

Witness Name: Neil Anthony Armstrong

Statement No: WITN1078001

Exhibits: 0

Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NEIL ANTHONY ARMSTRONG

I, Neil Anthony Armstrong, will say as follows:-

Section 1. Introduction

1. My name is Neil Anthony Armstrong, of GRO-C
GRO-C. I was born on GRO-C 1977.
2. I was diagnosed with haemophilia A at an early age, as was my brother who is also a Haemophilia sufferer. My parents and my brother have also prepared written statements for the Inquiry (WITN1077001, WITN1623001 and WITN1079001).
3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I was very young when received Factor VIII so I cannot recall my treatments very well. I know that I was treated with the product whenever I hurt myself and had a bleed.
5. I received Factor VIII at St Richard's Hospital, Chichester under the care of Dr Bateman. I was also treated at Great Ormond Street Hospital by Professor Hadisty.
6. I was happy at my primary school but my parents wanted me to attend Treloars School because it offered specialist haemophilia care. Despite my resistance I started attending Treloars in 1986.
7. I recall that they had a medical centre in the lower school but the main haemophilia department was in the upper school, so if I had a bleed I would be taken there.
8. Dr Bateman at St Richard's warned my parents away from the American blood products and I don't believe I was given any at Treloars although I cannot be sure as I was only a child. I do remember that on one occasion I confirmed that I only have british treatment and Dr Roy commented to me that American products were the same as British products so it didn't matter but, despite my age I insisted that I only ever have British treatment.
9. I also received prophylaxis whilst at Treloars, although I tried not to as I was a child and did not want to receive injections every week.
10. I had my first positive test for Hepatitis B in 1984. I was 7 years old.
11. I was later told that I had also contracted Hepatitis C.

Section 3. Other Infections

12. I have been told that I may have been exposed to vCJD.

Section 4. Consent

13. I was a child when I was tested for Hepatitis and HIV. I do not recall being asked for my consent to testing and am unsure if my parents were asked to consent.

Section 5. Impact

14. My education definitely suffered attending school under such difficult circumstances. I was held back a year and moved into a class with severely disabled children, which obviously stifled my learning.

15. It was extremely difficult growing up in a school where all of my friends were becoming ill and dying. I lost my two best friends to HIV, one aged 17 and the other aged 19, and I think, to this day, I suffer from survivor's guilt that I am living with my wife and children whilst they were never given that opportunity.

16. I moved on to college where I tried to put that part of my life behind me.

17. It was extremely difficult to talk about my infection when I first met my wife, but fortunately she was very understanding.

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18. I have always tried to not to dwell too much on the illness, because if I did, I knew I would spend all of my time worrying. I did my best to live a normal life, whilst in the back of my mind I was always aware of how it could effect my life

expectancy. I am glad that I adopted this approach, as otherwise I wouldn't be where I am with my wife and children.

19. I received treatment for Hepatitis C in 2013. This consisted of Interferon and Ribavirin, and required injections into my stomach and tablets on a daily basis. I believe this treatment has left me with mild ongoing side effects.

20. I suffered from depression whilst undergoing this treatment, and to an extent, I still do, as it brought back all of the memories I had tried to suppress after leaving Treloars. I asked for counselling sessions to help me with this.

21. My family and I experienced financial difficulties when I was undergoing treatment as I was too ill to work.

22. I have never been able to obtain life insurance and the only reason we were able to get a mortgage was due to my wife's income.

23. I am very conscious of the stigma surrounding haemophiliacs and Hepatitis C. I am conscious of whether people wonder if I have AIDS, although growing up attending Treloars meant that I was somewhat sheltered from the stigma.

24. I can't have a liver biopsy so I don't know the real damage that has been done to my liver from living with Hepatitis C and B for 30 years.

Section 6. Treatment/Care/Support

25. I do not feel like I had to fight to be put on treatment. I was advised by my doctors to undergo the treatment before I was 40.

26. I was offered counselling around the time of undergoing treatment to clear the virus, however after one session the counsellor went on maternity leave and I wasn't offered a replacement.

27. I wasn't offered counselling at any time before this.

Section 7. Financial Assistance

28. I received a one off lump sum payment of £20,000 from the Skipton Fund.

29. I currently receive monthly payments from EIBSS.

30. In the past I have had some assistance from the Caxton Foundation, who would occasionally help with general household items. Although I didn't personally have a bad experience with Caxton, I did feel uncomfortable at the system of having to essentially beg for things and the extent of justification for each request, especially considering it was the government that put us into this position.

Section 8. Other Issues

31. I find it shocking what happened at Treloars School and I think it needs to be closely investigated.

Anonymity, disclosure and redaction

32. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated 16/12/2018

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

?.05.1978	Chichester District Hospital. Bruise to head. Initially cryo not given but mother was concerned. GOS contacted and eventually 2 units of cryo given.
06.05.1978	Chichester District Hospital. Bruise to chest. 2 units of cryo given.
15.05.1978	Chichester District Hospital. Admitted to hospital for haemophilia.
03.06.1978	Chichester District Hospital. 1 unit of cryo given for bruising.
18.08.1978	Chichester District Hospital. Fell yesterday and cut lower lip...2 units of cryo given.
06.09.1978	Chichester District Hospital. 2 units of cryo given.
11.09.1978	Chichester District Hospital. Known haemophilia sufferer. 11 ½ months. C/o bruise, inner aspect R knee. Both parents well. No FH of haemophilia. No miscarriages....At age of 8/52 had inguinal hernia operation. Queen Mary Hospital....post op continued...diagnosis of haemophilia made....Looked after by GOS where he got cryo approx. every 2 weeks....Needs cryo [for bruise] 2 units given.

10.11.1978	Chichester District Hospital. Seen on ward. Bump on head not increasing. Parents both want further blood investigations to confirm haemophilia as they feel it is not as bad as first thought. Discussed with Dr Robinson. To discuss with Dr Bateman. 10 am path lab 27.11.78 for further blood investigation.
13.11.1978	Chichester District Hospital. Dr Robinson. Notes missing. Prof Hadisty April 1978 haemophilia. No other details....Mother wants further blood investigation, feels diagnosis may be incorrect. Find notes. If not write to GOS for summary. Factor 8 assay repeated at request of parents <1% (surprise?). Letter to mother.
17.02.1979	Chichester District Hospital. Given cryo.
25.03.1979	Chichester District Hospital. Blood blister on tongue increasing in size over weekend. 2 units cryo given.
31.03.1979	Chichester District Hospital. Blood blister. 2 units cryo given.
14.04.1979	Chichester District Hospital. Cut index finger. Given 88288, 83528.
16.05.1979	Chichester District Hospital. Fell on outstretched hand yesterday. Given 31556, 30600, 30565 IV.

02.12.1979	Chichester District Hospital. Fell off sofa and injured R groin. 2 units cryo given.
24.01.1980	Chichester District Hospital. Haemophilia Review. Hep B antigen negative.
31.01.1980	Hep B test negative.
1984	Hep b test negative
05.02.1980	Chichester District Hospital. Bruise L foot. 2 units cryoprecipitate.
10.03.1980	Chichester District Hospital. Swollen finger, swelling L knee. 2 units cryo.
01.06.1980	Chichester District Hospital. Cut on foot and bruising. For 30 cryo.
04.06.1980	Chichester District Hospital. Cut lower lip. For 20 cryo.
23.06.1980	Chichester District Hospital. Fell down the stairs. R hip haematoma. 3 units cryo.
11.07.1980	Chichester District Hospital. Cut hand in playground. 20 cryo.

13.07.1980	Chichester District Hospital. Clot came off whilst playing football... 1 extra unit of cryo.
21.07.1980	Chichester District Hospital. Seen on ward.....given Sterispan 2 packs to use at home.
08.08.1980	Chichester District Hospital. Painful swollen ankle. 20 cryo. Needs blood grouping done.
09.09.1980	Chichester District Hospital. Pain/lump/swelling ankle this am. Cryoprecipitate.
06.10.1980	Chichester District Hospital. Swollen foot. 30 cryo.
10.11.1980	Chichester District Hospital. 2 units cryo.
13.11.1980	Chichester District Hospital. Bruise on femur. 2 units cryo given.
07.12.1980	Chichester District Hospital. Bruising to buttocks. 3 cryo given.
13.01.1981	Chichester District Hospital. Swelling R side of abdomen. Plan 2 cryo.
19.01.1981	Chichester District Hospital. Bit his tongue. Needs 20 cryo.

30.01.1981	Chichester District Hospital. Bleeding from roof of mouth. 20 cryo given. Factor VIII if possible.
31.01.1981	Chichester District Hospital. Bruise on lip. Plan 1 unit cryo.
01.02.1981	Chichester District Hospital. Admitted. Bleeding from roof of mouth started 29.01.81 to ward 30.01.81 for cryo 2 units given. Further bump on lip 31.01.81 continued bleeding from roof of mouth gave 1 unit cryo.
02.02.1981	Chichester District Hospital. Could have intensive cryo or wait and see. Decision wait and see.
Feb 81	Hep B negative.
Undated	Chichester District Hospital. Bleeding behind left upper tooth. Given 5 units cryo.
22.02.1981	Chichester District Hospital. Cut lower lip, bruise L upper arm. Cryoprecipitate x 3 units.
01.04.1981	Chichester District Hospital. Fell down stairs. Given 3 units cryo.
05.04.1981	Chichester District Hospital. Fell on bike seat. 3 cryo.
20.04.1981	Chichester District Hospital. Tender right forefoot. 2 cryo.
??05.1981	Chichester District Hospital. Swollen ankle. 3 units cryo.

01.06.1981	Chichester District Hospital. Coughed up blood. 2 units cryo.
07.08.1981	Chichester District Hospital. Bump to head. For 20 cryoprecipitate.
25.08.1981	Chichester District Hospital. Worried lump spreading. For 2 units cryo.
27.08.1981	Chichester District Hospital. Brought in by father for review. Took to Bournemouth Hospital yesterday for 2 nd opinion.....Given 2 units Factor 8 concentrate yesterday.....parents obviously worried about the difference in treatment given here and at GOS and Bournemouth Here - cryoprecipitate, tends not to be given as often.....told here that can develop sensitivity to factor VIII concentrate. GOS & Bournemouth – given Factor VIII conc and given for trivial bruises on cuts and arms. There told he will not develop a sensitivity to injections. Parents confused – don't know who to believe. Causing family upsets – arguing etc.
28.12.1981	Chichester District Hospital. Fell from bike to L knee. 2 units cryo.
01.12.1981	Chichester District Hospital. Returned. 2 further units cryo.
21.02.1982	Chichester District Hospital. Fell from swing today. 2 units cryo.

02.03.1982	Chichester District Hospital. Bruise to right shin and knee. 2 units cryo.
08.03.1982	Chichester District Hospital. Fell from swing. 2 units cryo.
20.03.1982	Chichester District Hospital. Fell off chair. 2 units cryo.
25.03.1982	Chichester District Hospital. Fell at school. 2 units cryo.
10.04.1982	Chichester District Hospital. Swollen shoulder. 2 units cryo.
20.04.1982	Chichester District Hospital. Bleeding from R EAM. 20 cryo.
25.04.1982	Chichester District Hospital. L knee. 20 cryo.
19.05.1982	Chichester District Hospital. We agreed in January that this child should have freeze dried factor VIII concentrate in future (see my letter to GOS). The parents were told. It cannot be food for their <i>[illegible]</i> on our reputation to know that since that decision he has been given cryoprecipitate.....
21.05.1982	Chichester District Hospital. Bleed left knee. 2 bottles Factor VIII given.
30.05.1982	Chichester District Hospital. Bruise. 1 unit Factor VIII given.

01.07.1982	Chichester District Hospital. Bruise left thigh. Factor VIII x 2 units.
08.07.1982	Chichester District Hospital. Swollen L knee. Factor VIII x 2 units.
16.07.1982	Chichester District Hospital. R ankle. 2350 Factor VIII given.
18.10.1982	Chichester District Hospital. R foot. Father insisted Factor VIII given. 2 units.
05.04.1983	Bloods taken for LFTs, HepAg, Hb, Antibody levels.
16.05.1984	Blood screen for Hep B
?? .10.1984	LFTs N. Hepatitis B antigen present.
06.06.1984	Hep B risk explained to father.
07.02.1985	LFTs normal. Hepatitis B antigen present.
07.03.85	Microbiology. Hep B positive 10.05.84. HTLV status unknown
11.03.1985	Hepatitis B positive. Given cryo (had been having Factor VIII before)

10.05.1985	Heat treated factor VIII.
Cryo given.	
26.08.85	Factor VIII dried?
29.08.85	Heat treated Factor VIII
17.07.86	Accepted for Lord Mayor Treloars for 07.09.86
16.04.87	Hep B positive antibodies. Microbiology report. Known Hep B carried bloods should be clearly marked! HbsAG DETECTED.
06.04.1987	Haemophilia Clinic. LFTs normal. Hep B antigen positive. HIV negative.
28.07.86	HTLV test neative .
19.12.95	HIV test negative.
04.97	Hep C under...????
01.08.97	Told him Hep B/ Hep C positive.
25.09.2002	Chronic hep c

09.03.2004	Letter confirming that they knew he was Hep C positive but this time.
24.11.2004	Letter confirming vCJD discussed.
27.11.2006	Letter confirming that received batch of Factor VIII in 1988 implicated with vCJD.