

Witness Name: John Robert Dewhurst

Statement No: **WITN4605001**

Exhibits: Nil

Dated: 26 May 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOHN ROBERT DEWHURST

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2021.

I, John Robert Dewhurst, will say as follows: -

Section 1. Introduction

1. My name is John Robert Dewhurst. My date of birth is GRO-C 1957. I am 64. My address is GRO-C Lancashire, GRO-C I have lived here since 1992 and on the same estate since 1982. I am single. I have never worked as a result of my haemophilia and my HIV status.
2. I intend to speak about my infection with HIV which I contracted either from the blood products to treat my haemophilia or a blood transfusion at the Manchester Royal Infirmary (MRI) in 1985. I have also received an injection for some form of Hepatitis. However, I do not know definitively if I was ever infected or whether I am currently infected. In

particular, I intend to discuss the nature of my infection with HIV, how the illness affected me, the treatment received and the impact this has had on my life.

3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I can confirm that I do not wish to seek anonymity.
4. The Inquiry Investigator has also explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
5. I wish to acknowledge that as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates. My memory really isn't that good.

Section 2. How Infected

6. I was born in Manchester in 1957. My mum was a carrier of Haemophilia and she was aware of this. I had two or three uncles with the disorder. One died at the age of three and the other aged 19. This was before the formation of the NHS, when patients had to rely on private treatment or the Hospital Saturday Fund Charity. Treatments weren't available as they are now.
7. I can remember being told a story about one of my uncles suffering a bleed after falling on glass. My grandfather tried to take him on foot to the MRI but he sadly died before they could make it. My other uncle was working in a bus station and died after falling into an inspection pit.
8. I don't know if I was diagnosed at birth or when I was slightly older. It's possible that I was diagnosed after somebody complained about

bruises. My mum passed away in 2012. My dad passed away when I was only 16. His first wife died, following which he married my mum.

9. My family and I moved to Blackpool in 1970. Growing up, I experienced multiple severe bleeds as a result of my Haemophilia, particularly in my knees, ankles and elbows. Some of these were life-threatening. I once fell off a bike in Stockport having pulled the brakes too hard. On another occasion, as a young boy, I tripped whilst walking across a building site and injured my mouth, resulting in a bleed. I believe there was an ambulance strike so they couldn't bring us home. I was in a real state.
10. As a child, under the care of Blackpool Victoria Hospital (BVI), I was given cryoprecipitate. I can remember putting it on my teeth too. Subsequent to this, I was given FEIBA factor VIII bypassing agent, which I now receive, at the hospital every six to eight weeks.
11. Since the age of twenty, I have been in a wheelchair. This was a conscious decision as I was fed up of experiencing multiple bleeds. Prior to this, I was mobile and walking. I continue to suffer with bleeds and the effects of haemophilia to this day. There is practically nothing left of my left shoulder but bone. There is no movement there at all. My ankles are twisted and inverted and my knee caps are swollen. I have also recently damaged my right hand.
12. In May 1985, I was given a blood transfusion at the Manchester Royal Infirmary (MRI) after multiple bleeds including one in my hip. I have had a few life-threatening bleeds so they probably had to top me up. I have not had a blood transfusion in a long time.
13. At some point in the 1980s', I went to see my consultant at the MRI to notify him of my plans to go on holiday to America with a disabled group. I believe it was during this appointment that I was told that I was HIV positive. This was believed to have been contracted from the blood

transfusion I received at the MRI in May 1985. It is so long ago that I do not recall either precise dates or the details of the consultation or the exact conversation. I let the diagnosis wash over me. My main concern has always been managing my Haemophilia.

Section 3. Other Infections

14. As previously mentioned, I can also recall being given an injection for Hepatitis at some point. However, I do not know for certain if I was ever infected or if I currently carry any Hepatitis infection. It will be in my medical notes, which I believe run to 5 or 6 volumes. I am happy for the inquiry to examine my notes if required.

Section 4. Consent

15. Growing up, I relied on my mother in respect of my treatments for Haemophilia. Therefore, I assume she provided her consent on my behalf. I knew that I needed treatment because I had severe bleeds. Treating and managing my Haemophilia was always been my priority.

Section 5. Impact

16. When I was diagnosed with HIV, I tried not to let it shock or terrify me. I have now lived a substantial part of my life knowing that I am HIV positive. In order to cope psychologically, I put my diagnosis to the back of my mind. I just had to carry on and get on with my life.

17. Treatment wasn't immediately available. I now attend the hospital on a regular basis. My care is divided between the Manchester Royal Infirmary (MRI) which houses the regional Haemophilia centre and the Blackpool Victoria Hospital, (BVI) the latter of which I attend for my day-to-day needs. I also currently attend the HIV clinic at the MRI.

18. I am under the care of Professor Hay and another Doctor who I refer to as 'Dr Ash' although I do not know if this is his full name.
19. I currently take a combination of Ritonavir Mylan tablets and Darunavir tablets to manage my HIV infection. Overall, I take 25-30 tablets per day to manage my HIV and Haemophilia. I have been told that my HIV viral load is now undetectable. Of course, it's good news but what am I supposed to do? Put a flag up? Get the Brass bands to play? Life will and must go on.
20. I am a survivor. I only really worry about my health when I have bleeds or chest infections. In recent years, I have tried to live a healthier life style. I used to over indulge in biscuits, chocolate and microwaves meals. However, after becoming unwell following a microwave dinner, I now have healthy and nutritious meals delivered from Warren Manor Day Centre. It costs £7 a day for a meal and pudding which amounts to £49 a week. They're very good. I am also diabetic and I am not supposed to have the puddings but I do.
21. I have never had a job. My joints are exhausted. Many years ago, my then GP Dr Biswas at Glenroyd Moor Park Health and Leisure Centre told my mum that I would never work. He said that I was unemployable and that no employer would want to take on the responsibility of my health problems.
22. On reflection if I could work, I would work part-time, just to have a sense of belonging. I do have some hobbies. I like my aircraft and war planes. I used to go swimming but I don't do this anymore. I have always loved reading but my eye sight is no longer perfect so this is a struggle.
23. For the most part, I have not been subjected to stigma as a result of my infection with HIV. However, I think I also tend to look past any stigma if this does come my way. I have always been quite open with my HIV

status. I believe that if people wish to act negatively, that is their problem and not mine.

24. When I tell people at church, generally, people are understanding. The odd person does not react well. I can remember shortly after receiving my diagnosis in the 1980s', the AIDS advert aired on TV with the great tombstone falling to the floor. I thought it was a stupid advert. Adverts like this contributed to my decision to bring my own knife, fork and cup to anywhere I visited so as not to expose others to the risk of infection.

25. I can remember that on one occasion, I was at BVI for a bleed. When I shared my HIV status with a young nurse, she backed away in shock and horror. That was quite an interesting reaction from her. Again it didn't really affect me, it was her problem not mine.

26. Since my diagnosis, I have received dental work at BVI and MRI. Staff are always dressed in 'NBC' suits. The first time I encountered this, I was quite alarmed. I wondered what on earth was happening. It was difficult, but I got used to it. Now I understand that these measures may be in place to protect the patient as well as the staff as my immunity is compromised.

27. I have never been married. Over the years I have had one girlfriend. Because of my Haemophilia and subsequent diagnosis of HIV, I made a conscious decision to avoid romantic relationships. I didn't want to expose others to the risk of infection nor to impose the burden of my health needs on anyone else.

28. Whilst I am aware that quite a few Haemophiliacs have children or grandchildren, I have always felt reluctant to have a partner take on the responsibility of looking after me. Had my circumstances been different, I would have liked to have a partner.

29. I suppose that if I had my life again, I would change a few things. I think a lot of my memories have been buried and forgotten. I live on my own and so I am not used to discussing myself. I think I've repressed a lot of my feelings. Normally, I'm a good listener to other people's problems. When I try to share my own, people don't want to know.

Section 6. Treatment/Care/Support

30. On one occasion, I went on holiday to America with another disabled group. We had an accident on the bus and I broke my tibia and fibula in both legs. I was taken to hospital in Florida where I remained for two or three weeks. Fortunately, I paid extra for insurance as it cost \$600 just for the ambulance journey one way. As far as I recall, I was content with the treatment I received there.

31. I am content with the treatment I have received in respect of my Haemophilia. It has kept me going. When I have severe bleeds, I contact the hospital. Either my carer calls a taxi or we take the bus when I am unable to drive following a bleed in my hands.

32. My only complaint would be that now and again my treatments are stopped or alternatives are sought in order to reduce expenses. I have had to fight for my Tranexamic (TX) acid, a medicine to control bleeding. One doctor stopped me receiving it completely for a period of time because it is so expensive. This resulted in more bleeds and more pain. The pain was terrible, I couldn't sleep or relax at all. Sometimes the painkillers aren't effective in which case I contact the carer for assistance. Sometimes it takes a few hours for someone to attend.

33. I have never been offered any counselling or psychological support as a result of my diagnosis with HIV. For a while, I probably didn't want any support of this nature. I spoke to a lady from South Africa on a couple of occasions but I can't recall the circumstances surrounding this. As I've gotten older, I think it would be helpful to talk to someone.

I'm a good listener to other people's problems but I feel that other people are not always willing to listen to mine.

Section 7. Financial Assistance

34. Some years back I received £20,000 in the form of a lumpsum from McFarlane. I remember signing a few forms. I decluttered a few years ago and probably got rid of them. I remember that I was asked to sign a waiver agreeing not to sue the government for further payments. The Vicar witnessed my signature as a person of standing in the community.

35. I believe I continue to receive £3,000 a month from the English Infected Blood Support Scheme (EIBSS). Additionally, I receive a Christmas top up and most probably a winter fuel allowance.

36. I was happy when I received the compensation. It was a lot of money; I did give some of it to my Church. I am very comfortable and do not have any financial concerns. That said, no compensation could make up for being infected with HIV.

37. My view is that those people who have been infected with any type of blood virus should receive more than adequate compensation to assist them in their respective lives.

38. I live in a council flat, fitted to accommodate my disability requirements. I have my electric wheelchair and ordinary wheelchair. Motability supplies my vehicle which is a large van.

Section 8. Other Issues

39. As I said earlier, I am financially comfortable. However, I believe that Haemophiliacs infected with HIV and Hepatitis viruses as a result of receiving contaminated blood should be financially supported.

40. I feel that people were infected because the NHS tried to cut corners with costs, which they continue to do to this to this day. If infected parties or their families are struggling, particularly with the pandemic and the resultant economic downturn, I think it is important that they receive the support that they need.

41. If the NHS operated with the efficiency of the military, they could be providing world-class treatments.

42. I understand from the Investigating officer, that I was contacted by the Infected Blood Inquiry as a result of a questionnaire I completed and returned to the Archer Inquiry. This was many years ago and to be honest, I cannot really remember much about that. I do recall that there was no follow up from them after I sent my questionnaire back. I just left it at that. I'm also aware there was an Inquiry in Scotland but that's about it, I have no real knowledge about that or what happened.

Statement of Truth

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

Signed

GRO-C

Dated 26th May 2021.