

Witness Name: Gary Neil Berwick

Statement No.: WITN0895001

Exhibits: **NIL**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GARY BERWICK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 February 2019.

I, Gary Neil Berwick, will say as follows: -

Section 1. Introduction

1. My name is name is Gary Berwick. My date of birth is GRO-C 1965 and my address is known to the Inquiry. I am married with two children and I am currently employed by an electrical wholesaler.
2. I intend to speak about my infection with HIV, Hepatitis B Virus ("**HBV**") and Hepatitis C Virus ("**HCV**"). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

3. I was diagnosed with severe Haemophilia A when I was 6 months old at St George's Hospital in Tooting ("**St George's**"). My condition is considered severe because I have less than 1% of normal Factor VIII activity levels in my blood.
4. As a child, I would attend Crawley Hospital to be treated with cryoprecipitate when required. I recall them using large blood bags, much bigger than anything they use now. I was treated by Dr Pead at Crawley Hospital until 1980, when I moved out of the paediatrics ward at Crawley to St George's.
5. I recall the hospitals suggesting that I attend Lord Mayor Treloar College, however I did not want to go there and my parents did not want me to either. It was a long way from home and I do not think that I would have coped with it very well at that age. I believe that a lot of the people who attended Lord Mayor Treloar College were using prophylactic treatments and I understand that this may have led to difficulties for many of those people later in life.
6. When I was 15 years old (1980), I started using Factor VIII home treatments as it saved us making any trips up to St George's. We were initially treated by Professor Flute at St George's and he taught me how to administer the home treatments. My older brother, Graham Berwick, is also a severe haemophiliac and we would use the same batches of Factor VIII. I'm unsure what the treatments were called, however I would generally need them on demand once every couple of weeks.
7. Sometimes I would be required to take extended periods of time off from school because of my haemophilia. If I was required to attend the hospital to be treated, it would generally take me a lot of time to recover. Over my final five years of high school, the amount of time that I was absent from school due to haemophilia related illness was equivalent to one whole year.

8. I was diagnosed with HIV at St George's in February 1985. It is entirely possible that I had these infections prior to 1985, as I am unsure when they actually started testing for it. I had no idea about what it was or what it meant and I am not even sure if the doctors did either.
9. When I was diagnosed, I was seen by Dr Bevan (who had just taken over from Professor Flute). I am unsure why Professor Flute left St George's and it is hard to know whether or not he was hiding something by leaving. It may very well have been a straightforward retirement due to old age, but it may also have been the case that he knew something or was trying to blow the whistle. It is too long ago to know. Dr Bevan had quite a straightforward approach and he was a very good man.
10. Graham, Anita (my now wife) and I attended St George's together when we were diagnosed. Anita and I had only recently started dating at this point, so it would have been quite a confronting experience for her. I went in to Dr Bevan's office with Anita when he gave us the news. He did not provide us with a lot of information, he just told us that I had returned a positive result and that there was a possibility that I had been infected some time before the diagnosis.
11. I was later diagnosed with HBV and HCV; however, I am unsure how much time had passed since being diagnosed with HIV. In any event, the circumstances remained the same – I was seen by Dr Bevan at St George's and I was given little information about the diagnosis.
12. Looking back now, there was no real way for me to pinpoint the moment that I was infected. I do not recall a time where I felt different or had any symptoms – nothing really stands out to me.
13. At the time, Graham and I tried to figure out whether there was a batch of home treatments that we had not shared, but we were not sure. We do not have our home treatment records from back then, but I think they might be at St George's. We used to have to take our records up to St George's

every six months when we had our regular check-ups, but now we just load them onto the computer.

14. We were not really given much information about the risks of infecting others or any kind of precautions that we should be taking. We just left the hospital and continued living our lives.
15. I think that it must have been the Factor VIII that caused my infections, as the cryoprecipitate that I was given was British and I think that St George's was almost self-sufficient by then.

Section 3. Other Infections

16. I have not received any infections other than HIV, HBV and HCV. I think that most of the problems I experience now are likely just long-term side effects of the treatments I have been on in the past.
17. There is a possibility that my organs could begin to struggle later in life due to the treatment I have been taking, but you will not know until it happens. At the moment everything seems fine, but there is certainly a chance that it could happen later.

Section 4. Consent

18. I do not believe that I have been treated without my consent or for the purpose of any research. I was usually fully informed about those things the whole time.

Section 5. Impact

19. After I received my diagnosis, there were no major changes to my lifestyle. No one really knew what HIV, HBV or HCV was at the time, but we certainly had some idea that it was pretty serious. We knew it was likely that I would have a shorter lifespan and that treatment was going to be a

long way off, but I did not really have any information to help me deal with it properly at the time of diagnosis.

20. I continued to work following my diagnosis and I just carried on with my life. My relationship with Anita continued and we remain together to this day. I have remained very secretive about my diagnosis and in addition to Anita, I have only told my mother, father, brother, sister, my two sons and a couple of close mates. I have not expressly told Anita's parents, although I have a feeling that her father might have an inkling.
21. I have told my employer that I am a haemophiliac in case I have an accident, however I have never told an employer that I have HIV, HBV or HCV. I've certainly made a conscious decision to conceal my infection from people and there is always the risk that someone might associate the fact that I have haemophilia with the possibility that I could be infected. I feel like that assumption might be slowly disappearing, because people might think that if I had been infected, I probably would not be around anymore given how far down the line we are now.
22. There is certainly still a stigma around HIV and Hepatitis, although it is far from what it was when I was diagnosed. Back then people would just assume that you had been up to no good or that you were a drug addict – no one would have thought that you had contracted it from the hospital. People used to say that is all associated with the "H's" – Haiti, haemophiliacs and homosexuals. I was not exposed to much of this directly, although not many people knew that I was infected.
23. When I was diagnosed, it was initially quite difficult to keep it quiet and sometimes I had to lie to people to conceal the truth. I think that the Inquiry will help with all this though, as we have spent a lot of time trying to hide the truth and it is time that we let the truth out rather than avoiding it.
24. From a physical perspective, I did not really suffer too many side effects. They would continually check my CD4 and viral load counts which suggested that whilst I was not at 'normal' levels, I was not necessarily at

risk of health problems. My CD4 counts generally sat around 500 – a 'normal' count is 800+ and you were considered to be 'at risk' if you dropped below 300.

25. I have lived a relatively normal life really, with the exception of having to attend St George's every so often and having some operations. Generally, if I had some fluid get into my joints after a bleed, it would need to be drained to avoid irreversible damage. I have had some damage to my right knee and my left elbow – both of these joints are what they call 'target joints' as they are quite prone to damage.
26. I am not sure that I would have believed someone if they had told me in 1985 that I would still be here with the health that I have today. Back then they used to say that you would only make it ten years after being diagnosed with HIV before you started going downhill. I thought I was only going to make it to 30 years old. I think in some respects it is your mental approach, but a lot of it has to be your genes and how your system deals with it.
27. My infection has not necessarily had a huge impact on my emotional wellbeing, however it caused Anita and I great difficulty when we wanted to start a family. It was a dangerous thing to be doing and we knew this when we got married, but looking back it was a very difficult time. We put off having children for a few years after we got married and at the time, the only option available to us was to conceive naturally.
28.

GRO-C

in 1994, Anita fell pregnant with our first child.
29. We did not really receive any advice about trying to have a child, we just tried to reduce the risk as best we knew how. I think that I was more worried about infecting my wife than she was, but she was really calm

about it. We were fortunate enough that Anita was not infected and our son was born free of any health complications.

30. About seven years later, we decided to have another child. By this stage,

GRO-C

was available at Chelsea and Westminster Hospital

GRO-C

GRO-C

. We found out about GRO-C through a letter that we received from the Macfarlane Trust, however it was not initially paid for by either the NHS or the Macfarlane Trust.

- 31.

GRO-C

32. About two years later, we attempted to have a third child using the GRO-C procedure. This time we were able to secure funding from the Macfarlane Trust, however after two or three attempts we were unsuccessful.

33. This was obviously a hard time for both Anita and I, but it is something that I had not really thought about for some time.

34. I think that the overall impact is worse for Anita than me – it is certainly worse for the person on the outside looking in. There is absolutely nothing she can do to change it, so it impacts her all the time. Despite this, she has remained incredibly strong throughout everything we have been through together.

35. Anita and I also encountered some difficulty when trying to obtain a mortgage in the late 1980's. In order to purchase our house, we had to set up a repayment mortgage through a broker who had managed to find a company that did not ask any questions about our medical history.

Section 6. Treatment/Care/Support

36. In 1988, I took part in what was referred to as the "Concorde" trial. It was a double-blind trial using AZT, meaning that neither the patients or the doctors knew whether we were given AZT or the placebo. From memory, this was one of the first trials of its kind.
37. I took part in the trial for somewhere between three to six months, until I dropped out as I started feeling unwell. It is in all likelihood that I was being given the AZT and this was causing.
38. At some time in 1997, my CD4 counts dropped to about 300 which is about the threshold at which you become exposed to further health problems. There were some HIV treatments available by this stage, so Dr Bevan suggested that I commence the HAART treatments (I am unsure what HAART stood for).
39. The HAART treatment involved taking a combination of three drugs about three times a day. At one stage, I was required to take about 16 drugs a day. I continued the HAART treatment for quite a few years and my CD4 counts eventually stabilised and climbed. I was generally seen by Dr Mark Wansbrough-Jones at St George's during this treatment.
40. In terms of HIV treatments, it is generally considered successful if your CD4 counts remain at a steady, acceptable level and you do not experience any side effects.
41. I felt generally fine when I was on the HAART treatment and there did not really seem to be any physical side effects. My CD4 counts remained steady and my ALTS tests (for liver function) were also stable.
42. Strangely enough, I experienced a bit of morning sickness during the HAART treatment. Some days I would feel unwell from about 7am (when I would take the tablets) until about 12pm. Once I got past 12pm it would typically subside, so I was still able to work and carry on with my life. After about six months, the morning sickness disappeared and I became used to taking the treatment.

43. In the early 2000's, I commenced my first round of HCV treatment. The treatment involved a six-month course of pegylated Interferon (pegylated meaning there are two products mixed together).
44. I was required to inject the treatments, which made it quite a tough process. I managed to get through about five and a half months of this treatment, before I was admitted to St George's with flu like symptoms. I was in hospital for about a week until I was discharged.
45. I ceased taking the HCV treatment when I was discharged and I continued to have regular check-ups for about a year afterwards. The regular check-ups showed that the treatment had worked and that I was clear of HCV. It was all worth it in the end.
46. In the mid 2000's, I began my second round of HIV treatment (although I am unsure what this treatment was called). I suffered some long-term side effects from this treatment, as I experienced Lipodystrophy, which a condition that restricts your ability to move fat around the body. As a result, I am now quite thin in the face and it is unlikely that I will be able to change that in the future.
47. Before you begin a new course of treatment, you are generally told about a number of potential side effects and a couple of them are normally highlighted as the main possibilities. For this second round of treatment, I recall Lipodystrophy as being one of the main side effects that I was warned about.
48. When we first started noticing the Lipodystrophy I had already been on the treatment for quite a while, but there was nothing that we could really do about it. There was no alternative available at that time, so I had to remain on the treatment and deal with the consequences.
49. In 2012, I commenced my third round of HIV treatment. Again, I am unsure what this treatment was called, however it involved taking about four tablets a day and I continued the treatment for about five years.

50. This treatment involved an older drug (I am unsure what it is called) that was identified as potentially causing issues to blood pressure and cholesterol levels. I was not experiencing any issues with this myself, however they cancelled the treatment for all participants due to the possibility of it affecting us at some stage.
51. I commenced my fourth round of HIV treatment in December 2017 and I remain on that treatment today. It involves taking a lot less tablets (about one or two a day) and I am told that the treatment itself works differently to what we have been given in the past.
52. The treatment I am on now works in two ways, some attach to the cells and work from the inside, whilst others attract the disease and fight it away. Each method compliments the other and they work in combination to achieve the same result.
53. All my treatment has been undertaken at St George's and I continue to be treated at this hospital. During the course of all treatments, I continued to work regardless of any side effects that I may have been experiencing.
54. I have not had any treatment in relation my HBV – I do not even know if there is such a thing. We continue to keep an eye on my counts (ALTS levels etc.) and I have regular scans on my organs. Everything seems fine at this stage, even my liver. There is another count that they do regularly (the name escapes me), where my results tend to go up and then it naturally corrects itself, so it is just a matter of monitoring those levels at the moment.
55. I do not recall any specific times where I was offered psychological support. I think that I might have been offered it after being diagnosed, however I am not sure. In any event, I have not received any counselling or support as a result of my condition.

Section 7. Financial Assistance

56. In February 1990, I received a £20,000 payment from the Macfarlane Trust. I was told about the Macfarlane trust by the staff at St George's and I think I applied for my first payment in late 1989.
57. About two or three years later, I received a second payment of £24,000, also from the Macfarlane Trust.
58. I did not really encounter any difficulties when applying for either payment – I recall it being relatively straightforward. The process itself was generally fine, however I remember essentially having to sign your life away as part of the application process. When I applied for the second payment, I recall signing a document that said I would not be taking any legal action against the NHS for what happened, but I do not have the paperwork for it anymore.
59. In my eyes, I thought that the payments were for contracting HIV through the NHS. When I received the first payment, I just thought that the NHS had made an error and they were trying to make up for it with some money. It was not until I received the second payment and I had to sign a document saying that I would not take any legal action that I really began to think that there might be more to this than meets the eye.
60. As I have mentioned above, I received some funding from the Macfarlane Trust in relation to the ICSY treatment in 2003. This funding was only applicable to our second attempt at the GRO-C treatment and we were required to pay for the first round ourselves.
61. On 7 October 2004, I received a payment of £20,000 from the Skipton Fund. I did not think that I was actually registered with the Skipton Fund, but I think that it was in connection to my hepatitis. I think that because I was at a particular stage with my hepatitis, I was eligible to receive a fixed payment.

62. I currently receive a monthly payment of £1,833 through the EIBSS (which I believe was the Macfarlane Trust prior to 2010). I also receive a winter fuel allowance of approximately £500, however I do not get this every year – I had it for a long time, then it stopped for a couple of years and returned in 2018.
63. The only other payment that we applied for was for a new washing machine. This was many years ago when they were still offering grants for certain household products.
64. I have never been denied any payments, but I have not really applied for a lot over the years. There were never any preconditions to any of the payments that I received, nor were there any real obstacles.
65. I do think that there should have been proper compensation years ago, if they could have proved what happened. Particularly when you consider the amount of money that we have been given, compared to the compensation that some people can get for breaking their leg on the pavement.

Section 8. Other Issues

66. I had a small involvement with the Archer Inquiry, I did not give evidence but I had put my name down expressing my interest to do so. By the end of the Archer Inquiry, I had been sent three documents which were approximately five pages in length outlining some recommendations that they had settled on.
67. In the early 1990's, I looked into taking legal action against the NHS. I met with a solicitor in Holborn, however I did not take it very far as the cost was going to be far too high and I was not eligible for legal aid. It was very short lived.

Statement of Truth

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

Signed

GRO-C

Dated

29/09/19