Witness Name: Suzanne Roberts

Statement No.: WITN3149001

Exhibits: WITN3149002

Dated: February 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUZANNE ROBERTS

1. I, Suzanne Roberts, will say as follows: -

Section 1: Introduction

- 2. I am Suzanne Joy Roberts born on GRO-C 1975. I am a Baptist minister and was a TV and radio journalist for 18 years prior to becoming a minister. I was married in 2006 and lived in GRO-C for three years before moving to GRO-C in Dorset. I currently live in GRO-C and have three step-children who are grown, although no children of my own.
- 3. My father, John Algie, died as the result of infections he contracted from contaminated blood product administered to him to treat his haemophilia. During the course of this witness statement I intend to talk about the course of his infection and the impact his eventual death had on me.

Section 2: How affected

4. My father, suffered from haemophilia A. When I was growing up his condition seemed normal to me as it had always been there. I used to help with the injections of his treatment, usually by administering a plaster at the end. I do not recall this in a traumatic way, so I have to assume that it seemed perfectly

- normal to me. His haemophilia was simply a part of who he was, and I just had to be careful not to knock him.
- 5. While I knew that he could not always run or play, he was always a fun father and we got on well. My mother, Kathleen, can remember more of the details of the development of my father's condition and has included them in her own witness statement that has been provided to the Inquiry (WITN3109001).
- 6. While my father and I generally got on well I can recall some early frustrations stemming from his haemophilia. The family had gone on a trip and we were getting off a train. I was being particularly slow and unhelpful in getting down from the carriage and so he gently booted me off. It was not abuse, it was just frustration, probably caused by the pain that he lived with daily. He frequently had these bouts of frustration and so it seemed normal.
- 7. I can only recall my father being treated at home via injections for his haemophilia, and I can still picture the little bottles that his medication used to come in. When attending the opening of the Inquiry the sight of the memorial with the little bottles brought it all back, and it was a little jarring. I can still picture the small fridge that we had to keep his treatment in. I do not distinctly remember any difference between when he was receiving hospital and home treatment for a bleed, but I can recall that he was never the sort to expect a visit in hospital. Since I have become a minister I have had to learn that most people do expect to be visited in hospital, unlike my father.
- 8. I cannot recall ever talking to him about his treatment. My parents never hid anything from me, but they never stressed the difficulties of it to me either. It was simply part of life, and it was normal for us. I was not aware of my mother's negative feelings towards giving my father his injections, which she discusses in her witness statement, until recently.
- My father used to have to attend review sessions at the Haemophilia Centre at the Royal Free Hospital; my mother would go with him and I would often go too. I cannot recall precisely when, but at one such session, my father was diagnosed with HIV, however I was not in attendance on that occasion. I have

been told that this session was video recorded. While I cannot remember specifically being told about my father's diagnosis with HIV, I can recall the massive effects that it had upon the family. I also learned from my parents that my father's diagnosis had been known by the doctors for three years before my parents were informed. My mother said that during the interview with my parents the consultants said "Mr Algie is HIV positive and has been for 3 years".

- 10. I remember attending other review meetings at which there was a social worker called Mrs Miller. I do not recall what her role involved but I did not particularly like her. I would have been around 12 or 13 years old at the time.
- 11. At one point my mother told me that she had been asked very personal questions during these review sessions, regarding her and my father's private lives, and I recall being extremely angry towards the hospital about this.

Section 3: Other infections

- 12. I know that my father was also diagnosed with Hepatitis and that this diagnosis came before the one for HIV. We lived in Stockton until 1982 and I am confident that his diagnosis with Hepatitis came before we moved to St Albans. I did not know what strain of Hepatitis he was diagnosed with at the time, but I have recently learned that it was probably Hepatitis C.
- 13. Beyond this, I do not know of any other infections suffered by my father.

Section 4: Consent

- 14. I do not know much about what my father consented to in terms of testing and treatment, and therefore I would not like to speculate too much. However, I would not be surprised if my father had been tested without his consent.
- 15. I believe that it is significant that he was not told of his HIV diagnosis for so long. I am angry with The Royal Free Hospital for this.
- 16. My father later consented to a drugs trial at some point at the Mildmay Mission Hospital in order to assist with testing some new AIDS drugs.

Section 5: Impact

Diagnosis

- 17. The impact of my father's diagnosis upon the family was significant. We were all very angry with The Royal Free Hospital for not telling him about his HIV diagnosis as soon as they had known, and for keeping it from us for so long. We spoke about it as a family and all that I know was that the doctors had known for two or three years before they had informed him. My mother could have contracted it, as could I, and I cannot understand what they were thinking not telling us. I was also angered by the fact that they had recorded the meeting at which they had informed my parents of my father's diagnosis. This was so wrong and should never have happened. My mother and I have since asked for a copy of this recording but have not been provided with one. We asked for the recording when my father died, and although the hospital said that we could have one, it never materialised.
- I remember my father's condition slowly deteriorating as time went by. I do not know if this is as a result of his condition getting worse, his ageing or the fact that I was simply becoming more aware of things. I can remember him playing with me at home. He was pretending to be a dragon, and was rearing and roaring but he could not chase me. I can recall that by around 1986 his condition had got worse and I had to move in with my aunty for a period due to his ill health.
- 19. I remember one incident when I had fallen ill and was suffering from bad diarrhoea. I had been prescribed tablets however I noticed that these started disappearing and I discovered that my father was taking them. I have subsequently learned that diarrhoea is one of the signs of AIDS and so my father might have been trying to treat that condition.
- 20. Recently I have watched a documentary about Freddie Mercury and my husband asked me if I was finding it difficult. I realised then that my father had never had the sores depicted in the documentary. However, he had been

progressively getting more ill. He began sleeping downstairs and he was always ill due to the haemophilia regardless of how bad the symptoms of his HIV were at the time. My father was getting weaker because of the HIV and was unable to move around as much so his arthritis, caused by the haemophilia, got worse. To some extent my father being ill was normal and maybe this is why I cannot remember any great detail.

Mental Impact

- 21. I do not know a great deal about my father's mental health as a result of his diagnosis. My mother and I read from my father's medical notes from The Royal Free that the HIV had affected his mental health. We were not informed of this at the time.
- 22. I can remember that my father used to talk to himself and try to set the world to rights at times. On one occasion, when he was ill, I can remember hearing him downstairs talking about love and saying that it was not fluffy but more practical. He was obviously trying to reason and work things through in his mind and I believe at this point he was talking about his relationship with my mother.
- At some point my father said to me, "sometimes I feel like doing something really stupid". This comment absolutely terrified me as I was afraid "something stupid" might mean suicide. I did not tell my mother and I had no-one else to talk to about it. We had to keep his HIV diagnosis a secret due to the stigma associated with it.

Impact of the progression of HIV

As my father's HIV progressed he was at home more often and we created a room for him downstairs as he could no longer climb the stairs. While his faith helped him, the practicalities of life were still difficult. By the Christmas of 1989 I was sure that he was going to die and the entire house began to smell sweet, like death.

- During this period my mother was working evenings, while my father was at home watching me. I recall that one awful evening I was downstairs doing my homework. While I had a desk upstairs I preferred to do it on the kitchen table, but my father told me that I should go upstairs to my room. I told him that I could not. During this period his temper was short and he was becoming increasingly frustrated by his condition. When I told him "no", he completely lost it, and hurled a cushion at me. His face was absolutely wild and I ran straight upstairs. I considered phoning my grandparents, as I had no one else to turn to. My father immediately came up and apologised to me but I did not know what to do. In later life I was diagnosed with breast cancer and I have seen this frustration in myself, and in my reaction to the illness. It is a shame that he was not there to be able to say, "snap" or to point out that I reacted in the same way as he did. I cannot recall him losing his temper like that again.
- 26. We had always got on so well, and I can remember little things like quoting Hancock's Half Hour at each other. However, as he became more ill, he got grumpier. As a teenager I assumed that this was my fault.
- During this time, I continued to deal with normal teenage things as well as my father's illness. By my fifth year I was beginning to study for and take my GCSE exams, and I had already thought that I might be interested in learning Gaelic. I was not entirely sure about university but my father definitely pushed me towards it. We had further usual dad and daughter disagreements, about things such as boyfriends of whom he did not approve, but in retrospect I can see that his reaction was tetchier than usual.
- I remember that as his illness worsened my father began to suffer from peculiar fits. He had three of them and the doctors never established what they were. He would start shaking and would glaze over. On one occasion, it happened as he was coming out of the bath and my mother had to call me to help her. I had to come and hold my father who was completely naked on the loo seat while mother rang for help. It felt as though I was moving from being his daughter to his carer.

- 29. On the night my father was finally taken into hospital, I can recall the ambulance coming to collect him. There was an ambulance strike at the time, and so we had to wait for a volunteer, St John's Ambulance to take us. I remember that aged 14 I had to help my grandfather to lift my father in his chair up into the ambulance. The ambulance drivers had failed to secure the doors and we were driving along before they flung open and I could see my father in the back of the ambulance.
- 30. The new hospital, Mildmay Mission Hospital ("Mildmay"), was very good for my father and his condition seemed to improve greatly. He had previously been at death's door but at that hospital he went from that to being able to whizz up and down the corridors on his electric wheelchair or go in next door to play chess with the other patients. He went on to live for another nine months.
- 31. Mildmay was very good at providing bucket list activities and my father engaged with many of these once he knew that he was going to die. The hospital took him to see Starlight Express, and when he wanted to go on holiday with us to Portsmouth they got him into a home there so that he could accompany us.
- 32. The improvement in his care has raised the question with us as to what treatment he received there that he was not being given previously, and why.
- 33. His health went up and down but each time that it improved, it would never reach the same heights as it had previously; so it resulted in an overall decline. Latterly, he could no longer grip cutlery and had to be given knife and forks with large handles. He could not get up to go to the toilet and had to use a bottle; he sent me from the room to do this when I was visiting.
- About a month before he died, my father was interviewed for a religious programme, "This is the Day", about HIV and it was this programme that inspired me to go into broadcasting. In the course of this programme, he leads the worship from Mildmay, delivers several readings and speaks about the effect his illness had upon him. He talks about how his diagnosis was shocking, but that his faith helped him to get over it, and that because he was a Christian

he did not feel so negative about the diagnosis, and tried instead to find the positives. He also spoke to the programme about how his work and the Mildmay Hospital had tried to make things as easy and as comfortable as they could for him (WITN3149002).

- 35. However, the visits to the hospital were not easy for me. When he was ill, it felt like he did not want me around. Although I can understand that when you are ill you might not necessarily want people around you, it felt hurtful. I can remember telling my mother that I simply could not go to visit him anymore; I had just come to the end of my rope.
- My mother and I had planned to go on holiday to the Isle of Skye, which is what my father wanted. He had insisted that we carry on with our plans, and not come back should he take a turn for the worse. The last time that I spoke to him was on the phone and I said, "I love you dad". He could not answer me because he was coughing so badly. I knew he loved me too, but that has stayed with me over the years. It feels like I should be over it now, but these small things stick with you. The hospital phoned us to say that my father was deteriorating, and my mother briefly returned to the hospital via Inverness, leaving me with the people we knew on the Isle of Skye.
- On the night that my father died I can recall sitting in my room on the Isle of Skye. It had been so bold of my mother to go and visit him and leave me in Skye, but it was good that I was given the choice to stay. It was my first real night alone, and sat in my room I looked across the loch and saw a shooting star. I thought, "that is my dad". The next morning, I woke up with an amazing feeling of peace. My mother, who had just landed back in Inverness, rang me and told me, "dad has gone to be with Jesus" and I replied, "I know". I knew then that God was with me. It was not all awful, although a lot of it was.
- 38. My father died on 14 August 1990. I did not have to see him at the end or after he died which was the right thing for us. After his death we were asked if the hospital could conduct a post mortem on him. I simply could not bear the thought of it and I thought, "can we not just leave him in peace?" The hospital

really pushed for it, but the chaplain there assured us that we should not feel under any pressure, and we declined.

Stigma

- The stigma of his infection was huge. I can recall that in my third year in school there was a poster on the wall reading, "I have AIDS please hug me". It always made me think of my father and his condition; of which I did not need reminding. I did not want to share my worries with my parents, and I carried it myself. It was difficult but I wanted to try and carry on as normal. On another occasion, during a personal development class at school we were discussing drug abuse and were shown a film of a post mortem of an emaciated person. This person was clearly a drug user, but as they had track marks in their arm they reminded me of my father and this really upset me; I had to leave the room.
- 40. Later, after my father's death, I can recall once that a boy at the Portree School on Skye made an AIDS related joke and I turned on them and said, "don't you joke about that, my dad died of AIDS". This was only a year after his death so I think the physical distance of being in Skye allowed me to mention it. Apart from this incident I cannot recall any times when I suffered from the stigma, but I did keep it secret when my father was alive.
- 41. I can recall the things that were done or said to my parents more than those directed at me. My mother once received a horrid comment from someone in church and I cannot help but thinking if I had been there I would have thumped him.

Impact of my father's death on my family

42. The impact of my father's death upon my family was enormous. Shortly after he passed away, my mother and I decided to relocate to Skye as I was keen to study Gaelic. My mother did a cracking job and it was fantastic of her to move so that I could follow my passion that but it always felt as though half of me was missing. It has felt that way since, as no-one from my father's side of

- the family is alive. I have never been able to say I get my laugh from my father or be able to attribute other characteristics to that side of the family.
- 43. My mother is a very strong woman and comes from a long family of strong women but I know that she has a vulnerable side. My father was the comedian of the two and my mother balanced it out but after his death, her quirkiness has come through as though she is trying to rebalance it. She always had to be strong in order to support my father and I myself want to try and protect the vulnerable aspect of my mother. She is so generous and I worry about her financially. She has provided financial support to me and used money from the sale of her house to do so but I worry about the effect it has had on her and I wish she was more financially stable. My father's death has clearly impacted upon her in more ways than she would like to let on.
- 44. Looking back at photographs, I can see my mother missing my father. At my graduation her eyes are red and it is a shame that my father was not there with her, as he was not there with her at my wedding.
- 45. It's easy to look back and look at the treatment that my father received and that the hospital gave him and think that he should not have accepted it, but at the time I understand my parents were just trying to live from day-to-day. The "white coat syndrome" kicked in; they believed that the doctors knew best. I believe that the trust they put in the medical profession is still having an impact to this day.

Impact of my father's death on me

46. My father's death had a huge impact upon me personally. As mentioned above, I had always had to keep his condition a secret and I threw myself into studying in an attempt to distract myself. I was not a wild teen and I had activities like Scottish country dancing to occupy myself. I had a good group of friends, but as we grew older we grew apart and when my father died they pulled away, which I can now see in retrospect. My mother has told me that she has spoken to them since, and they told her that they simply did not know what to say after his death. I do not know what was known by those at school

- in regards to the cause of his death. I used to tell people simply that he was in hospital or, later, that he had died without mentioning his cause of death.
- 47. Despite the difficult time that I had in school I do not believe that my education was impacted and I received 9 A's in my GCSEs. After my father's death, our plan to move to Skye in order for me to learn Gaelic provided some relief, freedom and direction for my mother and me, which I believe was extremely helpful. The plan was successful and I studied Gaelic at Sabhal Mor Ostaig on Skye.
- 48. I thought that I was dealing with my father's death well and in honesty, I felt some relief when he passed away. However, I did find myself waking up and, for ten seconds or so, being at peace until I remembered what had happened. I kept having dreams about his illness and I still do sometimes. I had hoped that God would take it away but my mother once told me to ask God to instead make us strong enough to cope with it, which I thought was very wise.
- 49. In many ways people were amazed by how well I was dealing with my father's death. I think that I got attention for coping well and this might have been my way of getting through.
- 50. I have always reacted badly towards anyone who might present a new paternal figure. I would get very protective of my mother and would drive these people away. Oddly though I have noticed a pattern in some of the men that I dated, that they are older than I and this may be well related.
- 51. After my father's death I have felt very protective of my mother. When I went to the opening of this Inquiry I thought that I would be fine but I found myself crying terribly. I told my mother that this had brought it all out and that I had been worried about her for 28 years. I had felt that I needed to be a husband to my mother in a way, to be supportive, strong and protective of her.
- As a result of my father's illness with haemophilia as well as the other issues I have decided against having children. As a result of tests I undertook when I was 18, I know that I am a carrier and that there is a 50/50 chance that any son I had would be a haemophiliac. I simply could not face having to conduct

the injections upon my own child. I recall reading story about a woman who had to treat her haemophiliac son who said to her, "mummy, please don't hurt me". I know that I could not cope with that.

- 53. I met my husband when I was 30, and he was 46 and by the time we had met he had had a vasectomy. I then developed breast cancer and so I knew that I was not supposed to go down the route of having children. I do however sometimes wonder what it would have been like to have children of my own.
- 54. Fortunately, my treatment for breast cancer was not impacted or affected by my thoughts or feelings towards what had happened to my father. My anger is very specific, and I do not label all medics or doctors as problematic, just the ones involved in my father's treatment. My treatment was fantastic and I had no complaints about the way that the hospitals in Peterborough and Cambridge helped me. However, throughout the entire process I was made very aware of the risks and options and I felt involved, unlike the way that my father was treated.
- 55. More recently I took part in a session for trainee chaplains and medical professionals. I was invited because of my experience with breast cancer. At this meeting, it was said that the expert in the illness is the person who had had the illness. One of the doctors described an incident where a person had lost a baby and refused to let the doctors conduct a post mortem, which they found frustrating as they would be able to provide them with a reason as to why the child had died. In that moment I knew exactly how the parent had felt. The body was all that the person had left of their baby and this reminded me of how I had felt when the hospital had requested that my father undergo a post mortem.

Section 6: Treatment, care and support

56. I have never been offered any support in relation to my father's infection with HIV. I have, however, been having counselling over the past year to help with some of the issues raised by discussing my father's illness.

- 57. Before my father's death, Margaret, a support worker who was provided to us from the Lighthouse London, came to our house and was well meaning but could not really help. She simply looked at us sympathetically and said that she was really sorry. She certainly did not help and only attended a few times. I think that it was intended that she would come and sit with him and maybe do a bit of cleaning but it never developed into anything concrete. She had organised this herself as part of "Candlelight Help", her own organisation. This had a Christian element and was a nice idea but she simply did not understand the practical help that we needed in our situation.
- It would also have been nice if we could have received some emotional support. The Inquiry has helped me to talk about my father's death more frequently and I can see that it has affected me. Oddly, it has become worse since becoming a minister; it feels like it has opened old wounds as I find myself conducting a lot of funerals. We lost my grandfather in 2007, the same year that I was diagnosed with cancer, and I still now find myself wrestling with what will happen if I lose my husband or my mother. My faith takes me through but my father's death still has a lasting effect and I believe that emotional support and counselling would have helped. I received some counselling in relation to my breast cancer and found that it was very helpful not having to worry about the other person or their story, simply being allowed to focus on your own.
- 59. I do not feel I can really comment on any difficulties my father had in obtaining treatment. However, I know that his fits were never diagnosed and I recall that at the time that they were occurring a GP, who has long since died, offered to give him a little too much morphine should it happen again. I do not believe that these fits were ever really properly looked into. I feel like I am more inclined to anger about the treatment of my father than my mother is.
- 60. As for my mother, I think that tailored support and assistance would have been great for her as she does not like attending groups. I believe that counselling tailored to her personality and her situation as well as more practical help at the time of my father's illness would have been very helpful indeed.

Section 7: Financial assistance

- 61. My parents and I received some financial support. There was a pay out of £20,000 that I believe was related to hepatitis, which came through when I was about eight years old. The Macfarlane Trust ("MFT") also made smaller contributions towards household equipment when my father was alive.
- 62. After my father died there was also some compensation of around £60,000 or £80,000 from the MFT. However, I recall that the MFT was quite difficult about the payment of this, as some of it had to come to me and the letters seemed to imply that they could not release this to my mother while I was still a child in case she did not give it to me.
- 63. Before my father's death, he had specifically requested that we make sure we had a roof over our head. However, the MFT specified that this money was not to be used to buy a house. This was very troubling, especially given my father's request, and so my mother defied this instruction and purchased a property on Skye
- 64. Personally I do not think that I have ever suffered financially as a result of my father's illness but I do believe that my mother did and it has been hard to watch this. My mother has told me that she used to walk around Tesco's crying because she could not afford anything. She has recently become aware of the help that she can have from the EIBSS and the Skipton Fund and this has made a great difference to her life. However, it is important to know that money is not everything and we want the recognition and the restoration of some of my father's dignity.

Section 8: Other issues

65. As a minister, I wish to help those without a voice have one and I now know that talking about the things that were so long repressed and silenced is restoring dignity for my father. The Inquiry is now explaining what he went through and shining a light on how well he coped with it all.

- 66. More than anything I simply want to know what happened. Did someone say, "oh dam, this batch has HIV, oh well" and let it be used for treatment anyway? I simply cannot understand what happened and it does look like there has been a cover-up.
- 67. I cannot see what the hospital were thinking when they recorded the meeting at which my father was told of his diagnosis. People should never be treated that way.
- The issues with infected blood went on for so long and I do not understand why. The treatment should have been immediately screened the moment that it was known that there were issues with it and they should have stopped giving it out. As far as I am aware, the hospital treatment my father used to receive before he was put onto home treatment made from imported plasma, did not carry the same risks. Therefore, I believe that as soon as both the suppliers and the treating doctors became aware of the risks of infection with both HIV and Hepatitis, they should have stopped the imported treatment and reverted to the treatment they used previously. I strongly suspect that the reason this did not happen was because the imported treatment was cheaper.
- 69. Being completely honest I also hope that the Inquiry can help my mother be financially stable and get her into a position where she could buy a house of her own. I do not know if this could ever happen, but I hope it can. The fact that I still get so upset with all of this shows how important it is to me. I am still not over what happened to my father and I would like some closure. The lasting impact of this infection is that I feel robbed of half of who I am. I have never had a chance to have an adult relationship with my father and I cannot help but think that we would have got on very well.

Statement of Truth

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Signed	GRO-C
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Dated 15.02,2021