

Witness Name: I Venton
Statement No: WITN1580001
Exhibits: WITN1580002-3
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF IRENA WIESLAWA VENTON

I, Irena Wieslawa Venton will say as follows:-

Section 1. Introduction

1. My name is Irena Wieslawa Venton and I live at [GRO-C]
[GRO-C] Bristol, [GRO-C] My date of birth is [GRO-C] 1946. I have lived at this
address for 5 years and prior to that I lived at [GRO-C]
[GRO-C]
2. I am a widow who lives alone and I survive on Pension Credit and Disability Living Allowance. My second husband, Ronald John Venton died on 19th October 2010 as a result of receiving contaminated blood products. Ron and I had one son between us, Adam, and I have 3 other children from my first marriage.
3. At around the time of the American Litigation the Haemophiliac community were very concerned and the advice circulated was that we must destroy any evidence and documentation. I confirm that this included a DVD which was about American prisoners who were talking about selling blood and being drug addicts. I believe that Ron's good friend, [GRO-B] may still have a copy. I confirm that all of

Ron's medical records were sent to a firm of solicitors who were working on the American Litigation and I attach evidence of posting the medical records at Exhibit WITN1580002.

4. This witness statement has therefore been prepared without the benefit of access to Ron's medical records.

Section 2. How Affected

5. When I first met Ron I worked in C & A's in London, in their head office in Marble Arch. Ron's name for me was rainbow because of the C & A's logo. Ron and I met because he was working for a firm of accountants, and when I first broke up with my first husband, I was paying a horrendous amount of tax and my father said you must go and see my accountants and that was that. Ron was working at the firm of accountants and he was going through the same thing as me and was separated from his first wife. A few weeks later he asked me out to the cinema and I thought why not.
6. Ron told me that he was a Haemophiliac but I did not really know much about Haemophilia. I do not know exactly which treatment caused Ron's Hepatitis C. Ron believed that he was infected when he had to have some substantial dental work carried out on his teeth. The dental extraction was a serious operation and two days after the operation, Ron haemorrhaged and was rushed back to hospital and treated with Factor VIII. This was all at Stoke Hospital, Newcastle Under Lyme, Newcastle and I cannot recall the name of his consultant. I believe this was in or around 1990. I believe that Ron's exposure to Factor VIII was between 1990 to about 1996 but I am unsure of the exact dates because I do not have access to his medical records.
7. When we moved back to GRO-C which was in or around 1993/1994, Ron was under the care of Dr. Noakes. In any event, the alarm bells were not ringing fully and everything was dealt with very quietly and I would say that we were lulled into a false sense of security. However, I think Ron knew differently because he had researched matters.

8. Ron could not withstand the treatment for Hepatitis C and I will deal with this later on in my statement. Ron was about 67 years old when he managed to withstand only 1 day of treatment and had a very bad reaction and therefore he could not clear the Hepatitis C as the treatment had to stop. At this point he had full blown cirrhosis and his liver had effectively shut down. Ron died on 19th October 2010 and the causes of death are listed as Hepatocellular Carcinoma, Hepatitis C and Haemophilia and I attach a copy of the death certificate at Exhibit WITN1580003.
9. Ron had Haemophilia A which was the most severe type. Ron received a lot of blood products and I recall him telling me that whenever he had to have Factor VIII he always insisted on being given Lister but whether this request was adhered to I will never know. Ron was under the impression that Lister was an English product and was therefore safer than the American products but I suspect that he actually knew a lot more and kept information from me in order to protect me and also to protect Adam, who he was very protective over.
10. Ron was treated at the Stafford Hospital when he was in the Midlands and also occasionally at Newcastle Upon Lyme. However, all of his care was at Derriford Hospital when we moved to GRO-C
11. Before Ron and I became serious, he would not really tell me much about his hospital visits, during which he was administered the Factor VIII. However, this was a normal thing as Ron attended hospital regularly throughout his life. I suppose the severity of it all only came to light when we moved in together. Ron would open up to his greatest and probably only friend, GRO-B and his wife GRO-B to some extent and I am sure that they knew a little more about everything than Adam or I ever did as Ron wanted to protect us.
12. As far as I was aware, Ron was given absolutely no information regarding the risk of infection from having the blood products. From our conversations he would always say that he asked for Lister as it was a British product and I think he felt safe with that. I think I can safely say that he was not informed of any risks. He was quite savvy and he did his own research on things.

13. Ron was infected with Hepatitis C. He was told that he had Hepatitis C at Derriford Hospital. In Plymouth as soon as Ron was diagnosed he confided in [GRO-B] who was also infected, and [GRO-B] proved to be a great support for Ron. They discussed it a lot and started looking at which batch numbers were given to them and other matters but the information was difficult to obtain.
14. Ron was alone when he was told that he was infected with Hepatitis C at Derriford Hospital and I think that it was sometime in 1996, but I really can't be sure of the dates although I think it was when Adam was about 12 or 13 years old. Ron and I moved to [GRO-C] in or around 1996/1997 following his diagnosis. Ron was very protective of Adam and told him not to tell any of his school friends about this.
15. The reason Ron was on his own was because he used to go to hospital so often that it just became the norm that he would go on his own; it was just like he was going to work. We had to make arrangements because he couldn't walk to the hospital towards the later stages of his life so he used a scooter, which we purchased with the Skipton Stage 2 Payment. He would use the scooter to get into the car and then the hospital staff would use a wheelchair to get him from the car to the hospital.
16. Ron did tell me that he was not given much information at all regarding his diagnosis of Hepatitis C and that the diagnosis was given to him in a very matter of fact way, almost very lightly and that all the facts were basically skimmed over. I am not sure whether Ron watered down what he had been told so as not to worry me. However, I believe that he would have got his thinking cap on with [GRO-B] and they both became very knowledgeable between them so anything and everything they knew about Hepatitis C was as a result of having researched it.
17. Although the hospital did not give Ron much information about Hepatitis C or what the diagnosis meant in terms of his life and risks to others; he did tell me that he was told that there was a risk of cancer. He felt that this information should have been given to him earlier and despite everything, Ron still held a glimmering hope that something would reverse or stop the Hepatitis C progression. Unfortunately, he was unable to tolerate the treatment.

18. Ron was never given any information or advice regarding the risks of passing on the virus to others or of how to go on living a "normal" life. I used to be an auxiliary nurse in a private hospital so I knew how to be careful and was fairly clued up on things and Ron and I worked it all out between us (with the help of **GRO-B**) as to how to manage his infection.

Section 3. Other Infections.

19. Ron was afraid that he had been exposed to vCJD. However, because I don't have his medical records I can't confirm whether there is evidence to substantiate this.

Section 4. Consent.

20. I think Ron thought that he was being tested and treated without his knowledge. Furthermore, when AIDS came to light, they were testing for everything and I don't think Ron always knew what they were testing him for or why they were testing him. If he was tested and treated without his knowledge then it follows that this testing was also done without giving him adequate information. For example, when he had managed to withstand just one day of the Hepatitis C treatment (see later in my statement) he was definitely not advised about the side effects or the risks of the treatment and to make it worse the hospital had said that they would be able to support him all weekend and when we telephoned we were told that they were closed for the weekend. That was a real kick in the teeth particularly given how seriously ill he became almost immediately after being administered with the treatment. I don't know whether Ron was used as a "guinea pig" for research purposes but it would not surprise me although I think they often used younger patients for this.

Section 5. Impact

21. I would say that hell began in earnest when I was pregnant with Adam. I was offered an abortion so they must have known that Ron had Hepatitis C at this time. This was about 12 or 13 years before Ron was told of his diagnosis so it is unbelievable really. I refused an abortion and I remember that in my last months of pregnancy I

had to stay in hospital for the last four months in 1985 and that they took blood from me regularly. During my stay in hospital I was treated significantly differently to any of the other pregnant women. The medical staff would be dressed in gowns, masks and boots and looked like people exploring in space! However, after they had taken quite a lot of blood and carried out a number of tests (all without my consent or knowledge) all of this suddenly changed and I was treated normally again. No-one every told me why this happened and I felt like a complete freak. I did ask why but no one ever answered me.

22. I know for a fact that Ron was having trouble getting work even though he was fairly healthy at first. This was around the time when it came to light that Haemophiliacs were infected with viruses. It came to light that lots of Haemophiliacs had been affected with AIDS but not so much was heard about Hepatitis C. When Ron told **GRO-D** cut him off completely, almost overnight. They just stopped coming to visit us. Ron was so depressed and he cried at night about **GRO-D**. He was deeply hurt. We had no friends because we were scared to confide in anyone because when we did they never visited us again. I had no one to turn to for support really except my parents, but I did not want to burden them too much.

GRO-D

23. With regard to **GRO-D** it got to the stage that if **GRO-D** came face-to-face with him in the hospital she would completely blank him and this really upset Ron. In the end my poor Ron stopped admitting to even being a Haemophiliac due to the stigma which surrounded the viruses. **GRO-B** became Ron's greatest and only friend and a massive source of support for him. Ron was not well enough to attend any of the Haemophilia support groups so Ron just lent on **GRO-B** and I. I was a massive support to Ron and I had to lie through my teeth and put on my positive face for Ron and told him every day that it would be ok and that he must keep fighting to get better. Before Ron and I moved to **GRO-C** and before the diagnosis **GRO-D** **GRO-D** were always really lovely. However, once Ron told **GRO-D** totally disowned him and would not even come around for a cup of tea. This put a real burden on Adam and I as Ron said that we must never tell anyone due to the stigma that Ron has suffered. Ron did not really even tell Adam or I the full extent of things.

24. During his working life, Ron was working for a firm of accountants. He found it more and more difficult to find a job due to the fact that Haemophilia was being linked with AIDS. Coupled with this, Ron also had to take quite a few sick days due to his Haemophilia and the Hepatitis C and eventually he had to start working for himself. This was because when the illness progressed and we were still in [GRO-C] the people he worked for complained more and more about his work which was so upsetting for him. He was on so much pain medication that he was not totally with it all the time. When he found out that he was infected he had to give it up and eventually we moved to [GRO-C] to start a new life but I knew that he would die there.

25. In [GRO-C] Ron continued to go to the hospital on a regular basis to receive his Factor VIII but in the end his health was just so poor. He could not walk very far and then later on he could not even move. There was one time I recall that he was on his way to hospital and he had the runs so badly that I had to go outside and clean the pavement. I would do anything I could to help and protect my Ron.

26. I cannot remember which treatment Ron had but he did eventually end up starting a treatment for Hepatitis C, but it had disastrous side effects. It was given to him on a Friday at the hospital and he had a terrible reaction. The word "*Interferon*" rings a bell but I am not sure. The treatment was in the last few years of his life but I am not sure exactly when but I would say that he was about 67 years old. Before he agreed to it he asked what would happen and the medical staff advised him that they would be there all weekend to help him if he needed them.

27. Ron started the treatment on the Friday and never had anymore after that day. Due to the reaction we tried to ring the hospital but no one was there. We were told by hospital staff that the hospital was shut for the weekend. Ron came back home after attending for a few hours on the Friday and he went blue and was seriously ill. I actually thought that he was going to die. Unfortunately because they did not repeat the treatment, he was unable to clear the Hepatitis C. At this point he had full blown cirrhosis and his liver had effectively shut down. I had to give up work to care for Ron 24/7 towards the end of his life.

28. I recall that just before Ron started using his scooter (which I bought because his mobility was so poor) he was moving slowly from the kitchen to the living room with a walking stick and I heard this massive crack and he had cracked his bone. From then on he could not walk at all. He was taken to hospital and after the treatment on his leg the hospital said that he could not be discharged home because we did not have a room downstairs in our house to accommodate him. The social worker said that it could take at least a year to put him into a care home and I did not want this for him so I organised everything myself. With the Skipton monies of £20,000.00 we paid a builder to turn our shed in the garden into a new downstairs room for Ron. The builder knew about the situation we were in and did the most terrible job and took our money and left me with a room that leaked and was not fit for purpose. I then had to borrow money from the bank to put the job right and instructed another builder to make good the first shoddy job.

29. Ron had horrendous ulcers and his dressings on these had to be changed once a week. I suffer with chronic arthritis and curvature of the spine, scoliosis, so I could not get him out of bed. A district nurse came into our house for 10 minutes each morning and evening. Ron was completely deformed and he could not put any weight on his legs or they would break.

30. In his last year of life, Ron was taken into a hospice but because he was not dying fast enough they said that he would have to leave the hospice as it was only for end of life care.

31. Ron was very fond of Plymouth Hoe which overlooked the sea and I spent a long time looking into the best place in this area for Ron to go to. I eventually found it and it was called and I still have the brochure today. I chose his room which was on the ground floor and it had a bed in it which faced the window so he could look out to sea. He only stayed a couple of weeks as he passed away there very shortly after moving in but I am so pleased that I managed to get him into before he died.

32. Dr Noakes visited Ron regularly at to give him Factor VIII and after one evening (18th October 2010) visiting Ron, Dr Noakes telephoned me to say that

he was refusing any more treatment and that he wanted to die. I suffer from glaucoma so couldn't drive in the dark. I telephoned Ron and encouraged him to hang on and to fight some more but he kept apologising and saying that he could not do it anymore. This was 7 or 8pm on 18th October 2010 before he died on 19th October 2010. I then drove to see him on the Tuesday. GRO-C telephoned me at 5 minutes to midnight on the Tuesday evening to say that Ron had passed away. This was 19th October 2010 and the causes of death are listed as Hepatocellular Carcinoma, Hepatitis C and Haemophilia. Adam was at university in Bristol at that time and I waited until 6am the next morning to tell him as I did not want him driving through the night in a state of shock.

33. Mentally I had become very ill in the end. I had to have three separate and distinct faces. I had a separate face for Ron and I tried to tell him every day that it would be alright and to keep fighting yet I knew that his situation was dire. I had a separate face for Adam as I tried to shield him, as did Ron, from the reality of what was happening. I then had my face which faced reality and at the time I did not realise the immense and extreme pressure I was under. I just carried on regardless and never gave myself any time or care; I was at the bottom of the pile. Because of the nature of the Hepatitis C Ron and I could not confide in any of our friends. Ron and I did tell one couple and they never visited us anymore after that. It was so sad. Therefore I also lost my support network and any possible future support network.

34. Adam and I never really spoke about Ron's diagnosis or his death it was like we were both trying to hide our emotions from each other. Adam did however say that he knew that his dad had died at 5 minutes to midnight because he had woken up at around midnight and felt that someone had come into his room. At University in Bristol after Ron's death Adam immersed himself in charitable work and he also climbed Everest Base Camp. When Adam returned from Everest Base Camp he said that he had been sitting alone in the snow on the mountain and a robin had sat itself down next to him; robins were Ron's favourite birds.

35. Life was pure hell for me even though I loved Ron dearly it was still a hard life. I became very ill after Ron's death. I think that over the last few years of Ron's life I

was forcing myself to keep going because I was all he had. When he died I let go and it all caught up on me.

36. When Ron passed away I developed shingles almost immediately and was housebound and could not even get dressed because of the pain and was stuck inside for 3 months. Then I had a heart attack. I really believe that it was all the stress that caused this and my doctor agreed with me. I was so lucky that my neighbour's garden overlooked my front garden because they found me collapsed. As I opened my front door, I had a heart attack and collapsed outside. Luckily, my neighbours were in their garden and called an ambulance otherwise the outcome would not be so good. I am now left with Atrial Fibrillation (AF) and I have to take regular medications for this. To this day I am still on medication for shingles as it was so bad.

37. Ron's cat died exactly one month and one day after Ron and then the dog got a tic which paralysed him and he died a month after the cat. It was unbelievable really. I felt completely alone; I had no friends or anyone to talk to.

38. After Ron, the cat and the dog died I was so lonely living alone in GRO-C. Adam said that he could not really travel much to me as he had a new job so he suggested that I move to Bristol which was where he was living and working. I wanted to be close to Adam in case my glaucoma worsened and I was unable to drive. Adam found this flat for me and I did not see it until the day I moved in. However, my mother died a year ago and I am hoping that with her inheritance I can buy something more suited to my needs. I have slept downstairs in my lounge in a chair for 2 years now as my mobility is so poor and the bed is so uncomfortable and painful for me. I need a specially adapted bed for my scoliosis but because the house is so small it would not really fit and I cannot afford it.

39. When my mother was alive, it was only her and my father who supported Ron GRO-D
GRO-D My mother and father were a real support to both of us. My mother lived to 97 years old and was a fantastic woman. I really miss my mother as well as Ron now.

40. Most the flats here are full of young people who are out at work all day. I have to be careful because I am on warfarin and morphine and I can sometimes haemorrhage. I had to find a neighbour who I could trust and who I could give a key to. I have managed to find one and he is an older man but he is very reliable.

41. My other children from my first marriage have settled all over the UK, including GRO-C Manchester and GRO-C. I don't see them as often as I would like because I can't travel and they all have their own lives with their own children. I can't really ask them to come and stay and sleep on a chair.

Section 6. Treatment/Care/Support

42. Ron did struggle with access to dentists. He actually ended up losing most of his teeth and I don't think any dentist would touch him in the end.

43. Ron was never offered any counselling, psychological or psychiatric support. He leant on GRO-B and I. I think that this is what made me so ill in the end. I sought help from a Carer's Group which I had heard about from GRO-B wife, GRO-B. This was for anyone, not just for Haemophiliacs or their partners.

44. My mother was the only person who I could lean on, but she was already 80 odd when Ron died and 97 when she died herself. I would talk to her for support but I did not tell her everything.

Section 7. Financial Assistance

45. The only reason Ron and I found about any Trusts existing for the purposes of providing financial assistance to sufferers was through GRO-B. Neither of us were ever told by a doctor or medical professional. We received the Stage 1 payment of £20,000.00 from The Skipton Trust and then after this we received the Stage 2 payment of £25,000.00.

46. We used the first payment to convert the outside garden shed into a downstairs room for Ron because no one would help us. The second went on helping Adam

and on purchasing scooters for Ron when his mobility worsened. When Ron died we were only receiving pension funds and I had to apply for a bereavement grant from the Government to afford his burial. They sent only £6.50 which was insulting and derogatory. Their reasoning was that because Ron had a life insurance policy which paid out £2,000.00 for the funeral they would only pay the top up which was £6.50. If it had been a cheque I think I would have framed it but they paid it directly into my bank account.

47. Ron's funeral cost me £7,000.00 because he said he would haunt me if I cremated him so I made sure I got him a really nice grave in Plymouth and it cost £500.00 to buy the plot for 25 years which has to be renewed upon expiry. I had to take out a bank loan and borrow from my mother to give him the funeral he wanted. I made sure he had a headstone and a robin which was just the way he wanted it.

48. Ron and I did not receive any monthly income from the Skipton Fund.

49. The process for applying for Stage 1 and Stage 2 payments was ok because the medical evidence was there so there were no real obstacles for us. I have never applied for any grant as I did not know you could. The hospital gave Ron a wheelchair but it did not fit into the house so he could not use it. I bought him some scooters from the Stage 2 payment so that he could get around.

50. When Ron became ill I had to buy him out of the mortgage on our house. The only insurance he could have was from SunLife and this was for the funeral expenses for which they paid out £2,000.00.

51. Following Ron's death I have received nothing and have no support from any of the Trusts.

52. I have given up trying to push for things financially because you have to push so hard and I have no energy left. I survive on State Pension and Pension Credit. Ron and I fought for years for justice and I am so very tired now.

Section 8. Other Issues

53. Ron was involved in the American pharmaceutical litigation. We were made to sign something pertaining to this litigation and this was when advice was circulated amongst the Haemophilia community that all documents and records had to be destroyed.

Conclusion

54. I want somebody to admit that they are responsible for this mess. We have been fighting it for years and I am tired now. I was born in Poland and came to the UK aged 11 years old and this is my home but I am sad about what the NHS and the Government have done to my Ron and to thousands of other victims of this tragedy; not only the effect on individuals but whole families.

Anonymity, disclosure and redaction

I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I will not be able to give oral evidence to the Inquiry due to my poor health.

Statement of Truth

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

Signed... GRO-C

Dated... *20.12.2018*