

Witness Name: Steven Anthony Carroll

Statement No: WITN1139001

Exhibits: 0

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEVEN ANTHONY CARROLL

I, Steven Anthony Carroll, will say as follows:-

Section 1. Introduction

1. My name is Steven Anthony Carroll and I was born on the **GRO C** 1976. I am unemployed and I live at **GRO C** London, **GRO C** with my father.
2. 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 exhibited to this statement in the medical chronology.

Section 2. How Infected

3. In the late 1970s, when I was approximately 14-16 months old I fell and cut the skin on the inside of my lip and it did not stop bleeding. I was then diagnosed with severe Haemophilia A, with less than 1% clotting factor. I was not diagnosed at birth because I was the first male on my maternal side of the family to have Haemophilia. **GRO-C**

GRO C

4. When I was diagnosed with Haemophilia I was initially given Cryoprecipitate. I believe I was treated with Factor VIII (FVIII) at 2 or 3 years old, approximately early 1980s. I cannot recall the name of the products that I was treated with, but I know it was a Baxter product. I was then treated with a British product (8-Y or Lister), which gave me a bad allergic reaction.
5. In or about 1983-5, when I was 7 or 8 years old, the hospital taught my mum how to administer FVIII so she could treat me at home. However, prior to this I received all FVIII treatment at the hospital. I was treated at the hospital for severe bleeds and any dental procedures. I was treated at the Hammersmith Hospital, under the care of Dr Howe and Dr Porter. In 1986 when I was 10 I was under the care of Professor David Swerski, and I am now under the care of Professor Mike Laffan, Centre Director.
6. I was initially treated with FVIII on demand, but my bleeds became regular and I required treatment at the hospital. This resulted in me spending a lot of my childhood in and out of hospital.
7. In or about 1985/6, when I was 9, I believe my mother was informed that I had been infected with HIV from contaminated blood products. I do not know how this information was given to her and I do not know if any information was provided to either of my parents at the time, to help them to understand or manage the infection. My mother used to attend the appointments with me and she has now passed away.
8. At some point my mother tried to get involved with the social worker that was then assigned to the centre, I believe her name was Emily. She spoke to my mother about my life expectancy and I believe tried to get more information from her about the infection. I believe my mother was told that my life expectancy would be shortened and that I was at more risk to infection/illness.
9. In around 1989/1990, when I was 13, I was sitting with my mother in an interview with Department of Work and Pensions (DWP) and I heard the

interviewer mention the word 'HIV'. A few days earlier I had read an article about someone in 'Coronation Street' who had lost their son to AIDS. I had noticed that over the past few years my parents' behaviour had changed around me and they had become very obsessed around my bodily fluids and if a tooth fell out there would be a major commotion. When my mother mentioned HIV in this meeting I knew that this was what they had been so worried about. I asked her if I had HIV and said "that's what is wrong with me, isn't it?". My mother said "yes".

10. At the age of 13 I was going through puberty and started noticing girls. My mother booked an appointment for me to talk to a doctor about understanding the infection. I attended this appointment alone. The doctor also said that I had a life expectancy of 4 to 5 years. Hearing this information at such a young age was really difficult and I do not believe I fully absorbed it until later.

11. I do not recall if the doctor told me about the risk of infecting others. At some point along the way I remember reading that HIV was very dangerous and that you could infect others by kissing them. The information I was told was what was available at the time, so I believed it was accurate.

12. My mother later told me that I had also contracted Hepatitis C (Hep C), but I cannot recall when this conversation took place. I do not know when my mother was informed of this or what information was given to her about the infection. I did not really understand or acknowledge that I had Hep C until I was around 15 or 16 years old, when I had an appointment with a new doctor and he said "are you aware that you have Hep C as well?" I was not given any information about this infection or how to manage it.

13. I believe my parents waited to tell me about my infections because they wanted to protect me. I believe my mother did not want to have the conversation with me at the time, but because it was mentioned at the DWP interview, I believe she was forced to tell me.

14. I do not believe my parents were given any information about the risks of infected blood products. If they were told that there was a risk, they would not have treated me. My parents were of a generation where you trusted the doctors and listened to the information and advice that they provide, without questioning them.

15. I believe I was infected with HIV and Hep C between the late 1970s to the mid-1980s.

Section 3. Other Infections

16. In the early 1990s, I received an information pack from the doctors about vCJD. I then received a further letter stating that they did not believe I had received a batch that was infected with vCJD, however they said that they could not be 100% sure. I have not received any further information in this regard.

17. I believe I was not infected with Hepatitis B (Hep B), because I have been vaccinated against it.

Section 4. Consent.

18. I do not know whether my mother had any knowledge or gave her consent about me being tested or treated. However, I believe that she was not provided with adequate information.

19. I do not know if I was treated or tested for the purposes of research. However, I know that the hospital was interested in my genes and Haemophilia Centre did do research in this regard.

Section 5. Impact

20. As previously stated I was only 13 years old when I was told that I had HIV and told that I had approximately 4 to 5 years to live. I was unable to absorb

the information straight away. I went home and spoke to my mother and I made a conscious decision that I would do exactly what I wanted from then on. I left school, even though I had worked really hard to get into one of the best schools in London. I spent the next eight to nine months in bed playing video games. I believe I was very depressed and there was no help available to me.

21. From the age of 15 I made the decision that I was not going to have any children because of the infection. I felt I had no choice in the decision I made because I was scared and worried that I would put the children at risk. I also believed that I would not live long enough to raise them.

22. I was approaching the age that I had been advised I would not live beyond. I started to use drugs and it very quickly ruined me, by the time I reached the age of 20, I was not in a good place.

23. As a result of the infections, I always found it very difficult to engage with women as I believed that I was dangerous. This feeling still persists on some kind of residual level today. As a teenager all of my friends were experimenting with sexuality and being intimate with girls, but I shut myself off from this. This difficulty got a bit better over the years, but it was still my core belief that I would cause someone damage and I know I would not be able to live with myself if I ever infected another person.

24. When I was 21 years old, I had a cardiac event at my parents' house. I stopped taking the drugs, but quickly found prescription drugs. I realised at this time that the HIV was probably not going to kill me as stated by the doctors.

25. I would not go back to being a teenager if I was offered all of the money in the world. It was the most horrendous time in my life and I believe that the infections robbed me of my adolescence.

26. I believe I have now overcome that part of my life with the assistance of therapy. However, I believe I still have ongoing mental health issues, including OCD and anxiety.
27. I believe I had terrible outbreaks of cold sores because of the HIV. I also had a weaker immune system and I got ill quite often. I consider myself to have been very lucky, as I do not believe I have had it as bad as others.
28. In relation to Hep C, I believe I suffered from chronic fatigue. I have also had liver cancer scares one about 12 years ago and another around 4 years ago.
29. Despite having few physical effects from the infections, I have had terrible side effects from the treatment I had over the years. When I was around 17 years old, I was taking around 12 tablets a day, including AZT. One of these tablets had to be diluted in apple juice because it was so strong, this would often go in and come straight back out. At this time, I lost a lot of weight and I was very depressed. I wanted to die so I was also using drugs quite heavily. I stopped this regime at around 18 or 19 years old. When I was 22, I started triple therapy which consisted of taking three pills twice a day. I had this treatment for a while. I am now on my fourth combination of pills.
30. I consider that all of the treatment I had over the years has worked, if you do not include the side effects. The first two courses of treatment resulted in me suffering from nausea, vomiting, diarrhoea, chronic fatigue and a terrible rash on my skin. People would stare at me on the bus because of the rash, which made me feel terribly ashamed.
31. When I started the new drug recently, my skin would change and it would go very red in the sun. I have therefore grown a beard as a result to take the attention away.
32. I only started treatment for Hep C recently, which consisted of Viekiraz (Ombitasvir 12.5mg, Paritaprevir 75mg, Ritonavir 50mg) and Eiviera (Dasabuvir) 250mg. I was on this treatment for three months from 23/11/2017

to 23/02/2018. I suffered a reaction in the first few days which felt like my throat was swollen. This went down after a few days. I also felt quite tired at one point during the treatment. I have now cleared the Hep C and my blood tests before Christmas 2018 showed it was undetected.

33. I recall in the late 1990s the hospital tried to push Interferon on me and I refused it, because I did not trust the doctors at the time and I knew the side effects were terrible.

34. I faced difficulties and obstacles obtaining the above treatment for Hep C as it was not initially available to me. The hospital wanted to put me on a trial for different drugs, which also included one of the drugs listed above at paragraph 31. I refused to take part in this trial as I was not prepared to take the risk. I decided to wait until the treatment was available and approved.

35. I was not as savvy with the HIV treatment. I just accepted what the doctor told me. Ultimately, I did not believe any of the treatment would work and I thought I was going to die. As information is now available freely, I feel that I am able to keep myself updated with the treatment that is given to me.

36. I consider that my Hep C treatment should have been made available to me earlier. I had seen the cost of the treatment decline and it was only when it got to a certain figure that it was approved and available to me.

37. I believe my infected status also impacted my other medical care. I have found that if I stay within my specialities at the hospital, I will not encounter any issues. However, if I require any other medical care it has been difficult and I have encountered issues. In particular, I had seen a dentist and when he reviewed my file he refused to treat me, on the premise that they are not taking on new patients. Since the age of 22 I have been treated at a Special Community Dentist, which is a clinic that deals with people that have more complicated medical needs.

38. My infections have also affected my family life. When I was first diagnosed, the atmosphere at home changed and everyone became on edge. I was treated differently to my siblings and my parents spent a great deal of time worrying about me. There was strain put on my parents' relationship and as a child I blamed myself for the breakdown of their marriage. I now know that this breakdown was not due to the stress caused by the infections.
39. As a young child I was not really allowed to interact with other children due to having a bleed. However, when I was diagnosed with HIV it became a lot worse and my parents became controlling and worried about my bodily fluids in the home. I suffered from a lot of mouth bleeds and being a child, I would just wipe the blood on the tablecloth or my clothes. Whenever this happened there was a real commotion around me and my parents would become quite frantic. I had also been sharing a bedroom with my older sister up until the time I was infected, then my parents put us in separate rooms. I do not know whether this changed because she was at an age where she might have needed her own space, but at the time I put it down to my infections.
40. Our household changed after my diagnosis and my sisters were given less attention than they should have been given. I know that they feel they have missed out on quality time with our parents.
41. My parents were not equipped to deal with something like this and that was the reason that it became a family secret. My sisters were not directly told, but they picked up the information in a similar way to how I had discovered I was infected. My auntie and uncle were slightly better educated than my parents and they worked it out that I was infected. Aside from this, we kept this the family secret and it was hardly ever spoken about. I do not recall ever talking openly about it with my mother, except for the conversation we had when I first found out. Even today my father will not discuss it and it frustrates my youngest sister, who believes it is not something we should be ashamed of.
42. My father stated that if they were better educated then I may not have been infected. I know this is not true, but my father has never forgiven himself. This

has hugely affected GRO-C and he is very angry about it. It is very difficult for him to talk about all of this and he will not discuss what happened or how he feels. His coping mechanism is to talk about something else when the conversation comes up, otherwise he gets really upset and angry.

43. I decided I would tell people about my infections and give them the opportunity to accept me for who I am. There was a girl who said she loved me dearly, but when I told her about my infected status she said she could not carry on with the relationship. She called me a year later and said she was still in love with me, but I said there was nothing we could do because my infections would always get in the way.
44. Whilst I was using drugs, I was in a long-term relationship and it played havoc on my mental health because I was always worried that my bodily fluids may cause harm. Sex became highly anxiety-inducing, this continued up until my previous girlfriend who helped me with this. My current girlfriend is very relaxed and calm about it, which has helped me since.
45. I did not tell any of my friends about my infections, because I was worried about their reaction at the time. I have only felt comfortable enough to tell my closest friend about my infections, which I had been friends with for six years. He said that it does not mean anything to him because I had never put him in any danger.
46. My infections had always been something that we had kept private, due to the stigma associated with it. When I was younger there was a great deal of media attention surrounding HIV and AIDS. People were having their houses spray painted and they were receiving abuse due to their infected status. We kept my infections a secret, to protect the family. The societal shame has been the biggest obstacle for me to work through over the past fifteen years. I have since learnt that shame does not belong to me, it belongs to the society and I do not need to carry it. However, when I was younger it nearly killed me and it felt like it would have been better if I died than for anyone to have found out.

47. As my infections were the family secret, it affected all of our behaviour and our relationships with others. When I had my cardiac event at my parents' house, my older sister's boyfriend was there and he did not know about my status. My sister very quickly took him out of the room, because the emergency medical staff were asking about my medical history.

48. As stated above, my infections cost me the opportunity to continue in school and get a really good education. At the time I did not think I needed one, because I was told I would be dead in four/five years. I told my parents that I was not going back to school and they would have to deal with the consequences. My parents were not happy with the decision, but my mother understood. I felt a lot of anger towards my parents, but I managed to work through the anger with therapy.

49. In addition to the educational effects of my infections, I suffered massive financial effects. I believe that I was unable to get a job because of my infected status and I now rely on financial assistance and benefits. I am currently battling with the DWP and the EIBSS in relation to my benefits, which is very stressful.

50. I do not know what career I would have embarked on, had I not been infected. However, I believe that I was on track to get a good education and I would have liked to be the first member of my family to have attended university. I did not know what I wanted to do, but I knew I did not want to be poor like my parents. Prior to being informed of my infection, I had something to work towards and my school reports indicated that my teachers had high hopes for me. Once I was informed I had HIV, my enthusiasm to even get out of bed just disappeared.

Section 6. Treatment/Care/Support

51. I have never been offered any emotional support. When I was around 28 or 29 years old I had to seek my own therapy and pay for it myself. I believe that

had emotional support been available for me it would have made a huge difference. I am not sure if it would have changed my mind-set, but it would have given me an outlet to explore it.

52. My parents were not offered any therapy or emotional support. I am not sure if it would have helped them. My father had the opportunity to engage therapy independently later in life but had found it difficult to push through the difficult parts. My mother was a proud and private person. For her generation it would have been seen as a weakness to talk about things.

Section 7. Financial Assistance

53. I do not feel that I accessed as much financial help as I could have in the early days, as the process was difficult.

54. In or about 1991/2, when I was 13 years old, I received an ex gratia payment. I believe this was a payment of £20,000. A precondition was imposed that we would not take any future action. Some of this money went to my parents and some was held on trust by the Queen's Bench until I turned 18. My family used this money to go to Florida. This money enabled us to do things we had never been able to do as a family.

55. My father did not want this money because he thought it was blood money, but my mother wanted to use it to spoil me and the family because she had been told I only had a few years to live. Our living standards improved during this period, but it was not enough.

56. When I was 18 years old, we already worked our way through a considerable amount of money and I received a sum of approximately £18,000.

57. In the early 2000s, I received approximately £25,000 from the US Litigation. In order to receive this payment, we had to agree to not take part in any future litigation.

58. I received a Stage 1 payment from the Skipton Fund in the sum of £20,000. I cannot recall when I received this payment.
59. I later received an ongoing monthly top-up payment for my HIV, which was approximately £3,500 per year. I cannot remember when the payments started.
60. I now receive a monthly payment in the sum of £3,500 from the EIBSS. This payment is for HIV and a special category mechanism for Hep C. Although I am not a Stage 2 candidate, my Hep C does cause me enough problems to qualify for the special category mechanism which will be paid for the next year or two. In addition to this, I receive a discretionary payment which is linked to my benefits, which I have to apply for annually. My benefits have now been stopped and I am in the process of disputing this with the DWP and the EIBSS.
61. I also received a payment from the Macfarlane Trust of £1,000, which was towards emotional support. I have also spent my own money on therapy, which I have independently sought. More recently I have applied to the EIBSS for further financial assistance for therapy, but they were very awkward to deal with. I wrote them an email telling them that they have been set up to make things simpler, but they have just made things more complicated.
62. The process of applying for financial assistance with the Macfarlane Trust was initially very simple. However, when the Central Government cut the funding it caused complications with Macfarlane if you wanted to apply for any further funds. There was a real change in atmosphere and they went from being a supportive entity, to not being that way at all. At this time I disengaged with them, because I was still at a point where I was a little bit angry. I believe that I was entitled to financial assistance. I felt as though it was not worth jumping through the many hoops they wanted me to for the sake of a couple of hundred pounds.

63. When applying for financial assistance with the Skipton Fund, the gentleman that I dealt with always treated me with dignity and respect. However, when I applied for the Stage 2 payment on two occasions it was denied. I do not blame them for this; I believe they were constrained by the system that had been put in place for them.

64. With regards to the EIBSS, I feel as though I am just a number to them. It was going from eight or nine members of staff to the biggest organisation in Britain. I feel it is a very government policy-driven and there should be a much simpler process in place than the one there currently is.

65. I do not want to damn the trusts too heavily as I believe they were put in a difficult situation, with regards to the funding they received from central government. When their funding was substantial enough, they changed and there were fewer constraints put on us for what we had to provide to access funds.

Section 8. Other Issues

66. As a result of my infections, I have been unable to get life insurance. Due to not being able to get life insurance, I have been told that I would not be able to get a mortgage. In addition to this, I have been unable to have a job that would pay me enough to be able to get a mortgage, because of what has happened to me.

67. If I travel abroad, the travel insurance is very expensive and if I do so with a partner she usually has to go on the same policy, as insurance companies can be difficult with this. I now use a specific HIV travel insurance company, which is still very expensive.

Anonymity, disclosure and redaction

68. I confirm that I do not wish to apply for anonymity, as I believe providing this statement is part of the closure process for me. I understand that this statement will be published and disclosed as part of the Inquiry.

69. I would like to give oral evidence at the Inquiry.

Statement of Truth

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

Signed GRO C

Dated 1/02/2019