

Witness Name: Maurice Midgeley

Statement No.: WITN1938001

Exhibits: WITN1938002 -

WITN1938013

Dated: 26 June 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MAURICE MIDGELEY

Section 1. Introduction

1. I Maurice Midgeley will say as follows. My date of birth is GRO-C 1959. My address is known to the Inquiry.

Section 2. How Infected

2. I have mild Haemophilia A. It is hereditary, GRO-C, my two brothers GRO-C also had it. I was diagnosed when I was a teenager.
3. Because I have mild Haemophilia I do not always need to have treatment, when I hurt myself as a child I was ok without having blood products. I did not have any treatment for bleeds until I was about 18 and was given cryoprecipitate after having teeth removed at Kings College Hospital. After that I was given cryoprecipitate on several occasions for various injuries.

4. I was a patient at the Lewisham Hospital Haemophilia centre. If I had a bleed or cut myself I would phone Lewisham to say that I was coming in, they would take the Cryoprecipitate out of the freezer and so it would be ready for me when I arrived. I lived about 25 miles away, so it would take about an hour to get to the hospital. Once I arrived at the hospital a doctor would assess whether I needed the Cryoprecipitate or not. I did not always need it; there were other treatments available for bleeds at that time. Sometimes I would be given DDAVP/Desmopressin tablets or Tranexamic acid tablets; sometimes they would tell me to use an ice pack for bruising.
5. I was first given Factor VIII on 12 May 1983. On the day in question I had bruising to my forearms. I can't remember how I had injured myself. I called ahead to Lewisham Hospital as usual and told them that I would be there in an hour. When I arrived, my usual haematologist Dr Whitmore was not available, so I saw GRO-D. She has now retired.
6. GRO-D told me that they had forgotten to take the cryoprecipitate out of the freezer but that they had a new product called Factor VIII which she could use instead. She did not give me any information about this new product, or even ask if I wanted to try it instead of my usual treatment, she just gave it to me. My medical records state that I returned to Lewisham Hospital later that week for further injections of Factor VIII on 16, 17, 18 & 19 May 1983. I cannot recall returning to the hospital for these injections, however I may well have done. It was such a long time ago that I cannot remember clearly. All doses were taken from batch number 811110A011A.
7. GRO-D did not tell me about any risks of using the Factor VIII. I was injected with it and that was it. If she had told me there was a risk of anything I would have said no to this new product and would have just gone home. Anyone in their right mind would have done the same.

8. I am a mild haemophiliac, if I was a severe haemophiliac I would have needed to have had treatment but I did not even need any blood products that day. I could have been given DDAVP tablets or Tranexamic Acid tablets. These methods do not stop the bleed as quickly as if you have Factor VIII or Cryoprecipitate but they can be used instead. My condition that day was not life threatening, they could have given me any of these treatments.
9. The Sister used her own judgement to give me a product that I did not need, my injury was not assessed by a doctor. If GRO-D had checked my records she would have seen that in the years beforehand I had suffered several injuries including a puncture wound on my left wrist and a laceration over my right wrist and elbow, neither of which required treatment with blood products. These were more serious injuries than the bruising on my arms but both healed without the use of blood products.
10. About four weeks after receiving the Factor VIII I suddenly felt really ill at work, I was so lethargic and tired. I felt so ill that I went to a GP after work that day. The GP sent me for blood tests; one was a liver function test. I returned to see him around one week later for my results. He told me that my ALT levels were high, seriously high. My ALT level was 1431 U/L **[WITN1938002]**, a normal level for a man would be 42 U/L. My GP told me that I had raging hepatitis.
11. I went straight up to the Lewisham Haemophilia Centre. I saw Dr Whitmore who looked at my results and told me that I had non A non B hepatitis. I did not know what this meant, I did not know what it was.
12. I was not admitted to hospital. No one suggested any treatment at all. I was not given any other information about what non A non B hepatitis was, how to manage the condition or any risks of passing it to others. Dr Whitmore wrote to my GP on 28 June 1983 asking him to repeat liver function tests in four weeks or so **[WITN1938003]**. Around 3 weeks later my GP repeated the liver function test. This showed that my AST level was still very high at 773 U/L. I was not informed of these results at the time **[WITN1938004]**.

13. My medical records include a document titled Hepatitis Survey Form C1 & C2 [WITN1938005]. This document indicates that Dr Whitmore reported my development of hepatitis and details of the batch of Factor XIII that I had received to the Oxford Haemophilia Centre.
14. I was ill for several months, I lost a hell of a lot of weight and was jaundiced, my skin was totally yellow. The tiredness was severe, it was totally debilitating. I felt as if I had been poisoned, I was being sick all the time. I was unable to work and could not do anything. I have a photograph of me from that time; I look as though I have been in a concentration camp. The hepatitis made me look and feel so ill.
15. After around three months I started to feel better. I don't know if I was back to normal but I felt better than I had done. After being that ill it is difficult to remember where you started, all I knew was that I felt better than I had done. I may have still felt tired but I did not associate it with hepatitis because I had been told that I was fine.
16. I went to see Dr Whitmore who said there was good news and bad news. The good news was that I was over the infection; the bad news was that part of my liver was damaged. But he said that the damaged part would regenerate and so there was no bad news really. I accepted that what he said to me was the truth and went on my happy way.
17. I was told at the time that the infection probably came from the Factor VIII. We all know now that it definitely was the Factor VIII. I was so concerned after that and I was adamant that I was not going to have Factor VIII until I could be sure it was safe. I had to have blood products several times after May 1983, I was offered Factor VIII but always refused it and asked for cryoprecipitate instead. There was no way that I wanted to have hepatitis again, I felt that I could not go back to how I felt for the months that I had been ill.

18. My medical records include a list of the blood products that I was given from May 1983 until September 1998 at Lewisham Haemophilia Centre **[WITN1938006]**
19. In September 1984 I had to have my appendix removed. The operation was covered with cryoprecipitate. After being discharged my wound start to bleed, I returned to hospital and again was treated with cryoprecipitate **[WITN1938007]**
20. In 1989 I fractured my right ankle, I was offered Factor VIII which I only accepted after being assured that it had been heat treated.
21. I have an annual review appointment at the Lewisham Haemophilia Centre. This is a general check-up, where they ask about aches and pains and any other issues. They take blood tests and say that they will be in touch if there is a problem. I did not attend my annual appointment between 1989 and 1993. I had no reason to think that there was anything wrong; at earlier appointments I had been told that everything was ok. I occasionally had a pain here or there and sometimes felt sick or unwell but I thought it was the norm.
22. I have since found out that the results of blood tests taken at appointments in 1985, 1986, 1987 & 1988 showed that my ALT remained significantly raised **[WITN1938008]**. I understand that these results indicate an ongoing hepatitis infection. I was not informed of these results at the time, as far as I knew I had been cured of the hepatitis. My medical records indicate that I was tested for hepatitis B in 1984 and 1987 **[WITN1938009]**. I was not aware that I was being tested for hepatitis B at this time. I know now that the knowledge about hepatitis non A non B was growing over this time yet I was not warned that could still be infected with this virus.
23. In August 1992 and in May 1993 I received letters from the Haemophilia Centre **[WITN1938010]** asking me to contact them if I wanted an appointment. Both letters refer to the risk of being exposed to an infection through the use of blood products. Both were generic letters and looked like they had been sent out to a number of patients. Neither letter seemed to apply to me specifically, neither

made any mention of test results from earlier appointments. I remember receiving these letters but I did not think that I was at risk. I had been told by my doctor that I was healthy and had nothing to worry about, I had no reason to dispute the advice of these professionals. I did not phone to make an appointment. I felt that if there was nothing wrong with me then I did not need treatment and should not waste their time.

24. In March 1994 I went to the Haemophilia Centre because of a problem with my ankle. I saw a new Haematologist, Dr Dudley. During the appointment I had a blood test. A few days later Dr Dudley phoned me at my place of work. He said that I needed to get up to the Hospital quick. He told me that I had Hepatitis C and that my condition was quite serious. He said that he would be sending me a letter but that he wanted to tell me the result over the phone. He was stressing the urgency because it was clear that I had had the infection for such a long time.
25. I went up to the Haemophilia Centre the following day for an appointment with Dr Dudley. He said that I could end up needing a liver transplant and that my life was at risk. He did not hold any punches; he told me how it was. He set out exactly how we were going to proceed. He was very explanatory, he could not sugar coat it. He gave me a brochure with information about the infection.
26. I do not recall being given any advice or information about the risks of passing the infection to others during this appointment.
27. I could have shouted and cried but it would not have made any difference. I could not change anything. I believe that Dr Dudley gave me the best information that he could at the time. He was very caring about the people that he treated; he was a very nice man. I was angry when I found out that I had not been told about my abnormal results from the tests taken between 1985 and 1988. I felt that I had been lied to for years, Dr Dudley was the one who finally told me the truth.

28. I should have been told about my diagnosis earlier. As soon as they knew that non A non B hepatitis was something more serious they should have told me. I would feel terrible if I had passed the infection on, I would not want anyone to go through what I have been through.

Section 3. Other Infections

29. I was infected with hepatitis A as well as hepatitis C. Maybe they gave it to me at the same time, I do not know. They told me that I had hepatitis A at the same time that they told me that I had non A non B, it may have been from the same batch of Factor VIII.
30. In July 2009 I received a letter from Lewisham Hospital explaining that I was at an increased risk of vCJD. It said that evidence of vCJD had been found during the post mortem examination of a person with haemophilia. I later received another letter stating that there was a risk that the equipment that had been used during one of my operations, had previously been used to operate on a patient who was later known to develop vCJD. This letter stated that regular sterilisation of the equipment does not kill the vCJD proteins and therefore there is a risk that these could have been passed to me.

Section 4. Consent

31. I think that they knew what they were doing at the time but did not want to tell us that they were doing it. They had to find a cure for what was happening globally, we were not given a choice. They used us as Guinea pigs. That's why I think someone should go to prison for a long long time. I would be sent to prison if I infected over 4,500 people, and caused so many deaths.
32. That day in 1983 the staff at Lewisham Hospital could have got the cryoprecipitate out of the freezer like they had always done before. This time though they decided that they would use the Factor VIII. They knew at the time

the risk of us catching something through Factor VIII, they should have given us a choice. We now know that all haemophiliacs who were given Factor VIII at that time, developed either non A non B hepatitis and some developed both non A non B hepatitis and HIV.

33. In the years afterwards they knew something was wrong with me but they did not tell me. Why would they not tell me year after year? I think that they knew what they were doing but they did not think that it would lead to what it has done, with so many people infected and dying. I do not know what was in their minds or why they did not tell anyone, maybe they panicked, or maybe they thought it would never come out.
34. I do not know why Dr Dudley told me when others had not, maybe he had a conscience. Perhaps he could not sit by and let people think that they were healthy when they were not.
35. There are generic letters in my medical records which describe the financial constraints that the haemophilia centre was under in 1986. These letters state that there would be a reduction in the number of Senior House Officers available. The letters are signed by Dr Whitmore, in one dated September 1986 he states *"may I say how much I regret this deterioration in the service which has been forced upon us for financial reasons"* [WITN1938011]

Section 5. Impact

36. In the years before I was diagnosed I always felt a little bit tired and sometimes a bit sick but I did not really think anything of it. I realise now that these symptoms may have been caused by the hepatitis C.
37. When I was diagnosed I was so worried about the future and about what would happen to my wife and children. Both of my brothers were also told that they had been given hepatitis C through contaminated blood, I just could not believe

that all three of us had been infected. Both of my brothers have passed away as a result of being infected with hepatitis C.

38. Hepatitis affects the gall bladder; both my brother and I had our gall bladders out. I had the operation in 2000, the surgeon did not put enough stitches in and I had to be rushed back in to theatre as 4.5 litres of bile had leaked into my abdomen. I spent over four weeks in hospital, including a week in intensive care and a week in HDU. After recovering from this operation I had further problems, I had to have a cystoscopy and there were issues with the scar from the operation.
39. In March 1994, within a few days of Dr Dudley telling me that I had hepatitis C I was put on Interferon Alpha. I did not face any difficulties or obstacles in accessing this treatment. At first I was given 3 mega units three times per week which I had to inject myself. I took this dose for over a year however it was not working. My dose was increased to 4.5 mega units but I could not tolerate it at this level. My symptoms just got so much worse and after only a few months the dose was reduced again. I continued to take interferon but my liver function tests kept coming back with abnormal levels. The interferon was eventually stopped in April 1996, I had been on the treatment for over two years.
40. I know that at the time that I was having treatment, Interferon was quite an experimental drug. My medical records indicate that my doctors found out in March 1995 that I had HCV genotype 1B [WITN1938012], which I understand is quite virulent and aggressive. In April 1995 I was informed that the hepatitis genotype I have is the least likely to be responsive to standard course of interferon. The letter states It is therefore not surprising that the tests in your case have remained abnormal inspite of having Interferon three times weekly [WITN1938013]. My doctors continued to treat me despite the horrible side effects that I was dealing with and with the knowledge that the treatment was likely to be unsuccessful.

41. For the two years that I was on Interferon I was a totally different person mentally and physically. I had really bad mood swings. I had diarrhoea, nausea, retching, stomach cramps, loss of appetite, weight loss, hair loss, sore eyes, itchy skin, tiredness, fatigue, headaches. The list of side effects goes on and on.
42. I became very depressed, I often found it difficult to sleep and had recurrent nightmares. I felt suicidal at times. If you can't see the light at the end of the tunnel, it gets to a stage where you just think what is the point.
43. After two years of being on interferon they suggested that I start on a new drug called Ribavirin, the plan was for me to take this on top of the Interferon. Ribavirin was unlicensed at the time. Eventually they changed their minds and it was not prescribed. I think it is fortunate that I did not start taking it; I think it would have made me feel more depressed and suicidal.
44. In January 1996 I was found to be HCV RNA negative. In April 1996 I was referred for a liver biopsy, this was a very painful procedure. A few hours after the procedure they told me that the sample taken had been from my diaphragm only and that no liver tissue had been taken, so it had all been for nothing. However as I remained RNA negative I was told that I could stop taking the interferon.
45. I get days now when I don't feel great. The virus is currently undetectable but I still feel the effects of the damage that it did to my body. In 2000 I had another liver biopsy, this time it was successful and showed mild chronic hepatitis with mild fibrosis. I have been told that the hep C virus is now undetectable however I still go for a check-up every year.
46. As a family we suffered collectively. When I was diagnosed in 1994, my wife and I had four young children. I had to be careful around my family, if I shaved and cut myself I had to be careful not to kiss them. All of my children wanted to

kiss me, we had to be so careful. I had to wrap them in cotton wool a bit more, life did change.

47. When I went out I did not feel as confident as I had done before, even when I drank out of a cup the risk of infection was in my head because I had been told to be so careful about what I did. It has impacted my life but also my wife's life and my children's lives. It had an effect on what we could do and what we couldn't do. I could not take them out to play football, or down the park to mess about on the swings just in case I cut myself. I feel that I missed out on spending this time with them.
48. Sometimes if I went in the car I did not want to travel long distances, I used to get panic attacks when I was too far away from the comfort of my home. There were some people who had it worse than me. As a family we did have good times, but particularly while I was having treatment there were more bad times than good.
49. When I started taking interferon it was quite dramatic for my family. I was like Dr Jekyll and Mr Hyde and would take everything out on them. How my wife and I stayed together at that time I do not know. I was the most horrible person; my eldest son took the brunt of it. I was always shouting at him. I can't take that back now, it is in the past but I would change it if I could. I kept a diary at that time, my daughter found it recently. It was hard for both of us to read and remember how I was feeling back then. It had a knock on effect on everyone.
50. When I was first diagnosed I was treated differently because of the Hepatitis C, a kind of hands off sort of attitude. In 1994 when my wife was in labour with our youngest child, the staff found out that I was a haemophiliac and that I had previously had hepatitis. They moved her to a private room straight away and she had to have extra blood tests. I found this strange and did not understand why the staff would need to take these steps. This was before my diagnosis of hepatitis C; as far as I was aware I did not have non A non B hepatitis anymore.

51. When you say HCV people hear HIV and they associate the two. When people know that you have it, it does have an effect on the way they are towards you, that is human nature. It has got better over the years, HCV is more common now and people know it is not the worst thing in the world. The stigma does not stick as much anymore.
52. I do not think that there has been an impact on my wife and kids because of the stigma. Only the people closest to us know about the situation. We don't shout about it, it is not something that I am proud of. Some of my friends know, I explain that it is not something for them to worry about and my really good friends are quite understanding about it. But you never know what people think or say privately.
53. While I was on Interferon I was working for a large company. They knew that I was on a drug which would affect the way I worked, they were very understanding about the whole thing. However in late 1996 I was made redundant. I do not think that this was because of the hepatitis; the company was just making cut backs.
54. I also had a part time job working early morning shifts delivering newspapers. I had to give this up in 1995, the interferon made me feel so exhausted that I could not work in the way that I had done before.
55. After that it was so difficult to get a job. At the job centre I had to tell them that I was a haemophiliac and that I had previously had hepatitis. I was never given a job. On many occasions I made the shortlist but the job always went to someone else. Whether it was because of the hepatitis or not, I don't know. In the end I had to start my own business and work for myself because no one would employ me. I had been out of work for around 1 year by that point.
56. It was very difficult to set up by myself at that time. I was on benefits because I had been out of work for so long and I hardly had any money to build up the

business. I had been given £10,000 for my redundancy which kept us afloat, otherwise we would have lost the house and gone under.

Section 6. Treatment/Care/Support

57. I have not faced difficulties in obtaining treatment care and support. I do not recall counselling or psychological support ever being offered to me. I think that counselling would have been helpful both for me and for my son.

Section 7. Financial Assistance

58. I was sent a letter in 2004 stating that because I had been infected with Hepatitis C I was entitled to a payment of £20,000 from the government. Those who had been infected with hepatitis C and HIV were entitled to a payment of £40,000. If we went on to develop liver cancer we would be entitled to another £20,000 but that first payment was it for me.
59. The letter made it clear that this was all the money that we would get. We were told in no uncertain terms that we would not be able to come back and ask for more; that was that, it was a first and final payment. They did not accept that this payment meant that they were admitting any fault. I felt at the time that this was a cheap solution for them; I could have been given more if I had had an accident in a factory.
60. I had to fill in a few details like my NI number and my hospital number and return the form. They probably knew that I had hepatitis C because I was registered as a haemophiliac, I thought that these letters went to everyone that was infected. I think they made it easy for us to apply for the money because they wanted it to be easy for them.

61. When EIBSS took over from Skipton I started to receive monthly payments of £252, these payments have now gone up to £333 per month. I haven't received any other financial assistance as yet.
62. I think that the difference in payments made to those infected with hepatitis C and those infected with HIV is unfair. At the time HIV was thought of as being more serious but in the scheme of things we all should have got the same. We were all infected at the same time. Regardless of what we got, we were all given an unsafe product without our knowledge which led to an infection. We were all given a ticking time bomb which we have had to live with.
63. I do not think that the payments made are adequate. No one knows how long anyone's life is going to be. The money from Skipton and EIBSS helps a bit but I tried for a year to get a job, if I had not been able to work for myself I do not know where I would be.

Section 8. Other Issues

64. Soon after my diagnosis I started legal action against the South East London Healthy Authority which was responsible for Lewisham Hospital at that time. I was never given a choice about whether to have the factor VIII or not and I was not told of the risks. When I found out that my life could be cut short I wanted to find a way to pay off the mortgage so if I passed away my wife would not have to worry.
65. When my solicitors obtained my records they found that there were relevant pages missing, some of the information had been doctored, there were irregularities in the paperwork. I don't any longer have the details of these irregularities.
66. Eventually after about 5 years of working on the case, my solicitors said that they could not continue. The first expert to write a report for the case had been

supportive and had said that I should not have been given the factor VIII in 1983. However he was later sued for giving factor VIII to a patient and therefore my solicitor said that his credibility was flawed. The next expert was of the opinion that it was current practice to give out factor VIII at that time without warning people of the risks. My solicitors warned me that this may weaken the case but my barrister was willing to go ahead and we nearly went to trial. However at the last minute he had to declare a conflict of interest.

67. The next barrister that was instructed had a different view of the case. His advice was that anyone who was infected before 1998 would be unable to bring an action for negligence as before that dated cryoprecipitate was not generally available. However this advice was not accurate as I had been given Cryoprecipitate many times before 1988 and I know others were too. I was getting Legal Aid, the new barrister said that he was not willing to spend any more of the public purse on my case. My solicitors said that they could not carry on.
68. I was absolutely gutted. I felt that my rights were being abused because no one was taking any notice of what I was saying. I went to the court in Maidstone and asked them to help me to refer the case to the European Court of Human Rights, they said that this was not the type of case that could go to that court. I applied anyway and received a letter stating that my application had no prospects of success. The case had been going on for years, to be told after all that time that it was going nowhere and to get nothing at the end of it was really hard.
69. More recently I took part in an action against Baxter Healthcare, the manufacturer of the batch of Factor VIII that I was given in 1983. I had solicitors who later informed me that they could no longer offer me a no win no fee agreement. I tried to continue the case on my own and represented myself at a hearing in front of a High Court Master, Baxter Healthcare had sent five barristers to represent them. The Master gave me one month to obtain a full medical report in support of my case but I could not find an expert who would

help me. Baxter Healthcare sent one of their barristers to my house with a cheque for £4,000. I had no choice but to take it, there was no way that I could have carried on with the case without lawyers on my side. I felt at the time that this was the only money that I was ever going to get. The barrister asked me to sign a letter preventing me or any member of my family from taking action against them again.

70. I have tried every avenue to try to hold someone accountable for what has happened. I do not feel as if I have anywhere left to turn.
71. I expect the Inquiry to find out the whole truth, to try to make sure that the people responsible get what they deserve and to make sure that proper compensation is paid out to those infected. The people infected in Ireland and other people around the world got a reasonable amount of compensation, we got £20,000. It is not always about the money but if you don't punish people with money then they don't learn the lesson
72. The Archer Inquiry went on for years and the people infected got nothing, the Inquiry led to nothing. We seem to have been here so many times, I doubt that it is ever going to happen but it would be nice to put it all to bed once and for all.
73. For this Inquiry I think it is important that there is no interference from government. Regardless of what they have said about being open and fair there are lots of us who have doubts about it. The Chair may make recommendations but whether he will actually be allowed to enforce these is another thing. We all hope that the government will take note of what he says and what he recommends but I am sceptical.
74. I have some old footage of a doctor talking on the news about contaminated blood. He says that if there was a major incident then they would use this blood if it meant that they could save people's lives. But giving someone contaminated blood is not saving their life. These infections last forever. Death

from a car accident is quicker; a person will suffer a more lingering death if they are given the contaminated blood. I believe that if a doctor says stupid things like that he should not be in his job. I have recently found this footage but it is on a VHS. If I can find someone to convert it to CD or a digital file I will provide a copy to the Inquiry.

75. They lied to me from the beginning. They knew that the risk of me being infected was huge. The biggest thing of all was that the government and health professionals would knowingly do this to us, they are supposed to look after you. You accept what a health professional says to be in your interests.
76. They did not give me any information for seven or eight years and then the doctors suddenly told me the truth. All that time they had kept the truth from me, they let me carry on with my life thinking that there was nothing wrong with me. That is not fiction that is fact.

Statement of Truth

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

Signed..

GRO-C

Date.. 26/6/2020