

Witness Name: MARGARET HOWELLS

Statement No: WITN1296001

Exhibits: WITN1296002-7

Dated: MAY 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF MARGARET HOWELLS

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I, MARGARET HOWELLS will say as follows:-

#### **Section 1. Introduction**

1. My name is Margaret Howells. I was born on the GRO-C 1942 and I live at GRO-C Wales.
2. My father, 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. This witness statement has been prepared without the benefit of access to my father's full medical records. My daughter, Rhian Thomas, has been notified that my father's records were destroyed despite my own request to the Medical Records Department back in 1999 to preserve them.

#### **Section 2. How Affected**

4. My father had mild Haemophilia A, with a clotting factor of 19%.

5. My father 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.
6. My father rarely needed Factor VIII (FVIII) treatment and never at home. My father 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 WITN1296002** being a copy of my father's dental appointment card in 1988.
7. I refer to **Exhibit WITN1296003** being a copy of my father's UKHCDO patient records. The patient annual treatment record may be incorrect as I believe that my father was treated with FVIII from the late 1970s. I also refer to **Exhibit WITN1296004** being a letter from Dr GRO-D to the Customer Relations Manager at the Morriston Hospital dated 18<sup>th</sup> January 2000 and **Exhibit WITN1296005** being a letter from Dr GRO-D to Dr Giangrande at the Oxford Haemophilia Centre dated 2<sup>nd</sup> August 2001. The two letters referred to at Exhibits WITN1296004 and WITN1296005 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).
8. My father 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. Dr Kingham, Consultant Gastroenterologist, carried out a large number of blood tests. 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 next door but one to my parents. My mother was agoraphobic and had a social phobia and, as a result, I accompanied my father to all of his hospital appointments. Rhian and I (and other family members) sat with him throughout the entirety of all the visiting hours when he was admitted to hospital.
9. My father was alone on a hospital ward when he was informed by Dr Kingham of the results of his blood tests and that he was terminally ill. My father rang

me from the ward and said "they know what is wrong with me now". I said "well that is good news as they can get on and sort you out". My father was crying when he told me "no, they said there is nothing they can do for me". My father was a stoic man and was not prone to crying. He was in effect given a death sentence. It was horrible for him to have received that news alone.

10. I do not believe any information or advice was provided to my father beforehand about the risk of being exposed to infection. I was never privy to any warning to my father of risk. If my father had been informed of risk of exposure to infection, he would never have agreed (as an example) to having his teeth extracted.

11. We had no idea how my father had contracted HCV until we read 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 father for a liver transplant.

12. I believe that my father should have been informed about his infected status much sooner and treated appropriately. Referring once again to Exhibits WITN1296004 and **WITN1296005** raised liver enzymes were detected in my father's blood in 1985 (possible myocardial infarction) and in 1986. I do not understand why there was no follow up investigations to include scans until it was too late in 1997. My father attended his haemophilia appointments and his blood was taken at those appointments. I refer to **Exhibit WITN1296006** being a copy of my father's appointment card for 1987 through to 1989.

13. I believe that the medical staff knew that my father had HCV as long ago as 1991 if not sooner. In 1991 my father had a problem with his thyroid. I recall mention then that there was 'an abnormality' with my father's liver. Shortly after that he was taken back into hospital with (another) suspected heart attack. I asked the sister on the ward what was wrong and she said "he is going to have to stop drinking". This was said in the office on the same ward

at visiting time. My father was a life long teetotaller and we exchanged puzzled looks with each other. I assumed she must have been talking about the wrong patient, believing my father to be someone else. There was no follow up appointment about the fact that my father had an abnormality in his liver so we just carried on as normal.

14. When my father was told that he had HCV by Dr [GRO-D] he was questioned about his lifestyle and whether he was clean living. He was asked where he had been on holiday and/or where he might have picked the HCV up from. My father was upset and taken aback by these questions. I believe Dr [GRO-D] to have been trying to blame my father even though he knew that the contaminated blood was in circulation.

15. I have two [GRO-C] with haemophilia. One of them has HCV. He was not told. My daughter, Rhian, alerted my [GRO-C] to the infection as his medical file had 'HCV' on a label on the front of it.

16. My father was not provided with adequate information to help manage his infection. The doctors did not give my father 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**

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

### **Section 4. Consent**

18. My father was tested for infection without his knowledge and consent. It is clear from Exhibit WITN1296003 that my father was tested HIV negative in 1987. He did not know about that. He would have said. As stated I believe that my father was tested for HCV at some time in or before 1991.

## **Section 5. Impact of the Infection**

19. My father was a strong man. We likened him to 'Pop-Eye'. 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 Rhian with him to all the matches. She idolised her grandfather. When he was admitted to hospital, he said "I can't stop here, I've got a dog (that needs walking) and a wife at home as well".
20. When my father 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.
21. When discharged my father was told not to drink more than two and a half cups of fluid a day (including the liquid in his food). His weight plummeted from 18 or 19 stone down to 9 stone. I gave up my job as a catering assistant to help my mother nurse him. Because he wasn't drinking he developed a hernia but wasn't the same after he was discharged from hospital following the repair. My father became so weak. My mother and I would help wash him near the end and he would struggle to just stand up. He was exhausted. The psychological and emotional strain we were under was terrible. I started taking antidepressants (I have never used them before or since) just to enable me to put a brave face on in front of my father without breaking down.
22. On Christmas morning (1998) I received a phone call from my mother asking me to come in. I knew when I opened the front door that my father was seriously unwell as I could smell something. My mother pulled the blanket back and my father's bed was full of pints and pints of red jelly which my father had passed through him. He thought it was diarrhoea but it was all blood. It was horrendous. We called for an ambulance and my father was taken into hospital.

23. When my father was dying in hospital Dr GRO-D and his nurse passed the cubicle without acknowledging my father. I told my father "they will be back to see you" to which he replied "no, they have given up on me". My father died that night, on the 28th December 1998.

24. We were all deeply affected by the loss of my father. I think I cried for a whole year. I never returned to work. My mother only ever left the house to go out in the car with my father. He would stop somewhere and she would wait in the car for him to come back with chips or an ice cream. After my father became ill and died, all that stopped. The loss to my mother of my father's support as well as his companionship was enormous. He was her rock. My father did all the shopping for my mother. He liked to buy us all things he enjoyed, like tinned peaches, cakes and pasties.

25. Everything had a knock on effect. As I was caring for my mother and father I was unable to help Rhian with her son, Elliott, and she too was unable to work. Elliott was just 5 years old when my father passed away.

26. My father was treated like a leper in life and death. He was treated insensitively and unprofessionally at hospital. We noticed when he went for blood tests that there were whispers and the putting on of gloves. The funeral directors would not allow my father's coffin back to our house and it had to be sealed.

## **Section 6. Treatment/care/support**

27. None of us were offered counselling and support to include GRO-C with haemophilia (GRO-C).

## **Section 7. Financial Assistance**

28. Rhian found out about the Skipton Fund through Facebook/the Tainted Blood Website. I received Stage 1 and Stage 2 payments (my mother passed away

in 2002) through the Skipton Fund and then the Welsh scheme (WIBSS) took over. I had no problem with the claim. I split the money between my family to use wisely. I loved and respected my father and did not want it squandered. I did not want to spend the money myself because it did not feel right.

#### **Section 8. Other Issues**

29. I refer to **Exhibit WITN1296007** being correspondence pertaining to the fact that my father's medical notes were destroyed despite my request that they be preserved.

#### **Anonymity, disclosure and redaction**

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

#### **Statement of Truth**

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

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

Dated 23/5/19