequently passed away on 16th May 2000.

7. In 2017, I was watching the BBC programme Panorama. The episode focussed on the contaminated blood scandal. During the programme, the audience was told how the UK had been importing blood from the US in the 1970s/1980s, with some of this blood being sourced from prisons. I honestly could not believe what I was watching.
8. After watching Panorama, I called the Skipton Fund. They sent me a form to complete that contained pages and pages of questions. I contacted Haemophilia Wales and was told that Professor Collins would fill out the form on behalf of my late father. I then received a letter from Professor Collins which confirmed in writing that my father contracted hepatitis C from contaminated blood. A copy of the letter dated 1st September 2017 is exhibited before me at **Exhibit WITN4166005**.

6. **Treatment/Care Support**

1. As I have said earlier in my statement my father received the majority of his treatment at UHW Haemophilia Centre.
2. With regard to self- treatment, I can't recall my father self-treating at home. If he ever had a bleed, he would take himself to UHW for treatment, apart from on the Majorca trip which I mention above.
3. I could not recall the exact names of the blood products my father received. However, since reviewing my father's UHW medical records and specifically the vCJD exposure assessment form exhibited at **Exhibit WITN4166004**, I can see that my father was treated with both factor VIII and factor IX.

4. I do not believe my father experienced any difficulties with regards to accessing treatment following his hepatitis C diagnosis. I don't recall my father ever receiving any counselling or psychological support. I can confirm I have not received any either.

7. Financial assistance

1. As I mentioned earlier in my statement, it was in 2017 that I contacted the Skipton Fund after watching the Panorama programme about contaminated blood.
2. After Professor Collins filled out the form, I received the sum of £20,000 from the fund. I felt quite sad that we were not notified that we were entitled to this money sooner. If we had applied for the money when my mother was alive, it would have made life a lot easier for her. After my father passed away, my mother was not entirely comfortable financially and I believe this money would have helped her tremendously.
3. I didn't have any problems with the Skipton Fund. In fact, I would go as far to say they were marvellous.
4. After the Skipton fund closed, I got in touch with WIBSS. I didn't find WIBSS as helpful, they weren't informative enough. I felt as though I had to ask them a lot of questions and was always kept at arm's length.
5. I can confirm I have never signed any waivers regarding financial assistance.

8. Other Issues

1. I would like to know what went wrong and why so many individuals received contaminated blood. It is quite clear that inadequate testing of blood supplies was a huge contributory factor in all of this.

2. When a request for my father's records was made to UHW in April 2020, only one hundred pages of my father's haemophilia records could be recovered. I found this quite disappointing as I have only been able to view a few pages of his records. As a haemophiliac, I believe my father would have had an extensive amount of medical records.
3. Following review of the small amount of medical records I have been able to obtain from UHW, I am left confused as to whether my father was medically deemed a 'mild haemophiliac' or a 'severe haemophiliac'. **Exhibit WITN4166002** states that my father was a severe haemophiliac. However, in a letter dated 18th January 2000 from Dr P Chowdary to my father's GP Dr Rogers, my father is labelled a mild haemophiliac. A copy of the letter is exhibited before me at Exhibit **WITN4166006**. As I have said earlier in my statement, my father's haemophilia deteriorated as he got older. Therefore, I think it was incorrect that my father was labelled a 'mild haemophiliac' in the last few months of his life.

Statement of Truth

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

Signed

GRO-C

Dated 20-10-2020