

Witness Name: Judith Anne Thomas

Statement No: WITN2407001

Exhibits: WITN2407002

WITN2407003

Dated: 19th March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JUDITH ANNE THOMAS

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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, Judith Anne Thomas, will say as follows: -

#### 1. Introduction

1. My name is Judith Anne Thomas. My date of birth is GRO-C 1948 and my address is known to the Inquiry. I have a Son and Daughter and five wonderful Grandchildren. I live alone and have worked as a physiotherapist since I qualified in 1969.

2. I intend to talk about my late husband Christopher John Thomas who died on 19th September 1990 as a result of being infected with HIV through contaminated blood products. I will discuss the impact this has had on my husband, me and our family.

## 2.How Infected

1. My husband was the first patient with haemophilia to be treated by Professor Bloom in Cardiff. He was a mild haemophiliac, and this was stated in a letter from Professor Bloom that my sister-in-law has. It said, "although he had considerable troubles, he is basically a mild haemophiliac, he gets no spontaneous bleeding. All his troubles have been brought on by his rather unwise and over-energetic activities". Christopher was the sort of person who loved life and lived it to the full in no uncertain terms. Exhibited before me at Exhibit WITN2407002 is the letter written by Professor Bloom.
2. Despite having had a "through hip" amputation of his right leg, at the age of 21, (which was due to gangrene following non-union of a fractured femur), he completed his college course and became a School Master. He taught in Cardiff and then Bangor for 17 years.
3. As a teacher he took outdoor pursuits and took the children on canoeing and camping trips. He enjoyed swimming, dinghy sailing and yachting and became a sailing instructor. He coached the mini rugby and wrote and performed in pantomimes for the Rugby Club at Christmas. He was very sociable and we had lots of parties and BBQ's. He was a very proud Welshman and loved showing visitors the beauty of Wales. Christopher wrote a paper when he was 26 for a social work magazine about living with haemophilia. Exhibited before me at Exhibit WITN2407003 is the article written by Christopher.
4. Christopher was never afraid to take on a project. He converted our end of terrace house, in Cardiff, into flats, fitting a staircase outside for access to the

first floor flat. He would dig holes and used a sledge hammer which occasionally would lead to a bleed.

5. We bought a derelict cottage in 1973/74 and lived in a caravan, on site, while we renovated it. We had builders to do the foundations and main structure but Christopher did a lot himself – fencing, cementing and even tiling the roof. He was good at rounding up his mates to give him a hand in exchange for a few pints at the pub.
6. Christopher had to fight to get a second artificial leg made, at The Limb Centre, to enable him to carry on normally, when his original one was being mended or serviced.
7. Christopher had a mild form of haemophilia A. He had been treated with Cryoprecipitate until Factor VIII came in. Up until 1974 he was under the care of Professor Bloom at the University Hospital of Wales, Cardiff (Heath Hospital). From 1974 Christopher was under the care of Dr Tom Korn, Consultant Haematologist, at Ysbyty Gwynedd in Bangor.
8. If Christopher had a bleed, he would have to go to Bangor Hospital for treatment with Factor VIII. He would then be allocated a couple of day's treatment to be administered by our GP's. The GP's at the time were Dr Paul Langley, Dr Robin Pritchard and Dr Hywel Parry-Smith at Rhydbach Surgery in Botwnnog. They were all fabulous, I can't fault any of them and we had amazing support from them all.
9. I can't pinpoint the exact time he was given infected blood products, but I have the dates and batch numbers he received from February 1981 until he died in September 1990 on his medical records.
10. Christopher was well read and was aware of the threat of contaminated blood and was advised by Dr Korn (Consultant Haematologist at Ysbyty Gwynedd in Bangor) to have a HIV test in February 1984. It was an extremely tense two week wait for the results. We were told personally, by Dr Korn, in his office,

that Christopher was HIV positive. I immediately asked to be tested too. It was such a shock we couldn't really process it – I thought we were all going to die – we just had to take a day at a time.

11. We went back a fortnight later to get my results which luckily were negative. However, that posed a whole heap of other problems. We knew HIV was transmitted through contact with bodily fluids, so that hugely affected our physical relationship, as a married couple, and also we had to be vigilant about hygiene with the children to avoid cross contamination.

12. You build up a trust with the medical professionals in the team. In 1966 the trust Christopher's parents had in Professor Bloom was huge after he successfully operated on Christopher saving his life. However, I want to know a) when Professor Bloom and his colleagues became aware of contaminated blood products being imported from America, b) if immediate action was taken to alert Government bodies and patients at risk and c) if not, why not.

13. As soon as the medical profession suspected the blood products from America were contaminated, patients should have been informed and tested immediately, to limit further transmission of the virus. The risk of transmission was explained clearly to us at the time of Christopher's diagnosis.

### **3. Other infections**

1. I'm not aware that my husband was infected with anything other than HIV through the infected blood products.

### **4. Consent**

1. I'm not aware that my husband was ever treated without his knowledge or consent or for the purposes of research.

## 5. Impact

1. When Christopher was first diagnosed he was shocked, very angry and upset. He had a few physical outbursts of aggression and crying, which was out of character. It was very stressful having to explain to the children but not being able to share it with anybody else. Later, Christopher had to cope with exhaustion and not being able to function as he used to and also with the realisation that he wouldn't see his children growing up. Finally he had to cope with the physical trauma of the condition and the fact that he was dying.
2. Initially, he physically suffered from flu like symptoms, diarrhoea, tiredness, weakness and exhaustion. Later he had problems with eating, sinusitis and weight loss. He was always cold so we'd have the heating on full. He had neurological symptoms like tingling in his fingers and toes. Eventually, his fingers became too sensitive to hold a pen and write to our daughter in college as he used to. His leg became too weak to support him wearing his artificial leg so he had to resort to using the wheelchair full time. He was unable to use his crutches because of the weakness in his leg and also the problem with his hands. Eventually, he suffered very high temperatures, due to various infections, resulting in very disturbing hallucinations. He became anaemic and had to be hospitalised for blood transfusions. Finally Christopher was bedridden with 24 hour nursing care until he died at home in September 1990 aged 46.
3. There was a huge impact on our personal and physical married life obviously as Christopher didn't want to risk infecting me as his wife or indeed our children through careless hygiene. We had to ensure his toothbrushes, razors and towels were separate and made sure that the children were aware of the risk of contamination. At the beginning, Christopher had taken early retirement, so I worked longer hours as we only had the one income coming in. This meant that the children had to help a lot more with meals, the garden and household chores. Later, as he became more frail, he couldn't help the children with their school work or exams as much as he would have liked.



They both had holiday jobs to supplement their pocket money. Eventually, they both helped me nurse him at home. My daughter also stayed at hospital with him to give me a break and my son carried his Dad to the bath when he was home from college at the weekend. Christopher was a big strong man of 14 stone and it was deeply distressing for all of us to see him deteriorate to a skeletal 6 stone.

4. Christopher's social life was curtailed when he had to give up driving as he could fall asleep at the wheel. He became too weak to enjoy the beach or sailing and even a pint at the pub was too much for him. He loved rugby and I remember him getting up at 3am to watch Wales beat The All Blacks despite strict doctors orders to rest.
5. Again, the impact of Christopher's diagnosis on my life was huge. At first I took it a day at a time to come to terms with it. Eventually, I had to give up work and nursed him. On the plus side, as a physiotherapist, I was confident in my abilities to nurse him to the highest standard. My coping strategy and saving grace was to go for a 20 minute run when I could fit it in and that made all the difference. My social life was the wonderful friends and family that called in and were so supportive.
6. Christopher's medical condition was confidential, of course, so it wasn't for us to tell anybody unless they needed to know. Christopher told the children not to discuss it as he was afraid that they might not be able to cope with the stigma surrounding it. He told close family members and one or two friends, all of whom were terribly upset but very supportive.
7. Christopher's parents were devastated but his Father, Canon John Elwern Thomas, bravely spoke on television very soon after Christopher's death about how angry he was that contaminated blood products were allowed to be used on patients. The impact of his death on his Sister and her two little GRO-C sons and on his Cousin in Spain, who also has two GRO-C sons, was immense. As was the impact on his two other

Sisters, who retain close family ties. My family too were devastated and many close friends too. One person may die, but his death affected so many more.

8. Both Christopher and I had to give up work putting a huge financial strain on the family, especially with two young children to support. My Son felt it affected his performance at school not having his Father to push him on.

## **6.Treatment/Care Support**

1. Christopher was treated with AZT when he was diagnosed with HIV until he died six years later. He was prescribed numerous different drugs and had various hospital procedures in the years after his diagnosis. These included the following: He had antibiotics for anaemia and went to Liverpool Hospital for neurological tests. He went to the Dental Hospital in Cardiff where he was treated by Chris Lewis for some dental work which I think might have been a tooth extraction. Christopher received specialist dental treatment with Chris Lewis because of his HIV status. He had cauterisation of an anal fissure as a day case at Ysbyty Gwynedd.
2. Christopher had some counselling, early on, from The Social Services Department at The Heath Hospital, Cardiff. Mary Dykes was the Senior Social Worker involved. She set up The Birchgrove Group, a support group for haemophiliacs infected by HIV and their families. Christopher saw the dietician, Liz Reid, in Cardiff too. Later in life he was prescribed sedatives from Consultant Psychiatrist Dr Deva Kuna, who visited us at home.
3. The only difficulties Christopher had accessing some of these treatments was that, early on, they were only available in Cardiff 180 miles away. We also weren't aware of any other treatments available to him at the time.
4. As I understand it Azathioprine is an immunosuppressant drug that is used to keep the virus under control. However, as in Christopher's case, long term

use can cause anaemia which resulted in Christopher having a number of blood transfusions towards the end of his life.

5. I can't fault the medical treatment, care and support Christopher received throughout his illness. I'd like to mention the valuable support given by The Birchgrove Group in Cardiff and The Women's Weekend in Newcastle-on-Tyne ran by The Haemophilia Society. Apart from the magnificent support from our family the unstinting help from my nursing friend was paramount in how we all coped.
6. I have mentioned the counselling and psychiatric treatment Christopher had in the impact part of my statement but I feel that some bereavement counselling for my children could have been encouraged.

#### **7. Financial Assistance**

1. We were allocated a Social Worker from Harlech who had access to our finances and he investigated what assistance was available. He helped us obtain the following assistance: The children got grants to go to college this was between 1988 and 1990. We had help from Christopher's Teaching Union NASWT. We had help from The Chartered Society of Physiotherapists Benevolent Fund. The Macfarlane Trust also paid for private night nursing care at home for the last two weeks of Christopher's life. I am not aware of any difficulties or any pre conditions imposed on making the applications and it all helped us to get by.
2. After Christopher passed away I received a payment from The Macfarlane Trust in September 1991 for £62,500 with £16,000 of this sum for our two children. On March 7th 2017 I received a bereavement payment of £10,000 again from The Macfarlane Trust. The third payment I received was on November 21st 2017 of £41,625 which was a bereavement payment consisting of a one off lump sum equivalent to three years annual entitlement at 75%. This third payment was received from The Velindre NHS Trust on



behalf of the WIBBS – Wales Infected Blood Support Scheme. Our Social Worker helped us apply for the initial sum in 1991 and Lynne Kelly, Chair of Haemophilia Wales, encouraged me to apply for the 2017 payments. I had no difficulty in applying for or obtaining these grants.

3. There were preconditions imposed on the payments received after 1991. These were as follows: 1) The deceased person (spouse) was a registered primary beneficiary with one of the current infected blood schemes 2) That your spouse was infected in Wales 3) That you were the spouse and co-habiting with him at the time of his death 4) That infection with HIV contributed to his death.
  
4. After Christopher's death we had five months with no financial assistance. Six months after my husband died, my Son had to re-take his final exams. As he was over 18 he didn't qualify for a grant and as he was an adult I no longer qualified for the Widowed Mother's Pension. As I was only 42, I was too young to be eligible for The Widows Pension either – you had to be 45. Fortunately I had managed to get some part time work and then, by September 1991, we received the first lump sum from The Macfarlane Trust, which saved the day.

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

1. Our family has contributed to the campaign against the use of contaminated blood products. I have already mentioned Christopher's father was interviewed in Welsh on S4C in 1991. I wrote to John Major during his time as Prime Minister and to William Waldegrave of The Department of Health in January 1991. Also, last year my daughter and I appeared on "Wales this Week" on ITV and "Y Byd ar Bedwar" on S4C supporting the campaign for a Public Inquiry.
  
2. Referring to the Terms of Reference 1 b); - "those with mild, moderate and severe bleeding disorders may require separate consideration during the

Inquiry". I understand that Department of Health guidelines were in place not to treat children or mild haemophiliacs with imported blood products. Christopher was a mild haemophiliac as confirmed in the letter from Professor Bloom in exhibit WITN2407002. If guidelines had been followed should Christopher have had the treatment at all?

3. With our family completely shattered by his death, we will never know how different our lives could have been if Christopher hadn't been infected by this cruel and devastating virus.

**Statement of Truth**

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

Signed. GRO-C

Dated. March 19<sup>th</sup> 2019.