

Witness Name: Mr John Batchelor

Statement No.: WITN0406001

Dated: 30/5/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MR JOHN BATCHELOR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7 December 2018.

I, JOHN BATCHELOR, will say as follows: -

Section 1. Introduction

1. My name is John Batchelor. My date of birth is GRO-C 1961 and my address is known to the Inquiry. I am a self-employed plasterer. I am a Christian and I regularly attend my local church where I worship throughout the week and volunteer.
2. I have 3 siblings, which consist of an elder brother and sister and a younger sister. I have 2 children from a previous marriage both of which are boys, named Christopher and Daniel.
3. I remarried on 1 July 1995 and had 4 daughters with my wife Vikki. My daughters are Lottie, aged 22, Josie (20), Gemma, (17), Connie (14).

Section 2. How Infected

4. I was born with haemophilia A but my parents were first made aware of my condition when I was 5 years old by Royal Sussex Hospital. I had twisted my ankle and had to be admitted to hospital to reduce the swelling.
5. The doctors informed my parents that I was a moderate haemophiliac because I only had 5% clotting factor in my blood. My parents received a green card in the post which listed the implications of my haemophilia condition.
6. My parents did not have any prior knowledge about haemophilia at the time of my diagnosis but when I was discharged from Royal Sussex my mum searched through the dictionary to find the meaning of haemophilia, in layman's terms, and it mentioned something about 'bleeding until you die'.
7. From then onwards my mother cocooned me and always set an alarm before bedtime because on some occasions, whilst sleeping, I had spontaneous nose bleeds, so my mother's alarm would wake her up at various points of the night so she could check on me and see if I was okay.
8. My mother also made me wear a silver dog collar with my name and address on it so that if I had a bleed at school or anywhere else they could contact my parents immediately. However, this led to some social difficulties as I used to get bullied at school for wearing it.
9. I attended GRO-C and there was a strict school policy that prohibited the use of any jewellery so the other children would pick on me because I was the only pupil allowed to wear the collar.
10. On one occasion the head teacher called me up in front of the whole school assembly and told all the children, "please refrain from punching or kicking John Batchelor because he could die".

11. The bullying increased thereafter and I remember coming home one evening quite upset and telling my dad that the other children at school were calling me a 'bleeding nuisance'. My dad told me to agree with them and they would never bother me again.
12. There were other pupils in the school who were bullied for having other medical conditions or physical disfigurements and we all formed a group and became friends as we were all being bullied, so that helped build my confidence too.
13. At some stage in my childhood I was referred to Royal Alexandra Children's Hospital but they did not have the facilities to manage my condition so I was then transferred to Great Ormond Hospital. Later in 1975 at the age of 14 I was transferred to St. Thomas' Hospital which was where I received most of my adult care.
14. I was treated with cryoprecipitate from the age of 5 until the age of 18 but I cannot recall the exact date I moved onto Factor 8 blood products. I only remember being told by St. Thomas' Hospital that this new form of treatment for haemophilia would make my life easier.
15. Initially I used cryoprecipitate at St. Thomas' twice a month as I was in the football team from the age of 7 and sometimes sustained injuries as a result of playing.
16. By the time I moved onto using Factor 8 I could treat myself at home which was more convenient for me as I had a lot of football related injuries which meant that I had to use Factor 8 regularly without visiting the hospital.
17. I left school at the age of 17 and joined my dad to be a plasterer. My first son was born when I was 20 and my second son came two years later so I decided to stop playing football altogether when I was 22.

18. Thereafter I became a football manager so that I could be around more for my boys rather than being injured all the time and in need of Factor 8 treatment.
19. In 1980 I went to St. Thomas Hospital for my routine treatment following a bleed/haematoma and the doctors found a foreign body in my liver but they could not specify exactly what this foreign body was. They simply said it was 'NANB hepatitis' and they would keep me informed.
20. Later, in 1982 at another routine appointment at St. Thomas', the doctors told me that the foreign body that had been discovered in 1980 was indeed hepatitis C.
21. The doctors said I may have contracted hepatitis C via Factor 8 blood products. They explained that the blood products had been formed by pooling various donations of plasma, which had originated from America.
22. At the time the consultant told me that the virus would lay dormant for approximately 20 years but they would monitor my liver in the intervening time.
23. I was also told that hepatitis C was a liver destroying disease and it would take approximately 20 years before my liver would become cirrhotic. I was absolutely devastated.
24. I was also told not to partake in sexual practices that would cause bleeding and could lead to transmission of the virus. I was also tested for HIV at the time, which thankfully came back as negative.
25. I do not have any piercings, tattoos and have never taken any intravenous drugs so I could not have contracted hepatitis via any other means.

Section 3. Other Infections

26. I did not contract any other infections aside from hepatitis C.
27. I received a letter from St. Thomas' Hospital, either in the 1990's or early 2000's which stated that a haemophiliac patient had died and his post mortem showed that he had vCJD.
28. The letter went on to add that there was a possibility that via the blood products I may have been exposed to vCJD as well as hepatitis C but that there was only a very small chance of this happening.

Section 4. Consent

29. I don't believe I was made aware of the risks of infection prior to receiving Cryoprecipitate or Factor 8.
30. However I would like to think that my consultant, Professor Ingram at St Thomas' Hospital looked after me in the best possible way he could as he was a wonderful person who asked for my consent at all times.
31. I watched a panorama programme which showed that some doctors did not inform their patients of their HIV/hepatitis C diagnosis and their medical notes were simply stamped with a triangle to show that they were infectious.
32. What was most shocking was that the doctors waited 8 years after they had conducted the original tests to inform those patients of their HIV positive status, which I believe was just unacceptable.

Section 5. Impact

Impact on Relationships within the Family:

33. When I began treatment I had to take a lot of time off from work because I felt quite drained most of the time. Whenever I did manage to go to work there would be times where I would come home and tell Vikki that I was going to bed, without asking her how she was or about her day.
34. I was so tired all the time and just wanted to get through each day as it came. I only had the energy to focus on myself. My wife GRO-C and I remember us both helping each other out at times when one of us couldn't do something.
35. However I think I became a bit selfish whilst I was receiving treatment because sometimes I couldn't focus on anything but myself due to the exhaustion.
36. When I got my hepatitis diagnosis I came home and told my family but they didn't know what it was or what the implications were.
37. Also, when my children were little, I use to inject myself with Factor 8 in front of them and later on they saw the Interferon treatment injections so there was no secrecy and I don't think it affected our relationship.
38. We would all sit around the table as a family and each discuss what our highs and lows were during the week so my children were aware of the difficulties that I faced whilst undergoing treatment. My wife and I shared everything with them.

Stigma

39. I didn't receive any stigma from my friends and family before or during my hepatitis C treatment and I was always honest and open with them.

40. However there were some occasions that occurred quite early on where people who lived in my area and were aware of my haemophilia condition would stop me in the street and ask me if I had AIDS which wasn't very nice but I would tell them that I didn't have AIDS and they would leave me alone.
41. I disclosed my hepatitis C diagnosis with my dentist and I did not receive any stigma whatsoever.
42. When we re-mortgaged our house it was expensive as we had to declare my hepatitis C and Vikki had to GRO-C which meant it came under critical illness. I was never refused a mortgage but I was told that due to my hepatitis C it would be at an increased rate.
43. Our insurance was considerably higher. Luckily we met a man that also had haemophilia and he sorted our insurance for us so it wasn't at such an expensive rate.

Impact on Physical and Mental Health:

44. There were times when I felt that I couldn't go through with the treatment as it was so tiring and I use to feel low sometimes. I remember one day I sat down and had a little cry and felt sorry for myself.
45. I was very emotional during the hepatitis C treatment. Whenever I looked at the picture of all my daughters on the wall in my living room I would be filled with so much fear worrying that I wouldn't be able to walk each of them down the aisle on their wedding days.

Impact on Work

46. During my treatment for hepatitis C, sometimes I would take a day or two off as I was mostly exhausted.

47. I was earning approximately £150 a day but I don't believe there was a significant financial impact as I was aware that my income was sometimes lower than usual but it wasn't significantly low.

Section 6. Treatment/Care/Support

48. There were some doctors that would give me a hard time when I was younger because I played football quite regularly which led to a lot of bleeds and stints in hospital so I would lie to them about what had caused my bleeds and why I needed treatment.
49. My treatment started after I got married to Vic in 1995. I had blood tests and ultra-scans to monitor my liver and shortly thereafter I had fibro scans too.
50. I was monitored twice a year and the results would be emailed to the consultant in the same hospital and my consultant would make me aware of any updates.
51. I honestly believe that most of the doctors treated me in the best possible way throughout my treatment and even thereafter. I was offered counselling but I told them that I didn't need it as I had God, my family and my parents so I had a strong support system.
52. I remember rather early on, before I remarried, the nurses would look after me with great care and concern.
53. They were there for me when I got divorced from my first wife and I remember feeling so comfortable with them and I even had a little cry about it at one of my appointments and I left feeling better. They even put it in my notes too so that other nurses were aware.

54. The only bad experience I think I had was in November 2003. St Thomas' enlisted a liver specialist called Dr [GRO-D] and I sat in the waiting room with my consultant at the time who was called Savita.
55. When we went in to Dr [GRO-D] office he looked at my results and told me that my liver would completely fail in 20 years' time. My default mechanism is to make a joke out of things when faced with saddening or scary news and I remember saying to him, 'are you sure you have that right, [GRO-D]
56. Dr [GRO-D] was one of those slightly arrogant doctors that thought he was a 'big man' in the liver ward. After he told me my liver would fail in 20 years I sat in my car and I felt so scared. I wasn't offered any treatment at the time.
57. I remember saying to Savita my consultant that she should to tell Dr [GRO-D] that the manner in which he informed me of the hepatitis C diagnosis was so cold and in future he shouldn't tell others in the same way he told me.
58. Dr [GRO-D]'s manner and delivery was so bad that I think others with a fragile nature would have left St. Thomas' hospital that day, after being told that they only had 20 years until their liver completely disintegrated, and jumped off Lambeth Bridge.
59. Every year after that I use to cross off every November and say to myself 'I've survived this year, 19 to go'. Although I didn't start treatment until later on, the doctors would inform me of clinical trials for hepatitis C treatment and I signed up for every trial that they offered.
60. My wife's best friend's sister was married to a liver specialist and I contacted him to discuss my options and whether there would be a cure for my liver.
61. I then started Interferon treatment in 2006, which initially consisted of one subcutaneous injection every day for 12 weeks. Before I started the

course of Interferon I was told that Interferon is what makes a person feel ill, when they have a cold or flu, as it doubles your white blood cell count.

62. It was an unpleasant experience and I remember crossing off each day on the calendar to monitor my month-by-month progress.
63. Every month thereafter I had blood tests to see if the Interferon was working and after only three months I was told that it was working. However after 6 harrowing months of the Interferon treatment I was told that it wasn't working at all.
64. Whilst I was on the Interferon treatment I used to sleep for about 17 hours a day and I was tired all the time. I was absolutely devastated that the Interferon didn't work as it was 6 months of absolute hell.
65. The doctors then told me they would try again with a combined course of Interferon and Ribavirin. They said that the addition of Ribavirin would prevent the hepatitis C cells from splitting. However I was told after 6 months of this combined dose that it wasn't working either.
66. Shortly after this my consultant, Savita contacted me and said 'I have something to tell you but do you want the good news or the bad news first?' I replied saying I wanted the bad news first.
67. Savita then said that the Interferon and the Ribavirin combination that I had been on before was in fact working but I was given someone else's results over the phone and the nurse who told me the results had read them from another patient's file by mistake!
68. Savita apologised about the mix up and said I should start the Interferon and Ribavirin combination again but as I came off it before based on the incorrect results starting it again didn't work.

69. Consequently in 2015 I had further fibro scans and I was given another course of treatment for hepatitis C and this was called Harvoni. I had to take one tablet of Harvoni every day for three months.
70. I do not recall having any side effects to the Harvoni treatment aside from a sensitivity to light in the first 3 weeks. Thankfully after 3 months of the Harvoni treatment the doctors said it had worked and it had completely cleared the hepatitis C.
71. My daughter Lottie is getting married this year so I am happy I get to walk her down the aisle completely cleared of the virus.
72. When I was fully clear of the hepatitis C virus, Savita, my consultant at St Thomas' asked if I could come to the hospital and speak to others about my experience of the Interferon/Ribavirin combination and Harvoni treatment which I did for a while.
73. I would talk to others that had been diagnosed with hepatitis C and tell them to take it if they thought there was even a small chance that it could cure them.
74. Some of the hepatitis C sufferers that I saw at the treatment clinics looked like 'death warmed up'. It was quite difficult going in each time and seeing people in such difficult circumstances like that.

Section 7. Financial Assistance

75. I received a letter from the Skipton fund in 2001 and they said they were offering an ex gratia payment in the sum of £20,000 and they made it clear that I wouldn't receive any more lump sum payments after that.
76. I filled out the form for other payments under the Skipton fund and thereafter I received further letters about winter payments but I didn't take any notice of it as I had already received the £20,000.
77. Approximately 3 years ago the Skipton Fund started paying me £3,000 a year which has now increased to £4,000.

Section 8. Other Issues

78. This whole situation has made me learn that through adversity you either come out stronger or you don't.
79. When I was told that I had cirrhosis of the liver I remember being so worried that I wouldn't see all my daughters get married or walk them down the aisle.
80. My parents helped me immensely whilst growing up with haemophilia. They really looked after my sister and I, as she was born GRO-C
GRO-C They were always running around making sure we were okay. Our family unit was very strong.
81. For some people this Inquiry will bring closure and for others it won't. I don't believe that the outcome of the Inquiry will change anything that has happened so I think what needs to change is our attitude to it all.
82. I believe that those that have suffered greatly have to try and forgive. It is what it is and I don't think it does anyone any good worrying about it.

83. Although I think it did take a very long time for us to get here just like the Inquiry into the Hillsborough disaster. I know that there was a cover up in this situation but I think things happen like that in life sometimes and there is nothing they could do now to change the past events.
84. I am just very happy that I am still alive and I got through the treatment successfully and I originally didn't think I needed to tell my story or that it would be worth listening to but I am happy that I am doing it now.
85. I think people that have been affected by this should be offered counselling as it is important because it allows you to share your burdens.
86. Most people don't really want answers but they want someone to talk to and let out their frustrations with. I think that is the first step to finding closure from this.

Statement of Truth

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

Signed

GRO-C

Dated

30/5/2019