

Witness Name: Anthony Roderick Lane

Statement No: WITN2365001

Exhibits: WITN2365002- WITN2365003

Dated: 4th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANTHONY RODERICK LANE

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 Anthony Roderick Lane will say as follows: -

1. Introduction

1. I confirm that I was married to Patricia Bertha Lane. We married on the 16th April 1966 and unfortunately, Patricia died on the 11th October 2015.
2. I have two children.
3. As background, throughout her life Patricia or Trish as I call her, was very active and a member of the Pontyclun Players and also the Church Choir from the age of 11 and that continued up to the 12th June

1985 when she was diagnosed with Acute Myeloid Leukaemia (AML). It took 5 years before she returned to the stage.

2 How Affected

1. Trisha became ill on the 10th June 1985 and went to see her General Practitioner (GP) Bill Jarrett. He took some blood and I recall he called her back the next morning because there had been an issue with the blood test and the readings from it. Her GP then telephoned her in the afternoon of the 11th June and she was admitted to the University Hospital of Wales Cardiff at 10am on the 12th June 1985 to ward A7. I was told that evening by Dr. J. Whittaker that my wife had less than a 5% chance of living until the end of the week. She was diagnosed with acute Myeloid Leukaemia and remained at the University Hospital of Wales until the 23rd December 1985, having had 7 doses of chemotherapy, plus platelets to achieve remission. Days after her first dose of chemo I agreed to Dr. Whittaker's request for nude photos of her to be taken and included in a "Case History" book in which he was recording all her treatments and all departments notes on her condition whilst in the University Hospital of Wales, Cardiff were to be recorded in this book I was told. N.B. In 1986 I agreed to a copy of this history of her treatments to reach remission being sent to Chernobyl to assist the doctors in Russia
2. She was therefore able to come home for Christmas 1985. She slept on the sofa in the lounge, with myself practising "barrier nursing" to assist my wife whilst she was home. We were, however, back and forth to the Heath Hospital over Boxing Day and through the New Year.
3. From January to and March 1986 Trisha was checked, at regular intervals, leading to the harvesting of her own bone marrow in readiness for the very first autologous bone marrow transplant in the UK. She was admitted to the barrier room on A7 at the UHW at 10pm on the 16th June 1986. She was immediately given a dose of chemo.

At 7pm she was transferred in a bubble ambulance to Velindre Hospital, where she underwent 12 hours of full body radiation. Then on the 17th June at 8 am she was taken back to A7 at the UHW. From that point in time until 10.10 a.m. on the 27th June when Dr. J. Whittaker told us both that "she had regeneration of white cells" and she was okay, no more treatments, home shortly. Tears of joy all round. Trish came out of hospital 3 weeks later in remission for the rest of her life. The only blood products given to my wife in 1986 were platelets given to her from the 17th to 27th June. Logic states that one of her donations must have been from the AIDS infected donor identified by the Welsh Blood Transfusion Service exhibited at WITN2365002.

4. To make it clear, Trisha was treated throughout all treatment for the AML at the UHW, Cardiff, on Ward A7 (hospital number A368821S. We then had 5 years (following the autologous BMT) of visiting the special clinic on Ward A1 where Dr. Roy Bailey Wood was the Consultant with respect to "Post Transplant Syndrome"
5. I wish to emphasise that every time Trisha had chemotherapy, she would receive an infusion of blood platelets.
6. In 1987, Patricia contracted shingles which resulted in the loss of eyesight in her left eye, constant pain, and also in issues with her memory and balance, all of which remained with her for the rest of her life.
7. On top of all the above, Trisha was also admitted to Ward A7 at the UHW on one occasion where she was diagnosed as having suffered TIA mini strokes by Dr. Dawes.
8. In addition to the long lasting after effects of shingles, Trisha also had to cope with skin radiation burns to both legs (a result of the radiation treatment she experienced whilst being treated with FBR for AML). Notwithstanding all she was coping with, Trisha was determined to try to enjoy a reasonable quality of life, and remained quite active.

9. In March 1997, we receive a letter dated 26th March 1997 from the Welsh Blood Service which is exhibited as WITN2365002.
10. At that time Tricia indicated that she did not want to go back to the hospital and took an attitude of whatever would be would be.
11. I indicated to her that she need to be tested because she had children. She needed to be tested for the children/family's benefit.
12. Tricia's view was simply, if she had anything, she simply wanted to die at home. I did eventually manage to persuade her to go back into the Haemophilia Clinic at UHW. I believe we attended this clinic on the 19th July 1997. There is a record in the Haematology/Haemophilia Departments at the UHW and Welsh Blood Transfusion Service of this under record number A368821S
13. We were told at that appointment (19th July 1997) that they had been able to check the blood products that had been given to Tricia and it transpired that she had been given infected blood platelets in 1986 she had a bone marrow transplant at Ward 7 at the UHW, barrier room. The donor of those blood platelets subsequently died of AIDS in 1997.
14. After a discussion, I can remember commenting how on earth did they manage to track the infected donation from a male donor back over that period of time (i.e. 1997 back to 1986)?
15. Regarding platelets, upon Tricia's admission to Ward A7 in 1985, I became a platelet donor. I have a Gold Certificate, having donated more than 250 times up until the August of 1997, when the Welsh Blood Transfusion Service stopped me giving any further platelet donations on the grounds that my wife was diagnosed with Hepatitis C.
16. I used to give platelets regularly, one a month, plus I was platelet matched on the Welsh BTS system, which allowed them to call me out at any time over a period of 12 years (up to August 1997).
17. Being platelet matched meant that my platelets would go to particular patients and could therefore be given quickly in an emergency. In 12

years I calculate it is highly likely I must, at times, have been in close proximity (while attending at Rhydlafa/Llantrisant Hospital, near Cardiff main platelet donation centres) to the gentleman who was the contaminated blood platelet donor who infected my wife. The reason I think it is likely I unknowingly came into contact with my wife's donor is because, over the years, I must have donated a total of 144 times, may be more.

3 Other infections

1. Trish caught cellulitis (leaking skin) in or around July 2015. The Hepatitis nurses at the Royal Glamorgan Hospital allowed us to take a weekend break to stay at a hotel in Cheshire to cheer her up.

4. Consent

1. In terms of consent, I would confirm of course Tricia needed to receive blood platelets as a result of the treatment she was undertaking. I confirm that I can recall a number of discussions with Paul Trenchard Deputy Director of the Welsh Blood Transfusion Service and he was also Vice President of the Leukaemia Research Appeal for Wales (LRA) when he stated that "all Welsh blood is fully tested"
2. All patients and relatives were concerned about blood transfusions and were concerned at stories in the press about AIDS, Hepatitis C all were told all blood fully tested.
3. As a result, a number of discussions took place as to the risk of catching AIDS from transfusion of platelets on Ward A7 during our time on A7 in 1985/86. It was agreed that if a donor with AIDS gave blood products deliberately deceiving the BTS, they were guilty of murder.

4. We were assured by Professor Trenchard that "all Welsh blood was fully tested". During meetings of patients and the Committee of LRAW of which I was a member.
5. The letter dated 26th March 1997 of course confirms that was not the case and it is only since 1991 that full testing has been carried out.

5. Impact

1. In 1997 Tricia was tested and it was confirmed that she had Hepatitis C. We were told that "there was no known cure" and she was offered a biopsy to confirm diagnosis but she refused.
2. She was given some tablets to alleviate the rate of increase and she took those.
3. I cannot recall there being any liver testing carried out although I am aware from my daughter having considered medical records that there is evidence of liver scans being carried out on the 6th December 2011. Her notes and any possible treatments were transferred from UHW to the Royal Glamorgan Hospital, Llantrisant and the 4th October 2015 where she died 7 days later.
4. Other than the above Tricia did not receive any other treatment at Royal Glamorgan Hospital for her Hep C
5. As I have indicated, another impact in my view, is that I had to stop making platelet donations due to my wife's condition. I was also taken off the Anthony Nolan & British Marrow Appeals register.
6. I assume that the AIDS infected donor in my wife's case must have given much of the same number of donations as myself, and therefore, I would query whether everyone else who may have been infected has been informed of the potential for infection?.

7. As a result of Tricia's infection with Hepatitis C, she was extremely down and commented "why me", and effectively indicated she simply wanted to be left alone to die at home. Fortunately, after that we discussed and decided that we needed to try and battle on and make the most of it and we were able to enjoy some holidays.
8. For example for our 40th Wedding Anniversary in 2008, we went to St Lucia for a week which was done as much as anything to get me out of the house as I was doing all of the cooking and cleaning and looking after Tricia. We then holidayed in places like Antigua and Barbados in 2008 and 2010 respectively, and were able to enjoy those holidays. Barbados was our last holiday because of Trish's deterioration and the fact that she could not get on or off the aeroplane without a wheelchair because she had developed vertigo (fear of heights).
9. Tricia had continuing issues with her hearing, her loss of sight and on going issues with her balance and her memory. We were also unable to have penetrative sex due to pain she would suffer and would have to resort to cwtching or finding sexual relief in other ways, although I couldn't say that was specifically down to the Hepatitis C.
10. In July 1997 when Trish and I were told that she had Hepatitis C, we were also told that it was not advisable for us to have penetrative or oral sex due to the risk of possible blood infection.
11. Tricia's attitude was good but also remained one question "why her".
12. In terms of my own health, I continued working by this stage, we had sold a Spar Shop that we previously owned and I had various jobs until I obtained a position as Resourcing and Facilities Manager for Mid Glamorgan Training Enterprise at Treforest. I remained working there until 2001, continuing as a consultant working from home.

13. Tricia's condition gradually deteriorated until in September 2015 she was admitted to the Royal Glamorgan Hospital until she passed away.
14. In the early October at the Royal Glamorgan Hospital, it was obvious that her condition was deteriorating and bizarrely they wanted her to go to Llwynypia Hospital, Tonypany, Rhondda for physio. Quite rightly, Tricia didn't want to do that, she remained at the Royal Glamorgan Hospital. I felt that at the UHW "there had been hope" but in the Royal Glamorgan Hospital (RGH) "there was none". The last two days of my wife's life were pure hell at RGH because she had given up hope. She asked me to "take her home to die". I had to tell her that the hospital would not agree. They told me I would never cope. My wife's last words to me were "leave me in peace, I'm okay". I held her hand to the end and watched her pulse go. I then said "go to your God". On the 11th October 2015 she died of hospital acquired pneumonia and secondary Cirrhotic liver Disease secondary to Hepatitis C. I had to insist that the word "Hepatitis" appeared on her death and hospital documents.
15. I would confirm that after Tricia's diagnosis with Hepatitis C whilst I tried to battle on for her sake, I found it an incredibly stressful time. At no time, despite my daughter's request, would the consultant haematologist at the Royal Glamorgan Hospital see us.
16. I came out with a rash (white spots) on my skin and began biting my finger nails which I believe was caused by stress, itching skin requiring E45 cream plus paracetamol.
17. The diagnosis of Hepatitis C also had quite an impact as there was some significant stigma attached to it and we were very secretive of the fact that Trish had Hepatitis C and were keen not to tell friends and relatives. A common question was "is it infectious?"

18. We did however have to tell medical professions and it was very difficult to have to tell our Doctor, our Dentist, Hospital staff and the like. I would also have to wear gloves and like to help Tricia, and to deal with her personal items. We would not sit close to others if possible.

19. Whilst Hepatitis C was lesser known there was also of course a big stigma in relation to blood born diseases like AIDS.

6. Treatment/Care Support

1. In terms of the treatment and the care, that we received there was very little information provided. At the time that we went into see the Doctor in July 1997, we were simply given a sheet explaining Hepatitis C. I now exhibit copy of that sheet at W2365003.
2. No further information was provided and no counselling was offered.
3. Through the time, that Tricia had Hepatitis C she was monitored and had blood tests every 6 months. No other support was provided however, on two occasions I made firm appointments to see the Consultant Haematologist at the Royal Glamorgan Hospital Ward 20 but on each day, they were not available and the two nuses from the clinic came to try to pacify me. Only a ward Doctor was left, who stated basically, no hope, will not be long now, better get your children to come in soon.
4. One of the big things for me was that there was a new drug to treat Hepatitis C, which was available from America.
5. I can remember during the summer of 2015 speaking to the clinic nurses at the Royal Glamorgan Hospital telling them about this new treatment and they indicated that Tricia was first on the list for that new American drug.

6. She never ever received that treatment, which was very frustrating and upsetting, and this caused me to wonder whether she had that treatment, if it could have prolonged her life.

7. Financial assistance

1. We were fortunate in that when my wife was in the UHW, I made contact with McMillan Nurses. When she was subsequently diagnosed, with Hepatitis C, I still had some contact with them and they were excellent in terms of directing me towards the Skipton Fund.
2. I confirm that we received £20,000 payment from them and then a further £50,000 from the Skipton Fund.
3. As I understand it, the Skipton Fund then became the Caxton Fund and they paid funeral expenses of £3,163 on the 1st June 2016.
4. In turn, Velindre NHS Trust then made a further payment of £34,875 on the 25th November 2017.

8. Other Issues

1. I would like to pose the following questions to the Inquiry; how many people were infected by infected platelets from a male donor who died of AIDS in 1997 as per the list of the Welsh Blood Transfusion Service which contained my wife's name? Were they, or their relatives informed of the possibility of infection or the reason for their death established as being caused by infected blood products?
2. I would also ask the Inquiry to investigate who told Dr. Paul Trenchard, Deputy Director of the Welsh Blood Transfusion Service that he should tell doctors and patients on Ward A7 at the University Hospital of Wales and the Committee of the LRAW that "All Welsh blood is fully tested" in 1985/86

3. I would like the Inquiry to note my fervent opinion that the UK Government should transfer control of the issue of compensation from the Group Litigation Order to the Inquiry Jurisdiction.

9. Addendum

1. At the 7th March 2019 meeting in the City Hall, Cardiff, I mentioned to a member of the Inquiry staff that Trish and I were invited in 1987 by the Chief Psychiatrist of Wales to address a "group" of interested NHS staff on the subject "Why do you think you have survived?". I was advised by the member of staff that "you should have included the answers and data you both gave in your witness statement". The data and answers are as follows:-

You must remember that all the NHS staff were aware of the following data:-

Trish was diagnosed with AML on Wednesday 12th June 1985 by J.Whittaker at Ward A7 at the UHW. I was told at 7pm that Trish had less than 5% chance of living to the end of the week. 12th June to 23rd December 1985 had 7 doses of Chemo to achieve remission from AML. Harvest her own bone marrow March 1986. 1st Autologous BMT 16th to 27th October 1986. 1987 Shingles – lost sight in left eye – no short term memory – FBR to both legs. Trish agreed to be "inspected" by doctors present in a separate room. N.B. I answered most of the questions due to Trish having no memory. To the basic question "Why do you think you have survived?" answers as follows:-

Faith in the doctors – listening to all staff's advice, will power, needs of children. Evaluating and risk assessing all options re treatments, SWAT analysis – talking. Family and friends back up – interest – obeying all safety – hygiene rules – heating. Barrier nursing in hospital and for 3 months at home post BMT. Including clinics. Positive attitude – We will walk off the Ward A7. To sleep in my own bed ASAP. Camaraderie on ward with all telling one another jokes and funny stories etc. Help hospital staff – do as much as you can, treat

others as you wish to be treated. If you can back up and help all charities associated with your treatment.

2. The Inquiry should understand that up until July 1997 as far as we were concerned, we had beaten AML. When we were told she had Hep C, our views of the BTS changed when we were told "no known cure of Hep C.

Statement of Truth

I believe the facts stated and this witness statement are true.

Signed.....

GRO-C

Dated.....

4TH April 2019