Witness Name: PETER ALAN ADLAM
Statement No: WITN1068001
Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PETER ALAN ADLAM

I, Peter Alan Adlam, will say as follows:-

Section 1. Introduction

1. My name is Peter Alan Adlam. I was born on GRO-C 1976 and I live at GRO-C GRO-C, Hants GRO-C

2. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

3. I have severe Haemophilia A which was diagnosed in May 1978. The diagnosis wasn't a complete surprise as I had a haemophiliac uncle and my mother is a carrier.

4. I was treated with Cryoprecipitate immediately upon diagnosis. We moved to Scotland between 1979 and 1982 and I received treatment at Yorkhills Childrens Hospital, Glasgow under the care of Dr Pettigrew. It wasn't until May 1982 (when my family and I returned to GRO-C from Scotland) that I started home treatment with Factor VIII (FVIII) concentrate. I was treated at

the Southampton Haemophilia Comprehensive Care Centre at Southampton General Hospital under the care of Dr Morag Chisholm.

5. I am co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products.

6. I tested HTLVIIII negative on 20th November 1984. I believe that up until that point I had only been treated with NHS Factor products, predominately BPL. On 10th February 1985 I was treated with an Armour product (batch number x57910) at hospital for a recurring ankle bleed. I believe the 10th February 1985 to be the first occasion upon which I was treated with an American product. It was from around the date of 15th April 1985 that both my home and hospital treatment switched mostly to Armour products, until the September of that year. I have a full record of my home treatment. I tested HTLVIIII positive for the first time on 24th April 1985.

7. My parents were informed that I had HIV via a letter sent to them on 16th May 1985. When we saw Dr Chisholm thereafter my parents, were provided with very little information apart from the basics. They were told that nobody else needed to know or be told. My parents told me as much about it as I could understand at that time. I was just 8 years old when first infected. Contrary to the advice of the Haemophilia Centre, my parents decided that my teachers needed to be informed. Eventually the media got wind of it and I was turned into a test case on how to deal with infected children in school, with specialist doctors coming to my primary school to reassure and educate the parents of the children I was at school with. As a result, everyone received a better than average education on the virus and what was known about it at that time.

8. I tested negative for the Hepatitis B Virus in May 1990 and was vaccinated against it. No mention was made of any risk of HCV. I do not know when I was first tested HCV positive as I was unaware of it. I don't think I really became aware of the infection until around early 1998 when a nurse at the HIV clinic told me in passing that *'basically all haemophiliacs will have Hep C'.*

The only information I received about HCV was from my HIV doctor (Dr Rowan at the Royal South Hants Hospital). It was explained to me that having HCV could cause liver problems in the future (every problem was always a potential 'problem for the future') but that it wasn't worth worrying about it now other than how it limited my HIV medication options.

9. I was not provided with any useful information until HCV clearing treatment was suggested to me at the end of 2004. I am very disappointed that I wasn't told that I had HCV (as soon as it was known). I was 18 years old in 1994 and could reasonably be expected to be consuming alcohol from that time. Earlier information and advice to me would have changed my behaviour in relation to consuming alcohol in order to limit the risk of liver damage. Between going on the first round of unsuccessful treatment in 2005 and clearing HCV after a second round of treatment in 2012 I was completely teetotal.

Section 3. Other Infections

10. I received a letter telling me that I hadn't been exposed to 'at risk of variant CJD' batches of FVIII concentrate and do not have any other infections than HIV and HCV. Nevertheless it was very stressful knowing that yet another virus was risking the health of haemophiliacs.

Section 4. Consent

11. I believe I was tested for HIV and HCV without my (or my parents) knowledge or consent. The doctors just did what the doctors did. Generally blood tests were treated as routine without explanation of what they were for (at least before my HIV diagnosis). After my diagnosis my parents were tested with their consent - testing negative.

12. I do not believe that I was tested for research purposes. However, the 1991 litigation solicitor I used was not convinced an American product could be proved as the likely source.

Section 5. Impact of the Infection

13. The majority of problems I have encountered have been from infections due to the collapse of my immune system and the side effects of the many medications I have been on. An incomplete list of the medications I have been on is as follows. To treat my HIV I have been on: AZT, Lamivudine, Indinavir, Stavudine, Nevirapine, Atazanavir, Ritonivir and Descovy. For my HCV I have been treated with: Pegylated Interferon, Ribavirin, Prozac, Citalopram.

14. As a result of being infected with HIV I contracted PCP three times in 1996. Whilst in hospital with PCP I caught MRSA. To treat the PCP: Septrin (highly allergic), Dapsone (highly allergic), Atavaquone, Pentamadine (nebulised and IV). Lastly, and to treat my blood pressure, I have been on Ramipril and Amlodipine.

15. As side effects of the HIV medication I developed peripheral neuropathy and have been left with significant kidney damage (with about 40% of kidney function remaining). I have also suffered with nausea, lipodystrophy, ingrowing toenails caused by dry skin and nephrocalicnosis of the kidneys.

16. Prior to clearing HCV I suffered from occasional jaundice and developed mild liver damage. The most commons side effects I experienced from the medication for HCV are flu like symptoms, anaemia, depression, mood swings, brain fog, fatigue, low appetite and the thinning of my hair.

17. Sometimes its difficult to tell what side effects come from what, I have been on so many different treatments that they all just blur into one.

18. Psychologically and emotionally, I have pretty much always suffered with varying degrees of depression and anxiety. I have often isolated myself and lacked the confidence to have relationships with people. I have struggled to

do any regular work due to my repeated health setbacks, causing me always to play things as safe as I can.

19. Whilst I completed school and college, the uncertainty about my future stopped me from trying hard and doing all I could. Throughout school I had adult 'carers' accompanying me to my classes. The carers were with me I believe to reassure others: teachers; pupils and their parents and staff rather than being there for my own assistance and protection. The presence of carers at all my classes was like having a big flag flying over my head. It isolated me and all the pupils knew what was going on with me. At college I spent more time enjoying the fact that I no longer had adult carers with me. My A level results were very poor as a result albeit I got decent grades in my typing courses.

20. Having everyone know about my infection had it's up side and it's down side. It meant I didn't have to live a lie but children can be nasty and say horrible things. As a family we were always very open about my having HIV and tried our best to educate anyone who asked. When I was first diagnosed, about a quarter of the children at my school were taken home for a week or two until things could be explained to them. Our family dentist refused to treat me (and the rest of the family) so we had to move to another one. In the end only one family avoided me and my family. On the whole, I believe we were lucky to have such supportive neighbours, family and friends.

21. I managed to have about a year and a half of fairly good health and work after leaving college. I did warehouse work, data entry and sorting at the Post Office. The agency job I had taken had just offered me a full time position when I went down with PCP and spent a year in and out of hospital after which I tried getting back into work a few times without success.

22. The people that I became friends with at school are the people I am still friends with to this day. I find it difficult to make new friends and I have stuck with the friends I have throughout my life. Girls were never interested in me. I would be at a party and everyone would be drinking and wanting to play

games like spin the bottle. They would say 'not whilst he's here', referring to me. I would have to leave rather than spoil the fun for everyone else and I found that to be very emotionally damaging to my confidence levels.

23. My parents ran a local haemophilia support group. I used to go to Treloars College as an outpatient on a weekly basis for physiotherapy, socialising and swimming. I saw a lot of the boys there. I would have boarded there had my own school not been so understanding in keeping me on. I made friends at Treloars. I didn't know any other haemophiliacs apart from them. It was distressing to watch them die. Eventually the local group disbanded because of the amount of funerals we had to attend, driving a wedge between all of us.

24. Financially I was always aware of how uncertain my future was. At school I never saw myself having a future and never believed I would make it into the year 2000. I religiously saved the initial HIV and HCV lump sums and regular payments in high interest accounts so that when I moved out from my parents in my mid twenties I was able to buy a flat outright and live on the regular MacFarlane Trust payments while saving. I have had be very careful with my money. The current payments are sufficient but only because my outgoings are modest. I have never even tried to get life or travel insurance. I tend not to go on holidays. Had things been different I can't even imagine what my life would have been like.

25. When I was diagnosed it was a very hard on my parents as they had to deal with a huge amount of press interest whilst also caring for me. They had to work out a lot of new problems and come to terms with the uncertainty of how HIV would affect my future. I believe they handled it all incredibly well and were able to calm and educate many other people on my illnesses, even when they didn't have all the answers. My dad had some trouble getting time off work around this time. Later we had difficulty getting permission to on a family holiday to America, and during the legal action we took my parents struggled paying the monthly legal fees. My mum could have done without all the press attention. I don't think they regretted telling the school at all and

to this day I know they think it was the right thing to do. The doctors were so adamant that we should keep it all hush hush, and maybe it made my life a bit harder but in the bigger picture it educated other people.

26. I am unsure as to how much impact my diagnosis had on my sister (one and a half years older) as I was protected from a lot of it, being so young at the time. It must have been very stressful with the ongoing worry within the family. Occasionally, she would spend time away with friends to have some 'normal' time elsewhere. I know that when I was in the hospital for several months it was very hard on my family. At one time the doctors were preparing them for my death as they though I had only a couple of weeks left to live.

Section 6. Treatment/care/support

27. Growing up I was never offered any counselling or psychological support. I think it really would have helped me if it had been offered to me when I was a teenager and when I got out of hospital after the PCP. I was psychologically broken at the time but it seems that my doctors were focused on improving my test results rather than helping me as a person. I was told about three years ago at my clinic (now at Basingstoke) that they had some counsellers on their staff but I haven't seen them.

Section 7. Financial Assistance

28. I received the initial HIV lump sum and the Stage 1 Skipton Fund lump sum and have had the ongoing MacFarlane Trust payments. I now get the ongoing HIV and HCV payments from EIBSS. I think I was introduced to the MacFarlane Trust through my parents taking part in the 1991 litigation so our info was already 'in the system'.

29. I only made one application for a grant from the MacFarlane Trust (in or around 2008) for a new boiler and that was fairly straightforward once I had supplied them with three estimates.

30. I haven't had much to do with EIBSS thus far but they do seem to be more bureaucratic than the old schemes in their approach, sending a form back and forth asking me to complete the address section despite them having that information.

31. What I receive by way of income is manageable for me but I don't have anyone to support or any housing worries so I'm probably an outlier. I do feel that it was very bad that there has only been a regular payment for HCV very recently, with decades going without people getting regular support for their HCV infection.

Section 8. Other Issues

32. When I was reading through the Tainted Blood Timeline I was frustrated to come across the Minutes of the Haemophilia Centre Directors meeting for 17th October 1983. Dr. Chisholm (my own doctor) raised the problem of "patients refusing to take up commercial FVIII concentrate because of the AIDS scare". She wondered (in view of the worry of the patients) "whether the Directors could revert to using Cryoprecipitate for home therapy." Professor Bloom replied that he felt that there was no need for patients to stop using the commercial concentrates because "at present there was no proof that the commercial concentrates were the cause of AIDS". Dr. Chisholm pointed out that there was "a further problem in her region because of problems in getting large amounts of commercial concentrates whereas she could get unlimited supplies of Cryoprecipitate." Other Directors reported that they had the same problems. After discussion it was agreed that patients should not be encouraged to go over to cryoprecipitate for home therapy but should continue to receive the NHS or commercial concentrates in their usual way.

33. So, a year and a half before my infection my doctor had raised the correct concern and offered a solution and it was seemingly dismissed. As patients we weren't aware this discussion was taking place.

Anonymity

34. I am not seeking anonymity and I understand that this statement will be published and disclosed as part of the Inquiry. I wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... **GRO-C** ....

Dated...03/09/2019................