

Witness Name: Marjorie Parr

Statement No.: WITN0889001

Exhibits: **WITN0889002**

Dated: 10th July 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARJORIE JOYCE PARR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 March 2019.

I, Marjorie Joyce Parr, will say as follows: -

Section 1. Introduction

1. My name is Marjorie Joyce Parr. My date of birth is GRO-C 1948 and my address is known to the Inquiry. I intend to speak about my late husband, Mr Ronald Parr ("Ron"). Ron was infected with HIV and Hepatitis B Virus ("HBV") following treatment with Factor VIII and blood transfusions. He died on 21 December 1990.
2. I am a mother and a grandmother. My two children, Simon Parr (WITN0889) and Sharon Parr-Veck (WITN3443), are also providing statements to the Inquiry. I live in Telford and I am retired. I never met anyone else after Ron's death. No one could ever take his place.

Section 2. How Affected

3. My husband, Ron, was born in Liverpool on GRO-C 1944. Ron had full blown, severe Haemophilia A. It was discovered when he was around 18 months old. Ron's brother and father did not have haemophilia. They went back as far as they could in the male line, but could not work out where it had come from.

4. Ron was home educated because, in those days, you were segregated if you had haemophilia. He was wrapped in cotton wool and was always in and out of hospital as a child. His mum told me that he had been given the last rites five or six times.
5. Ron's parents and brother had to go and live in the Isle of Man for work. Ron was left with his mother's older sister in Leek, Staffordshire for around four years when he was eight or nine years old, as hospitals weren't as good on the Isle of Man. It put stress on their family. Because of this, Ron and his brother weren't close as kids but they became closer as they got older.
6. Ron had a good education. Initially, he did civil engineering and designed dams during an apprenticeship. He would work from old fashioned maps and figure out where to put the coal mines. However, he couldn't hold the job down as he was in and out of hospital. Although they were impressed with him, he eventually had to give the role up because of his haemophilia.
7. Ron's father brought him down to Telford when he was around 19 or 20 years old. In 1966, Ron and I met in a pub in a little village called Dawley. We got married on 3 August 1968. In GRO-C1969, I gave birth to our son, Simon, and in GRO-C1971, we had Sharon.
8. After Ron left his engineering role, he went to Exeter University to learn horticulture. To start with, he was a gardener for the local council. At times, he would get scratched while doing the digging. Once, a pneumatic drill flew back on his chest and he was out for weeks. Despite all this, he didn't give in to the haemophilia. He was very resilient. When he couldn't dig anymore, he later worked in offices and a factory.
9. Initially, the only treatment Ron had for his bleeds was a lotion made of an opium and led mixture. When he had bruises, that's what the doctors gave him. When Simon was born, I refused to have the mixture in the house at all. I thought that it would be awful if my son had got hold of the mixture. We therefore went to the doctors and asked if there was anything else Ron could take and we were given cryoprecipitate.
10. Ron would take cryoprecipitate injections once or twice a month. It depended on what he was doing. I would help Ron with the injections. He took these injections for five to six years and then we changed doctors to Sutton Hill Practice. They told Ron about Factor VIII and he began this treatment around 1974 or 1975. It was seen as a

'miracle drug'. We got the Factor VIII from Royal Shrewsbury Hospital under Mr O'Shea, who I believe was a haematologist. I remember we had a fridge full of Factor VIII ready for Ron.

11. In 1983, Ron had a knee operation in New Cross Hospital, Wolverhampton. The surgeons were supposed to put a pin in Ron's knee, but they gave him the wrong procedure. The surgeon nipped a vessel and an artery that had fused together. The skin burst from the front of his knee all the way down to his ankle.
12. As a result of this, Ron was in hospital for three months, during which he was permanently on Factor VIII. He would have also received a huge amount of blood whilst he was in the hospital through blood transfusions. They gave him as much blood as they could. It seemed like gallons. I believe it was likely during this time that Ron contracted HIV. At the end of the three months in hospital, they sent Ron home but his wound was still open.
13. At no point were we informed of the risks associated with blood transfusions or blood products. We had no idea that Ron was at risk of contracting an infection. We first heard about these risks on the television years later.
14. Within about a year of Ron leaving the hospital, there was an occasion where Simon and I went to pick up Factor VIII from the Royal Shrewsbury Hospital. Mr O'Shea took both Simon and I into his consultation room. We were not asked to sit down and he had absolutely no bedside manner or compassion. Mr O'Shea said to me, "You do know Ronald has HIV".
15. I was in shock. Simon was only in his early teens at the time so I don't think he understood what was going on. The news was devastating and yet Mr O'Shea just opened the door and showed us out. He didn't even explain what HIV was and he was very rude.
16. The only advice Mr O'Shea gave us was, "You need to have safe sex". For years, Ron and I had been having sex without protection. I had also been injecting Ron with Factor VIII without knowing that he had HIV. We were given no advice regarding transmission via blood and cuts.

17. It was left to me to break the news to Ron and our GP. Even our GPs were shocked. They hadn't been notified. However, I had a feeling from the way Mr O'Shea communicated Ron's diagnosis to me that the consultants had known for a while.

18. Our local doctors wanted to test me immediately but I refused. If Ron had given me HIV, it would have made him feel worse. After Ron died, I was tested for HIV and was clear. GRO-C

19. After Ron's diagnosis, he was living in limbo for months. We only knew what HIV was because of the television. Everything that we knew about managing and understanding Ron's infection came from documentaries and the haemophilia newsletter that Ron used to receive.

Section 3. Other Infections

20. In 1989, Ron's eyes and skin were yellow as a result of jaundice and so I suspected that he may have also contracted hepatitis. HBV was listed as a cause of death on Ron's death certificate. However, I do not remember whether he was officially diagnosed with this before his death. As far as I am aware, Ron was not infected with anything other than HIV and HBV.

Section 4. Consent

21. We were not given any information regarding the risks associated with Factor VIII and blood transfusions.

22. Ron and I had no idea that he was being tested for HIV until I was told that he had it. I was the one who had to break the news of the infection to him. He was also not told that he was being tested for HBV and I do not know when this testing would have taken place. As far as I am aware, Ron was not treated without his consent or for research purposes.

Section 5. Impact

23. After his diagnosis, I initially did not notice any physical differences with Ron. However, he was good at hiding his illness. After his knee operation, he had difficulty walking and so had to use a wheelchair a lot of the time. He ended up using this

wheelchair for years. He returned to his job at a foundry after the operation; however, he did not work for long after that. I think he was told to leave. If you couldn't do the job, you were out.

24. I don't recall Ron getting any serious infections but he got the odd cold when he had HIV. I believe he also had issues with his liver but I can't remember the nature of these problems. As Ron became more unwell, he lost a lot of weight and spent a lot of time at home resting. He also started drinking more. I think he became quite depressed, as he was prescribed antidepressants.
25. Ron never received treatment for HIV, though I don't think there were tablets for it back then. The only medications he was on were antidepressants and Factor VIII when needed.
26. We were treated like lepers by many from the medical profession. When one of the community nurses came to dress Ron's wounds, she was unaware of Ron having HIV until we advised her. She stopped the treatment until she got permission from the local practice manager.
27. There were, however, two very compassionate medical staff, being Dr Kit Wynes, Ron's local GP, and Mr Slocombe, his haematologist at the Telford Haematology Department. Mr Slocombe was the only specialist that Ron saw for his HIV, and he did his best to monitor Ron's condition and give him advice. The local GP, Dr Kit Wynes, became a good friend. He used to come and sit with Ron when he went into hospital.
28. Between 1987 and 1988, Ron had a kidney removed. Fortunately, there were no complications with that operation. I do not know whether this was related to the HIV or HBV. Ron didn't become really unwell from his HIV until the very end.
29. In late 1990, Ron's health deteriorated suddenly. It wasn't a gradual decline; things seemed to go downhill within a matter of days. He had suffered some bleeds in his elbow and knee and had been in bed for a week or two. The doctor came to our home and after assessing Ron, he called an ambulance. The ambulance driver felt Ron's pulse but when I told him that Ron had HIV, he backed out. He lifted his hands, put his gloves on and refused to touch Ron.

30. Ron was admitted to a side ward for quarantine at Telford Hospital, now known as Princess Royal Hospital. They put a notice on the door saying that no one was to enter without being authorised. Data protection wasn't good in those days and it was clear that staff disclosed to their friends and family that there was "one of those" in the hospital. One of our friends was friendly with a hospital cleaner and disclosed that there was "one of those AIDS men" on a side ward. They never found out it was Ron.
31. When Ron went into hospital, they more or less told me that he was not going to come out. He fell into a coma and never spoke again. We would still reassure him and talk to him, but he never came out of the coma state. He died on 21 December 1990.
32. Ron's death certificate states that the cause of death was Staphylococcal Septicaemia, AIDS, Haemophilia A and Chronic HBV. I was not aware Ron had developed AIDS until I saw the death certificate. I produce a true copy of Ron's death certificate as **Exhibit WITN0889002**.
33. Ron's illness and death has had a devastating impact on us all. While Ron was alive, I tried to push his illness to the back of my mind. I had to. I wouldn't have survived if I hadn't. I continued with yoga, running, training athletes and doing sports within the community as a sports leader. I also volunteered for the Telford Entertainers. We would go into rest homes and do shows. Ron always encouraged me to do things like that.
34. Before Ron died, he was very sociable and volunteered in the community. He was passionate about helping people with disabilities. He would go to Stirchley Disabled Centre in Telford and run classes for disabled people. We also used to take them swimming. It was called Club 62. One of the people who attended had lost both of his legs and we used to take him on holiday to give his parents respite. Ron also advocated for the rights of disabled people and would meet with politicians regarding this. After he became ill, Ron still continued helping others for as long as he could.
35. Ron and I decided we wanted to foster kids. However, after attending two meetings, were told that we couldn't do it because of Ron's illness. They said that if Ron died, the child is going to lose someone else they love. That really upset and irked him. However, we still took a number of Simon's friends in who were from rough backgrounds when they needed somewhere to stay. Ron was always wanting to help

in any way he could. I would often come home and he would say that someone new was moving in.

36. Ron's illness also had a significant financial impact on our family. After he lost his job, he was on a disability allowance and I also got a job to bring some money in. I did factory work, shop work, whatever I could get. It was difficult because I was also looking after Ron at the same time.

37. After Ron died, things were very difficult for me financially but I had to survive. I was left with all the day to day bills. Ron's parents contributed to his funeral but I had to pay for the rest myself. I was on the dole for six months after Ron died. I was then told by someone at the dole office that my mourning was over and I ought to get a job. I got a full time role at a factory in order to save up so I could start my own business. I then bought and managed a café.

38. I'm on a pension now, but it only goes so far. I wasn't entitled to all of Ron's pension. I only received £1,000 of it. When he died, I couldn't claim widow's pension either, because I was told I was too young.

39. At the time, we could not tell anybody about Ron's illness due to the stigma created by the media climate of fear and hostility. We would have had bricks through our windows. The adverts on the television at the time were horrendous. In those days it was a "dirty disease" and so Ron did not want anyone but the two of us to know. I did not know that Ron eventually told the kids. If I had, it would have made things a whole lot easier.

40. Even Ron's parents did not know that he had HIV until he was on his deathbed. He felt he couldn't tell them, as he knew it would kill his mother. I was the one that had to break the news to them in the end. His mum was in pieces when I told her. She kept saying that we should have told her in the beginning. She couldn't understand that it was Ron who didn't want her to know and that he was only trying to protect her.

41. Up until two to three years ago, I still had not told anybody else about what happened to Ron. I was still fearful of people knowing. I wanted to tell people, but I was scared they would tell me to get out of their house and wouldn't want anything to do with me. It was as if we had a blackened name. It was horrendous.

42. It has now been 28 years since Ron's death, and life has never been the same without him. Ron would have been alive today if it were not for this terrible disease. He never had the opportunity to watch his children grow up to get married and have children. After his death, they missed out on an amazing, strong, and loving father and granddad. I have missed out on growing old with Ron. I have never met anybody to fill the space in my life. I remain single and continue to struggle to cope emotionally and financially.

Section 6. Treatment/Care/Support

43. Mr O'Shea gave us very little advice or support. However, our GPs were very helpful and, although there was no treatment available, they did their best to monitor Ron. They were as helpful as they could be during Ron's final month.

44. Ron and our family were never offered any counselling or psychological support.

Section 7. Financial Assistance

45. We received some financial assistance but I cannot remember where from. The Macfarlane Trust sounds familiar. I think Ron may have found out about this financial assistance through the haemophilia newsletter and he applied shortly before he passed away. I am not sure how difficult the application process was. I believe it was around 1991, after Ron died, when we received the payment of approximately £4,000 to £6,000.

46. I felt as though the money was blood money. I wanted to get rid of it. It was enough for us to go on holiday after Ron passed away but it didn't last long. I shared the money with Simon and Sharon. Simon travelled abroad and Sharon bought a car.

Section 8. Other Issues

47. I have never been involved in any previous inquiries or campaigns. Ron was pursuing litigation against the hospital for the knee operation that had gone wrong but he did not get any compensation. The solicitor said that the evidence died with Ron. I don't think he was a very good solicitor. He said "you can carry on, but I guarantee you will lose your house". I couldn't afford to do that.

48. I feel very bitter about the government and I hope that after this Inquiry, someone will finally be honest and say what really happened. More financial support would also be a big help as my pension doesn't get me very far.

49. I have always felt as though Ron didn't just die, he was murdered. Giving this statement has been one of the hardest things I have ever had to do in my life. I just want to get this story out and try to find peace and closure.

Statement of Truth

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

Signed

GRO-C

Dated

10 - July 2018