

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN2212002

Exhibits: None

Dated: 14th October 2020

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF **GRO-B**

I am giving this statement as a supplementary statement following my first written statement, which was provided in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

1. I refer to paragraph 3 of my first written statement and wish to expand on the treatment I received for haemophilia B, up until my diagnosis of HIV in 1985 and hepatitis C in 1991. I have received fresh frozen plasma as a young child of four, when I attended hospital for a bleed in my forehead. I am unsure on the details about what other treatment I received as a young child, however from the age of about seven or eight around 1976/1977, I remember that the treatment for my bleeds became easier and took less time to administer. This is the point I believe I started to receive Factor IX.
2. I started to receive home treatment with Factor IX in July 1982. Looking back at the evidence I provided during Penrose, Dr Lowe, who was then Senior Registrar, wrote to my GP advising him that I had commenced home treatment of Factor IX concentrate at this point.

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3. I refer to paragraph 4 of my first written statement. This incorrectly states that I do not know the names of the doctors who treated me at Yorkhill Hospital and Glasgow Royal Infirmary. I wish to clarify that I was treated by Dr Willoughby when I was a patient of Yorkhill Hospital, however I can't recall ever meeting him. When I turned fourteen, I was referred by him to Dr Forbes at Glasgow Royal Infirmary. My notes also refer to Mr Connor of the Orthopaedic Department at Yorkhill hospital being involved in my care from November 1979.
4. I would receive treatment when I had a bleed or before dental procedures. I was receiving physiotherapy at Yorkhill Hospital after a football injury in 1980. As I had long term knee problems, by 1982 when I was being treated at Glasgow Royal Infirmary, I was instructed to treat myself with regular weekly doses of Factor IX before physiotherapy sessions. This was over a three month period in 1982. When I took Factor IX prophylactically, I would note the details down in a record book for the hospital and submit this every time I collected more treatment from the Haemophilia Unit.
5. I refer to paragraph 6 in my first written statement. This incorrectly says that I was diagnosed with HIV and Hepatitis C in 1981. In December 1985 when I was around nineteen years old, I received a telephone call from Professor Lowe asking me to attend the Haemophilia Unit. I was advised during this appointment that I had tested positive for HTLV-III. I found out that I had been previously tested for HTLV- III in January 1985 which had come back negative. My seroconversion took place between January and November 1985. I knew there were various regular tests that occurred when I attended the clinic but I was not aware that this was one of them. I was under the impression that there were regular tests to check my factor level and tests conducted because of the concern about Hepatitis A and B.

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6. In my medical records, my diagnosis appointment in 1985 is recorded as "counselled re HTLV-III positivity and NANBH". This suggests that I was spoken to about having Non-A Non-B hepatitis at this point. I was not.
7. My memory of when I was diagnosed was that it took place in 1996. During the Penrose Hearings it was put to me that hepatitis C was discussed with me in 1991 at an appointment with Professor Lowe which I attended because of an injury to my toe. It was noted in the Hearings in 2011, that during this appointment in 1991, Professor Lowe recorded that I was positive to an antibody to hepatitis C and that this was the probable cause of my chronic hepatitis.
8. I refer to paragraph 14 in my first written statement. I wish to expand on the lack of information provided to me when I was providing regular blood samples to the hospital. When I provided evidence to the Penrose Inquiry, it was noted that in 1982, there was a handwritten note discovered in my medical records that said, "? Non-A non B hepatitis". No one ever discussed this with me or my parents in 1982.
9. I refer to paragraph 15 in my original statement, this incorrectly states that I was seventeen when I was diagnosed with HIV. I was nineteen years old when I was diagnosed with HIV.
10. I refer to paragraph 16 of my first written statement. I wish to expand on the point that. I was not aware of the existence of any treatment for Hepatitis C until 2000. Until then, my understanding was that doctors would continue to monitor my liver function test regularly and was to maintain a healthy lifestyle. I was under the care of Dr Alan Pithie from 1996 until Dr Andrew Seaton took over from him in 2000.

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11. During my review in 2000, it was discussed with me that while I had no symptoms that were attributable to HIV, my viral load had dropped a bit and my CD4 count had risen. I was experiencing symptoms of breathlessness, weight loss and night sweats. I was advised that it would be worthwhile treating the Hepatitis C if my liver biopsy result significantly changed. I was advised that it would be better to start treatment for hepatitis C before I required antiretroviral treatment. It was established when considering my treatment options, that I was genotype 3. I did not start treatment at this point.

12. I refer to paragraph 19 of my first written statement, I wish to expand on my HIV treatment. I made the decision to commence treatment in 2002. My CD4 count had dropped significantly at this point. I discussed the HIV treatment options with Dr Seaton and there was a concern discussed that commencing hepatitis C treatment first at this point, would likely lead to a further drop in my CD4 count. I therefore commenced treatment with Efavirenz and Combivir in September 2002 and tolerated this well.

13. I refer to paragraph 18 of my first written statement to expand upon my hepatitis C treatment. I started Hepatitis C treatment in January 2004 taking a course of Interferon injections. I also started taking weekly treatment to boost my red blood cell count as I had become anaemic. I started taking a weekly injection of erythropoietin for this. By the end of the hepatitis C treatment in December 2004, the virus was undetectable. I was advised that if the virus remained undetectable for two years I would be cured. I was advised that I was cured in 2007.

14. In October 2008 my antiretroviral therapy was modified from Combivir to Kivexa due to concerns about the potential long term impact of taking Combivir. I tolerated this change of treatment well.

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15. I refer to paragraph 26 of my first written statement which incorrectly states that I was absent from work for three months. I managed to continue working for the first eight months of treatment and I then had to take the last four months off work, due to the side effects.
16. I refer to paragraph 29 of my first written statement that discusses counselling my wife and I attended, when we explored our options with having children. My wife and I were unable to expand our family naturally as a result of the infection. I feel as though if it had not been for the HIV, we would have had more children.
17. In 2011 when I gave evidence to Penrose, our daughter was unaware that she was not conceived naturally. We were unsure on what the best way to approach this would be. We contacted the Brownlee Centre and the Macfarlane Trust to enquire if there was a way we could explain things to her. I was advised that there was no specific information tailored to children that they could assist with at this point. Since then we have discussed matters with our daughter and she is aware of the situation.
18. The support in the Brownlee Centre has been excellent. My wife and I have been wary about moving away from where we live because of the support system that we have set up for my treatment.
19. My wife and I funded two attempts at donor insemination and our daughter's conception was funded by the NHS. We also received a grant from the MacFarlane Trust for one attempt to have a second child.

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20. I refer to paragraph 30 in my first written statement which states that I was unsure when I started to receive money from the MacFarlane Trust. I started receiving support from the MacFarlane Trust in 2007.

21. I refer to paragraph 37 of my first written statement about the evidence I gave during the Penrose Inquiry. I provided evidence in Penrose under the pseudonym of "David".

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Statement of Truth

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

Signed

GRO-B

Dated Oct 20, 2020