

Witness Name: RHIAN THOMAS

Statement No: WITN3267001

Exhibits: WITN3267002-7

Dated: JULY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RHIAN THOMAS

I, RHIAN THOMAS, will say as follows:-

Section 1. Introduction

1. My name is Rhian Thomas. I was born on GRO-C 1968 and I live at GRO-C
GRO-C Wales.
2. My grandfather, Arthur Jones (born on GRO-C 1921), was infected with the Hepatitis C Virus (HCV) from contaminated blood products. He died from liver failure on 28th December 1998, aged 77.
3. My mother has provided her own Witness Statement to the Inquiry (Witness Number WITN1296001).
4. This witness statement has been prepared without the benefit of access to my grandfather's full medical records. I was informed that my grandfather's records were destroyed despite my mother's request to the Medical Records Department back in 1999 to preserve them.

Section 2. How Affected

5. My grandfather had mild Haemophilia A, with a clotting factor of 19%.
6. My grandfather was treated at the Swansea Haemophilia Centre at the Morriston and Singleton Hospitals under the care of Dr Khurshid initially and then Dr GRO-D GRO-D and Dr A Beddall.
7. My grandfather rarely needed Factor VIII (FVIII) concentrate treatment and never at home. My grandfather was treated with FVIII in November 1986 when admitted to hospital with haematemesis and when he needed teeth extracting (in the 1980s, possibly as late as 1988). I refer to **Exhibit WITN3267002** being a copy of my grandfather's dental appointment card in 1988.
8. I refer to **Exhibit WITN3267003** being a copy of my grandfather's UKHCDO patient records. The patient annual treatment record may be incorrect as I believe that my grandfather was treated with FVIII concentrate from the late 1970s onwards. I also refer to **Exhibit WITN3267004** being a letter from Dr GRO-D GRO- to the Customer Relations Manager at the Morriston Hospital dated 18th January 2000 and **Exhibit WITN3267005** being a letter from Dr GRO-D to Dr Giangrande at the Oxford Haemophilia Centre dated 2nd August 2001. Raised liver enzymes were noted from as early as 1985 and 1986 respectively. The two letters referred to at Exhibits WITN3267004 and WITN3267005 were apparently the only two letters to still exist (as acquired via Jennifer Nagle, Deputy Head of Health Records in 2017 found/located in Dr GRO-D's office).
9. My grandfather had no idea that he had HCV until he was admitted to hospital in 1997 for ascites and was told that he had HCV and cirrhosis of the liver. We are a very close family. Many of our family members live in very close proximity to each other in the same road GRO-C some of us next door to each other. I lived a few doors down to my grandparents. My grandmother was agoraphobic and had a social phobia and, as a result, we (usually my mother)

accompanied my grandfather to all of his hospital appointments. We (and other of our family members) sat with him throughout the entirety of all the visiting hours when he was admitted to hospital. No-one discussed with my grandfather the risk of infection and/or concerns pertaining to hepatitis in our presence.

10. Dr Kingham, Consultant Gastroenterologist, carried out a large number of blood tests and my grandfather was alone on a hospital ward when he was informed of the results. My grandfather was informed there and then that he was terminally ill. He should not have been given that news alone. My grandfather rang my mother from the ward and said "they know what is wrong with me now". She said "well that is good news as they can get on and sort you out". My grandfather was crying when we arrived on the ward and said "no, they said there is nothing they can do for me". I had never seen my grandfather cry. My grandfather was a strong and stoic man. We used to liken him to Popeye.
11. No information or advice was provided to my grandfather beforehand about the risk of being exposed to infection. I was never privy to any warning to my grandfather of risk. The news of the HCV infection came as a shock to him and to us all.
12. My grandfather became suspicious about the source of the HCV infection. We had no idea that my grandfather had been given contaminated blood products until he found an article in the local paper about someone contracting HCV through FVIII concentrates. That person had had a liver transplant. It was too late for my grandfather to have a liver transplant.
13. I believe that my grandfather should have been informed about his infected status much sooner and treated appropriately. Referring once again to Exhibits WITN3267004 and WITN3267005 raised liver enzymes were detected in my grandfather's blood in 1985 and again in 1986. I do not understand why there was no follow up investigation to include scans until it was too late in 1997. My

grandfather attended his haemophilia appointments and his blood was taken at those appointments. I refer to **Exhibit WITN3267006** being a copy of my grandfather's appointment card for 1987 through to 1989.

14. In 1991 my grandfather had a problem with his thyroid. I recall mention then that there was 'an abnormality' with my grandfather's liver. There was no follow up about his liver at that juncture either. Shortly after that he was taken back into hospital with (another) suspected heart attack and saw a cardiologist. My mother asked the sister on the ward what was wrong and she said "he is going to have to stop drinking". The nurse made the 'stop drinking' comment in front of us and in front of everyone at visiting time on the ward. We thought she was talking about the wrong person because my grandfather never drank alcohol. My grandfather poo-pooed it as a mix up with the wrong patient.

15. When my grandfather was told that he had HCV in 1997 they asked him where he had been on holiday and where he had picked up the virus. My grandfather was so clean living and never went anywhere. Telling us that my grandfather needed to stop drinking and in asking him about where he had been on holiday (knowing full well that contaminated blood was in circulation) was wrong and very unfair. In doing so, they tried to put the blame back on my grandfather and he was deeply upset when he learned the truth.

16. I would also add that I have two **GRO-C** with haemophilia, one of them is infected with HCV from contaminated blood products. He was not told that he had HCV. I was with **GRO-C** at one of his hospital appointments and saw that his file was marked with a 'Hepatitis C' warning on the front label.

17. My grandfather was not given adequate information to help manage his infection. The doctors did not give my grandfather any advice at all. We, as a family, had no advice, no counselling and were not offered any blood tests for ourselves.

Section 3. Other Infections

18. I do not believe my grandfather received any other infections. We were made aware of the vCJD issue from a newsletter sent out by Haemophilia Society.

Section 4. Consent

19. My grandfather was tested for infection without his knowledge and consent. It is clear from Exhibit WITN3267003 that my grandfather was tested HIV negative in 1987. He did not know about that. He would have told us if he knew he was being tested for HIV. I also do not believe that he knew that he was tested for hepatitis.

Section 5. Impact of the Infection

20. When my grandfather was admitted to hospital in 1997 with ascites, he had a huge stomach. He had waited for weeks for an appointment with a Cardiologist first before being referred on to Dr Kingham (Gastroenterologist) by our GP. In hospital they drained 26 pints of fluid from his abdomen. After a scan they found that his liver had shrunk from the liver disease.

21. When discharged my grandfather just went downhill. His weight plummeted from 18 or 19 stone down to 9 stone. My mother had to do everything for him. She gave up work because he couldn't do anything for himself. Because he wasn't drinking he developed a hernia and had to have an operation just a couple of months before he died.

22. On Christmas morning (1998) my grandfather hemorrhaged what must have been pints of concealed blood that had passed through him. It was horrendous. We called for an ambulance and my grandfather was taken into hospital.

23. When my grandfather was dying in hospital Dr GRO-D and his nurse passed the cubicle without acknowledging my grandfather. I told my grandfather "they will be back to see you" to which he replied "no, they have given up on me". They did not return. My grandfather died that night, on the 28th December 1998. The hospital staff were unprofessional and insensitive. We noticed whispers and the donning of gloves even when they were merely taking blood for testing. What really upsets me that that when he passed away we could not see him. We could not bring his coffin to the house. He was treated like a leper in life and death.

24. We were all deeply affected by the loss of my grandfather. My mother took antidepressants when he was dying. My son and daughter missed him. My grandmother only ever left the house to go out in the car with my grandfather. He would stop somewhere and she would wait in the car for him to come back with chips or an ice cream. After my grandfather became ill and died, all that stopped. The loss to my grandmother of my grandfather's support as well as his companionship was enormous. He was her rock.

25. My grandfather was the patriarch of his family. There was nothing he couldn't do. He could knock down walls and get up on top of roofs. He was always on hand to help us. He was unstoppable, a keen gardener. Even when he was ill he would still try to do his gardening. He enjoyed playing snooker and he loved watching sport, football, cricket and rugby. He was a Swansea season ticket holder and took me to all the matches. I was his only granddaughter and a tom boy. I was the only one that went to the football stadium. The boys did not want to go. He would bring us a cake every week. He would say "while I can do it, I will. The day I don't do it, you can worry". He loved to shop and brought us home things he loved himself to try, like a particular brand of tinned peaches. I loved my grandfather. I idolised him.

Section 6. Treatment/care/support

26. None of us were offered counselling and support to include my GRO-C

Section 7. Financial Assistance

27. My grandfather wrote to the Haemophilia Society in 1998 seeking financial assistance without success. I found out about the Skipton Fund by accident through Facebook/the Tainted Blood Website a couple of years ago. My mother and aunt received Stage 1 and Stage 2 payments (my grandmother passed away in 2002) through the Skipton Fund and then the Welsh scheme (WIBSS) took over.

Section 8. Other Issues

28. I refer to **Exhibit WITN3267007** being correspondence pertaining to the fact that my grandfather's medical notes were destroyed despite my mother's request that they be preserved.

Anonymity, disclosure and redaction

29. I am not seeking anonymity and I understand that this statement will be published and disclosed as part of the Inquiry. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signe: GRO-C....

Dated 3 / 7 / 2019