

Witness Name: Mr Gerald Stone
Statement No:WITN2554001
Exhibits: WITN2554002
WITN2554003
Dated: 26th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GERALD STONE

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, Gerald Stone, will say as follows:-

1. Introduction

1. My name is Gerald Stone. My date of birth and address are known to the Inquiry.
2. I live with my wife Janice to whom I have been married since 1972. We have two grown up daughters and three grandchildren together.
3. I have severe haemophilia B and I am known as a 0% haemophiliac, which is the most severe type. The haemophilia is hereditary, coming from my mother's side of the family. I was regularly in and out of hospital as a boy due to the haemophilia.

2. How Infected

1. I started having factor IX concentrated blood products in about 1971 at Cardiff Royal Infirmary and later in 1972 at the University Hospital Wales ('UHW'). This was administered at the hospitals by intravenous injection. From 1st January 1976 I kept a record of all of the factor IX products I was prescribed to treat myself at home with. All of the products prescribed up to 30th October 1985 were British Blood products. I know this because I had to record for the hospital each infusion, the batch number and the reason for needing the product. I kept a personal record of the batch numbers.
2. Throughout my time at UHW Haemophilia Centre I was under the care of Professor Bloom until he retired in the early 90s.
3. I remember the first time I was given blood products was in 1962. This was a one off in Oxford. I was told that it was a one off because it was too expensive to produce regularly. Between around 1960 and 1970 I was given fresh frozen plasma whenever I had a bleeding problem.
4. I started having regular factor IX blood products in about 1970. Initially these were administered at the hospital by intravenous injection. On the 2nd January 1976, I started treating myself at home with Factor IX supplied by the hospital. I know this because I have kept a record of each batch of factor IX I was given. I refer you to exhibit WITN2554002, this shows the record of the blood products I had between 1976 and 1989. The entry in red shows the American product I received. All of the products I was given up to 30th October 1985 were British products. This can be demonstrated in the exhibit. I have kept a record of every batch number given to me.
5. I believe the contaminated blood product prescribed to me was the one that I received between 30th October 1985 and 29th December 1985. The blood product prescribed between these dates came from America. From 29th December onwards I was placed back on the British products. I have never

understood why they felt the need to change the product at that time. It is a decision I find difficult to swallow, particularly given the fact I may not have contracted Hepatitis C but for the American product. Before this I remember being concerned with what I had read in the PHLS Communicable Disease Report for the week ending 6 May 1983.

6. I had access to this report as I worked for an Environmental Health Department. The report showed a number of statistics relating to HIV and AIDS and in the report it stated that a 20 year old man with haemophilia from Cardiff had acquired AIDS. This was the first report of AIDS in a patient with haemophilia in the United Kingdom known to CDSC.
7. I went to see Professor Bloom's registrar to ask him what he knew of the incident. I told him that I wasn't looking for any personal information on the victim, however, I wanted to know if I had received blood products from the same batch as the victim. I was petrified that this may be the case as I may have been infected, meaning, I may have in turn infected my wife. I remember losing my temper with the staff nurse who was trying to calm me down because Professor Bloom's registrar wouldn't give me a straight answer; all he was concerned with was how I was privy to such information. Fortunately I had not contracted any illness at this point, but my luck would eventually change.
8. This was a particularly difficult time for me. In the absence of medical information I became convinced that I contracted HIV. Each time I had an illness not related to a bleeding problem, for example, a chest infection, I associated it with AIDS. It truly was a horrific time.
9. Between the aforementioned dates I was given the Factor 9 product from America. When I queried why I was going on a different batch of products, they told me that it was safer than the British products I had been prescribed. I didn't question the medical professionals because I, along with many others, had complete and utter faith in them, especially Professor Bloom, who many held in high regard. On 27 July 1993 all of the above worries became a reality

for me when I was told by Dr H. Dasani that I was infected with Hepatitis C. On querying my life expectancy, I was told "probably 5 to 10 years". My concerns were further exacerbated as I was witnessing the death of haemophiliacs I knew for more than 30 years. This was very distressing as many of them were younger than me and I thought that I wouldn't be too long after them.

10. It has since come to my attention that they were aware of my diagnosis of HCV positive from 2 June 1991. I find it incredibly irresponsible that it took them 2 years to inform me of my illness. Had I not been so paranoid about having HIV, I could have infected my wife and children. I took every precaution possible, including practicing safe sex since reading the CDC report in May 1983.

11. I must admit that the information provided by Dr Dasani was very informative upon giving me my diagnosis, but that is not the point. I should have been told as soon as they knew. They had no idea I was taking precautionary measures myself. I know other couples were not so lucky. I was told that these viruses could spread through the transfer of blood and bodily fluids such as saliva and semen. This, therefore, affected my married life for over 35 years until I was cured of the illness in 2016.

3. Other infections

1. I have not suffered from any other infections as a result of my diagnosis.

4. Consent

1. I know that I was infected with contaminated blood between 30 October 1985 and 29 December 1985. I was told the contaminated blood that was imported from the US was safer than the UK blood I had originally been treated with. If they hadn't switched my blood products in those two months I would not be giving this statement.

2. Furthermore, I wasn't made aware that I was HCV positive until I was informed by Dr Dasani on 27 July 1993. It was common practice for the medical professionals to take my bloods on a regular basis, however, I was never informed that my bloods were being tested for potential infections. I was surprised to learn upon reading my medical records that they in fact knew about the infection on 2 June 1991. It is incredible that they let me continue to lead my life without any knowledge of this. It was wholly irresponsible and reckless. I dread to imagine how different things may have been for my family and I had I not been sensible in taking precautionary measures.
3. I was told I did not have HIV in about 1985, but I nevertheless continued taking precautions as I no longer trusted the products being virus free. When I was told I had Hepatitis C ('Hep C') in 1993 it substantiated my opinion.

5. Impact

1. Since my diagnosis I have lived a life of secrecy from my family, friends and work colleagues; and I still do to this day. My wife and I chose to do so in order to protect our family from the stigma. Many years ago we did not have the information and treatment that are available today and there was a stigma associated with the all of the diseases in question. I saw how people were being ostracised because of the prejudice surrounding the disease and I didn't want that to happen to me or my family.
2. After the diagnosis I found that I was very tired. I am not sure whether it was due to the disease catching up with me or lack of sleep through my constant worrying. I found myself waking up in the middle of the night sweating, wondering about my life expectancy and how my family would manage with the finances if I wasn't there to contribute.
3. I was frequently curt and moody with family, friends and colleagues, and in all honesty being pleasant felt like a strain or an act. I continued to work in order to pay the mortgage and see my children through university, however

convinced that I had limited time left, I chose early retirement in 2000 once my major financial commitments were over. If I had known I was going to live this long I would have worked for longer which my pension on retirement would have reflected.

4. The impact on my marriage has been agonizing. In addition to carefully ensuring I do not contaminate my wife, she and I have had to watch everything we say to keep my illness a secret. There have been times over the years where friends have discussed HIV, AIDS and HCV and we have been in a state of paranoia, thinking that they knew about my condition and were testing us to see if we cracked. It sounds preposterous but it has happened on numerous occasions, especially when the news started to break about contaminated blood in the 80's.
5. On 18 January 2001 I was told that I had received Factor 9 blood products produced from blood donated by a person who had died from vCJD, also known as mad cow disease. This caused me unimaginable stress as this disease was very topical at that time where I had worked.

6. Treatment/Care Support

1. Between 18 January 2007 and 15 February 2008 I was treated with Interferon and Ribavarin for my Hepatitis C. The treatment involved numerous visits to the University Hospital Wales for injections into my stomach tissue in addition to the tablets that I was prescribed. The treatment was worse than the Hepatitis C as it made me stressed and intolerant, it was a real struggle for me at this time.
2. The treatment I received on that occasion was unsuccessful. However, I was subsequently treated with Harvoni on 21 June 2016 for 12 months. This required me to take regular tablets and visit the University Hospital Wales every couple of months for a check up. On this occasion the treatment was successful and I am told it remains to be the case.

3. I must admit that I have not experienced any difficulty, in receiving treatment from the NHS. The problem has been a lack of transparency in the early the 80s and early 90s from those involved. The one occasion I felt I was discriminated against was when I received physiotherapy at another hospital. The physiotherapist suggested acupuncture and before she proceeded I brought up my condition. After I disclosed this she decided that it would be unwise to perform the treatment and shortly afterwards I was told that there was no more they could do for me. Whether this was due to my hepatitis is debatable.

7. Financial Assistance

1. I received a Stage 1 payment of £20,000 from the Skipton Fund on 17 August 2004.
2. I received a £500 as a heating allowance from 27 March 2013 from the Coxtton Foundation. This came to an end when the Wales Infected Blood Support Scheme (WIBSS) was introduced on 1 April 2016.
3. On 2 November 2010 I received £5,430 as part of a group of claimants who were successful in a Civil Action lawsuit in the US.
4. As mentioned, I am also in receipt of an annual payment of £4,500 from the Wales Infected Blood Support Scheme (WIBSS). This payment is adjusted for inflation.

8. Other Issues

1. I have submitted a document that has come into my possession dated 11 January 1982 addressed to all haemophilia centre directors. I refer to Exhibit WITN2554003. I feel this may be of interest to the inquiry. The document relates to the knowledge that the professionals had at the time they were treating haemophiliacs such as myself. I find it infuriating and upsetting that the medical professionals knew of the potential risks posed by the products

we were treated with but still chose to be so nonchalant with treating haemophiliacs with possible contaminated blood products.

Statement of Truth

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

Signed..... **GRO-C**

Dated..... *26th February 2019*