Witness Name: Christine White-Cannon
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CHRISTINE WHITE-CANNON

I, Christine White-Cannon, will say as follows:-

Section 1. Introduction

1. My name is Christine White-Cannon. I was born on GRO-C 1961 and I live at GRO-C

2. My (first) husband, Allen Jon White (born on GRO-C 1953), was infected with the Human Immunodeficiency Virus (HIV) through contaminated Factor VIII (FVIII). He died on 7th November 1991, aged 38.

3. This witness statement has been prepared without the benefit of access to Allen's medical records. I was told that they were all destroyed.

Section 2. How Affected

4. Allen had severe Haemophilia A. He was treated at the Bradford Haemophilia Centre at the Bradford Royal Infirmary (BRI) under the care of Dr Liakat Parapia.

5. Allen and I were married in 1979 and were blessed with two daughters: Sarah and Naomi. We were later told that the batch of FVIII which had infected him had been given while I was expecting Naomi, who was born GRO-C 1982. I believe that batch was manufactured by the Armour Pharmaceutical Company.

6. We always attended clinic as a family, so we were all involved and knew the staff very well. We were supported by the whole team including (over time) the dedicated social worker. I personally do not remember any conversations about the risk of infection before Allen moved from cryoprecipitate to FVIII treatment.

7. When it became public knowledge that AIDS was affecting people in the US and that treatment was coming from there from pooled blood, Dr Parapia (and Sister Pauline Sharpe) discussed the risks with us at clinic appointments. We were informed that the Bradford Haeomophilia Centre were going to give the newer, safer product to children and those who had not been treated before as there was not enough of it for everyone, and we agreed with that decision. We believed at that time that we were being kept informed and that we understood the information available. In retrospect, we did not appreciate the true extent of the problem and it may be that that information had been withheld from Treatment Centres. There was, as we understood it, very limited alternative treatment options and the reality was that unbeknown to us the damage had already then been done.

8. Allen continued with his treatment. No test was available until much later, maybe 18 months later. I do not remember any advice to us to take precautions

to avoid transmission until after Allen was tested positive. Once we knew that Allen was HIV positive, we were advised to avoid sexual transmission by using condoms. We were also advised that we should not mix his Factor VIII concentrate any more as we used to help or even get it ready for when he would come home from work when needed.

Section 3. Other Infections

9. Allen was tested for the Non-A Non-B Hepatitis Virus, but we were told that he was not infected.

Section 4. Consent

10. I had no reason then and I have not heard anything since to make me think that Allen was ever treated or tested without knowledge, consent, or full information or for research.

Section 5. Impact of the Infection

11. In terms of the impact on Allen of the HIV infection, I have divided the details of the effect upon him in three distinct phases:-

Phase 1 - Allen finding out he was HIV positive.

12. Allen was a very brave and pragmatic man, with an amazing sense of humour and very patient and kind. I only ever saw him lose his temper once and he did not sulk or hold grudges. He had grown up and lived with much uncertainty and limitation because of his severe Haemophilia. He spent a good proportion of his teenage years in an orthopaedic hospital because of the joint damage to his hips, knees and ankles caused by bleeds before proper clotting treatment was available.

13. After Allen found out he had HIV (in or around 1986), he was determined that he would use this time, when there was much fear about transmission, to be public and to help to educate people. To this end he spoke in local High Schools about safe sex, helped with a Royal College of Nursing training course and was widely used by media – television, video, newspaper, and radio. We still have many of these and it is a valuable resource to hear Allen speaking for himself about the impact. He felt that if he was open and public then news of his infection would not be gossip and would not result in people being afraid. He was right. While others hid away in fear and had eggs and worse thrown at their houses, we had much support and love from our local community.

14. Mentally, it was not fully understood what being HIV positive would mean in the longer term. We thought, at that time, that it may not progress or even that some antibodies may be a good thing, like an inoculation.

Phase 2 - being diagnosed with AIDS

15. As time went on, Allen began to become ill and it became harder to continue with work (he worked in Accounts and did some computer programming at a weaving mill). I think he officially stopped working in 1988 although he had had time off with infections. His work had been extremely supportive and there was a finality to not being able to continue to work that was hard for him.

16. Allen had extreme night sweats several times a night that were disturbing and added to the burden of coping with the symptoms. We had help from Sister Sharpe with this. We tried disposable sheets, but they were very uncomfortable. We got a washing machine with a larger porthole and had changes of bedding made up ready. When Allen woke in the night, wet through and shivering, I would help him to dry off and put clean PJ's on and he would get back into bed on my side which was still warm. I would change his side of the bed completely – quilt, sheet, mattress protector, pillows – and then get in on his side to warm it until he could move over. Then I would complete taking

the wet bedding off at my side and making up the bed again. When disturbed nights were happening all the time, we had night sitters from the hospice which the GP organised. This was very kind of them as that service was only for Cancer patients at that time.

17. After several chest infections, tests (bronchial washing investigations) revealed PCP, a diagnostic indicator for AIDS.

18. Allen was very weary, and his personality began to change. He was suspicious of me about money and was short tempered. He would be very upset and worried. I can think of two specific examples of this – the first when he was driving, and a squirrel ran into the path of the car. He pulled over to the side of the road and could see it in his rear-view mirror. It was badly injured and thrashing about. He cried. He said that he was not even man enough to reverse and put it out of its misery. The other example was one day when I was late home because of road works. This was before the days of mobile phones of course. When I arrived home, he was extremely upset and thought something had happened to me. This was so out of character. By way of example from the past for this, once when we were on a British Airways flight coming home from a holiday, we hit a storm and were in severe turbulence. The plane began to nose-dive and was shaking and creaking. The overhead baggage lockers were flying open and other passengers were panicking. Some were vomiting and others where standing up when the seatbelt warnings had come on. There were screams and cries around us. Allen looked at the girls and treated it as a fairground ride, shouting 'weeee, weeee!' engaging their attention and stopping them from being frightened.

Phase 3 - Terminal Illness

19. We wanted Allen to remain at home and he wanted to be at home so that he had as much freedom to do what he wanted as possible, but this was not easy. He did not like being dependant. He accepted all the help offered from District

Nursing and Night Sitting services because of the strain on me. He was occasionally frightened, and we often cried. He was very weak and wasted. He spent a lot of time in bed but when he wanted to be up in the lounge, he had little patience and really needed to put what he wanted on the television and be left in peace. This was challenging with two young children. My mum bought us a portable television to put in the downstairs extension so that the children could watch their programmes there when Allen was downstairs. We would not have been able to keep Allen at home if it were not for the support of my mum. He had several falls; one I remember was down the stairs. He grazed all down his left side on the wall. He continued to be involved with media, only newspaper and radio now. He did his last interview for radio at home the day before he died. It was about euthanasia and his view was that it should not be a person's decision when they die, it is God's. We had excellent support from our GPs and Allen was able to die at home in my arms.

Complications, obstacles to treatment and impact of HIV/AIDS on Allen's general medical care

20. Allen had problems with venous access and had a Portocath fitted. This had to be removed later because of an infection in the tunnel that the tube ran through. This meant that he had to go back to using veins for FVIII treatment and they would often collapse making it very difficult and frustrating for him. This was another piece of independence taken from him, but the GP's were so supportive of him, letting him try before helping. Our home became a constant stream of healthcarers. He was assessed by Occupational Therapy to assist with daily living as he became weaker and had an electric bath seat which gave him back a little independence, and, although he still needed some help, it did help how he felt about it. He had a male District Nurse, and this was very much appreciated.

21. Allen's PCP pneumonia was treated with toxic drugs in a nebuliser. This had to be vented out of an open window while he was using it. This introduced yet

another risk to me and the girls and that risk affected him mentally. He felt he was a danger to us and a burden. He was also treated with high doses of Acyclovir, an antiviral drug. This caused a lot of side effects including nausea and vomiting and made him very unwell. It reached the point where it was not possible for Allen to continue taking it.

22. There was an occasion when we were in London and Allen was suddenly vomiting in the street, so much that he was vomiting blood. I was trying to shield the children from seeing it and trying to look after him at the same time as well as worrying how we could clean it up safely.

23. We were not aware that there were any alternative treatments available.

24. In terms of stigma, it was an obvious fact that Allen's clinicians had to use gloves and aprons when providing care but, other than that, I do not think that he was treated differently to anyone else with an infection. We were blessed with the most professional staff who cared for us as a family as well as Allen. There may have been staff from other contractors/agencies that declined any involvement with us, but we were not aware of it.

Impact on me

25. The nebulised drugs affected me even though they were vented out of the window and I was not in the room when Allen was using the nebuliser. I developed a productive cough for which no other reason was found.

26. I felt that I manage to cope with the physical exhaustion I experienced through caring for Allen quite well while Allen's mental state was reasonable, but when he became muddled and accusative, it was very hard for me to keep going. I had a week off work, and we were cared for together which was lovely.

27. I am still affected mentally to this day by what happened to us. Although I was able to continue my career (part time) when our daughters were young because of the support of my mum, after our daughters had left home, I had a complete mental breakdown. I took early retirement 10 years ago. I remain on antidepressant drugs and am unable to work. I believe that I was holding myself together all that time for the sake of my children.

28. In terms of emotional support, we were blessed to have family nearby and to be part of a caring church with many friends who all continued to support us through this time and supported me after Allen's death. We did not blame the people from the Haemophilia Centre, who cared for us. We knew them as friends. Allen was very clear in his thinking during the first litigation that the decision to import FVIII concentrate from America was at government level, knowing the risks after failing to become self-sufficient for NHS FVIII blood products in Britain. We felt that this had been closed and that nothing more could be done about it. Therefore, I had to get on with grieving and looking after my girls and try to get on with life.

29. I am now aware that there is much lying buried in me emotionally that the Infected Blood Inquiry has brought back to the surface because it is not closed now. I do not have access to the information that we had back then. Allen's medical notes have been destroyed and, in my attempts to move on, I did not keep the papers from the first litigation. All we have is the videos of Allen talking. He wanted recompense for our daughters and that is the only reason that I am putting myself through this ordeal now. I would not suffer this again for me, or for the truth being revealed as I do not have a high hope of that happening.

30. I have been robbed of my soulmate and have had to watch my children grow up without their daddy. When they were getting married, I had to sit next to an empty chair where he should have been after <u>he</u> should have walked them down the aisle.

31. I have been blessed and have had joys since Allen died but what a different life to what we expected and blighted by the fact that it should never have happened. I did manage to have a career but was unable to sustain it because of mental health problems. This has obviously impacted every aspect of my life.

Impact on our family

32. Allen's parents had both died before him. He had three brothers and they were all impacted by his illness and loss and, I would say, particularly so his youngest brother Gary. My mum became like another parent to my children which was a great benefit at the time. However, this has also impacted Sarah and Naomi when my mum died nineteen years ago and we only lost her sister, my Auntie Ruth, a few months ago and she had become like a grandma as my mum had stepped up to be a parent.

33. I believe that both my children would have gone on to further education if Allen had still been here. They certainly have the aptitude and it was for emotional and mental reasons that they did not pursue professional careers on leaving school. Sarah just managed to complete her A level years at school but, due to her mental health at the time, she did not get the grades she was expected to get. Naomi dropped out after the first year of her A levels to take a job.

Financial Effects

34. Allen was a very popular man and had much sympathy in our hometown because of the publicity that he was doing and his work in senior schools. His work was very supportive of him having time off when needed it but had to let him go when he was no longer able to work at all. He was then on benefits.

35. At that time, I was in my second year of a three-year course to train as a physiotherapist so was in receipt of a grant. This was Allen's wish that I should have a profession and that I would be able to work part time enabling me to

support us and care for our children when he became unable to work and after his death.

36. There were many extra costs involved, extra laundry and buying extra bedding, having the house warm night and day. The money from the MacFarlane Trust (MFT) assisted with all of this and we had a downstairs extension built on to our terraced house, had central heating and double glazing installed.

Section 6. Treatment/care/support

37. We always attended clinic as a family and as Allen became more ill, it was not practical or appropriate for him to attend clinics in Bradford. Sister Sharpe would visit us at home occasionally and that helped particularly sharing how others were coping and passing on tips, and to know that we were not alone. The care when Allen became terminally ill was appropriately given by local services, but we did miss staff and other patients that we knew so well. So, with not attending clinic we did not have access to the rest of the team that we had had earlier. We had had a social worker. I remember having a session about releasing emotion as a family – we made sticks out of rolled up newspapers and hit a chair with them! It made us laugh at the time. Allen was treated by the dentist there but again as he became too ill, he did not have the energy or patience even to have his hair cut let alone bothering with dental treatment. Other than that, I am not aware of any treatment care or support that we did not receive. Everyone did their best for us.

38. We had a few family sessions with the social worker, and we were always able to discuss concerns with Dr Parapia and Sister Sharpe at any time by phone. Other than that, I don't think either of us had formal counselling or psychological support, but we were supported by the staff who cared for us.

39. I have had counselling during and since my mental breakdown for which I had to pay a contribution. In this respect I do not consider that there was, or is, appropriate or adequate support.

Section 7. Financial Assistance

40. Allen received a lump sum from the MFT. I do not know anything about the process of applying or the date when this was paid other than newspaper articles from the time. The award of that fund was based on the first litigation being dropped so yes, preconditions were imposed, and we have a video of Allen speaking about that. We very much needed the assistance at the time, I have explained above the added burden that was being put on us financially and the care needs that Allen had at that time. The lump sum did relieve suffering.

41. I do not think that I ever received any financial support for me personally. There was a grant towards funeral costs and a small monthly payment for the children until they came of age. I do not remember having to apply for either of these. I think they were automatic because of Allen's original application, or maybe a conversation over the phone but I did not initiate this as far as I remember. When they came of age, I had a phone call telling me that the payment would stop and hoping that I understood that others needed it more than we did. I do not really know how that was qualified, but I did understand it to be a fund for relieving suffering and not compensation, so I did not argue with that.

Section 8. Other Issues

42. As mentioned in the introduction, we do have copies of the media coverage that Allen was involved in, in the form of newspaper articles, cassette tapes of radio interviews and videos of television programmes and a video that was made about us called 'HIV Positive Thinking'. I now have no other documentary evidence.

Anonymity

43. I do not want to be anonymous and I understand that this Statement will be disclosed for publication to the Inquiry.

Statement of Truth

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

Signed... GRO-C

Dated 23.12.2020