

Witness Name: Mr Suresh Vaghela

Statement No: W1577001

Exhibits: W1577002 - 8

Dated: 27th November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MR VAGHELA

I, Suresh Vaghela will say as follows:-

Section 1. Introduction

1. My name is Suresh Vaghela. My date of birth is GRO-C 1962 and I live at GRO-C
GRO-C I am currently married to my wife, Rekha, and I live with my little dog Milo who is a Morkie. I was a senior librarian but my illness ended my career as I had to take many days off because I was too ill to work. I am currently retired and campaigning for the current community.
2. This witness statement has been prepared without the benefit of access to my full medical records. A summary of my medical treatment, based on memory and what records I have seen, is found at the end of this statement.

Section 2. How infected

3. I was born with severe Haemophilia A. I was tested straight away as my older brother had already been diagnosed.

4. I attended Hereward College of Further Education in Coventry ("Hereward College"). This was, and still is, a college for the disabled. This College gave me my first batches of Factor 8. The college was exemplary in the manner that it catered for the students. The delivery fell nothing short of excellent. Due to the nature of the college it had connections with two hospitals which I regularly visited as an inpatient. These were Coventry & Warwickshire Hospital and Walsgrave hospital. My doctor at the time was Dr Maurice Stevens Consultant Haematologist.
5. During the period of 1979 to 1983 I was administered with the contaminated Factor 8.
6. In 1978 I was tested for Hepatitis B and the results showed I was Hepatitis B surface antigen negative. In April 1979 I was tested again and they found a record of a test which suggested I was surface antigen positive. I attach a letter confirming this from Dr Wensley, Consultant Haematologist, Manchester Royal Infirmary dated 28th December 1990 as Exhibit W1577002.
7. I was infected with Hepatitis C between 1979 to 1980. I was identified with Hepatitis non-A / non-B in 1980 and I first tested positive with Hepatitis C in 1990. I was told of the infection in 1993.
8. I was infected with HIV between 1979 and 1983. I first tested positive in 1983 and was told of the infection at the start of the 1983/1984 academic year.

Advice Given regarding the Risk of Infected Blood Products

9. I was given absolutely no advice in terms of the risk of Factor 8.
10. I was infected as a result of being given contaminated Factor 8.

Discovery of Infection

11. When I was boarding at Hereward College in Coventry in January 1980 I suffered a huge bleed and went into hospital at Walsgrave. When I came out, my roommate looked at me and said *'your eyes are yellow.'* I went to see the nurse and was told *'There's nothing to worry about. We were expecting this.'* I believe I must have been tested in hospital and they had discovered I had hepatitis non-A / non-B and knew the symptoms would manifest at some point. I went back to my room half-an-hour later and my roommate, Antonio Russell, had been evacuated and told he couldn't stay with me. I was then in quarantined for six weeks. They never said it was Hepatitis, as demonstrated in Exhibit W1577002 which states *'he was not told what the diagnosis was.'* I did not think anything of it because I trusted my doctors, and thought it may be a side effect of the bleed. I now believe this bout of jaundice in January 1980 was the start of the Hepatitis C although at the time it wasn't identified as that, instead as non-A / non-B in line with medical knowledge at the time. Other than the above there was no other mention or advice of Hepatitis non-A / non-B. The nurse did not even mention Hepatitis.

12. I refer to Exhibit W1577003 which is an extract of Dr Baxter's notes taken at Hereward College. These make clear I was admitted in 1980 and tested for Hepatitis. The first mention of Hepatitis is on 17.01.1980. Hepatitis B was confirmed on 21.01.1980. Exhibit W1577002 is incorrect as it misses out on my admission and diagnosis in 1980.

13. With regard to the HIV, I refer to Exhibit W1577004, a letter from Dr M.D Williams, Coventry and Warwickshire Hospital, dated 02.06.1983, stated I needed to attend the blood bank on July 12th but this was a very general letter and as I had blood tests all the time I did not think anything of it. They did not state the importance of the test. The letter also stated I would have the results on the 19th of July but it was during this time I left Hereward College because I was going to University. They said it was too far for me to come so a nurse just told me over the phone that the test was positive. There was no advice given during the phone call except to get my affairs in order because I only had three to six months.

14. The blood test results were shared in a very informal way. I trusted them because they felt like family but when something major like this happens they should not treat it so informally. Even within families there is a certain protocol depending on the nature of the shared information.

15. I was not given adequate information to help me understand and manage the infection, in fact I was given no information what so ever. They thought giving us information would be a waste of time because I did not have enough time to live. They considered the HIV as a death sentence and they were not trained to deal with someone on death row. They were not ready for this kind of bombshell.

16. I feel I should have been provided more support at the time of the diagnosis instead of just being told over the telephone. I was left numb, lost and absolutely shell-shocked. Normally, when you become ill you are meant to have a social worker and a team to help you, everyone knows what their job is but there was nothing like this for me. It would have taken two or three months to get the social worker into place but by then they thought I would be gone. They considered us too far gone to provide value for money.

17. The way I was told lacked compassion. I was told on the telephone, alone, at university and at the start of the academic year I had no real friends to call upon. They said to go home, say goodbye to my family and get my paperwork in order due to my imminent death.

18. My brother, Praful, who is a year older than me died from aids in July 1995. Being petrified of the news he ran away from home when he was told the news and started saying his goodbyes. I do not know when he was told but it was roughly the same time. Whatever the doctors did in terms of advice, because we are brothers, they did to us both. Everything was done at the same time.

19. Now I reflect on what was done I honestly feel the doctors giving the news were in shock. The ones delivering the service were not responsible but they were bearing the brunt of it as they had to follow orders from the powers that be. They were too deep in the water and they did not know how to swim. There was no support. If you have not got anything but then you catch something the doctors come into play. However, in our cases we were already involved with the doctors so the mental support was never there. The doctors were very practical because I was already ill so they thought I did not need any more doctors looking after me. It was only when we had outlived our prognosis and the demand started growing that they realised they should have given support and that was when the McFarlane trust was born. However, it was only if you shouted loud enough you were heard. Those that did not shout were the ones who were really poorly; they were hit from both sides. I was one of the louder ones as I started campaigning to try to bring people under my wing. You cannot manage everyone though; bearing in mind we were and are all ill.

20. The Hepatitis B was not ever actually communicated to me. I also was not told of the Hepatitis C until 1993 but there is a letter, Exhibit W1577005, from Senior Registrar C. Babbs, Manchester Royal Infirmary dated 19th November 1991 which stated there was "*definitive chronic active hepatitis*" and they were treating me for Cirrhosis resulting from Hepatitis C without telling me I had Hepatitis C.

21. I was not given any information regarding the HIV at diagnosis but as time went on we were given plenty. For example, being told to not have children. This all came too late though. They had taken our life away but then they said we cannot enjoy what little we did have left. They failed to help us.

Section 3. Other Infections

vCJD

22. I refer to Exhibit W1577006 a letter from Dr CRM Hay, central Manchester Hospital, dated 16th May 2003 which stated '*there is a small theoretical risk of transmission of variant vCJD.*'

23. I had an appointment on the 25th June. When I went for the appointment it was a room of wall to wall doctors. I was asked if I do not mind a few people being there. I thought they were all students who wanted to learn. Normally appointment takes five to ten minutes but this took thirty minutes as the lead doctor struggled to get to the point. I asked if I had it and he said I am afraid you do. As soon as we went in we knew something was afoot and one did not have to be Sherlock to figure that out.

Section 4. Consent

24. With regard to the HIV, I only knew half the story because the letter at Exhibit W1577004 was not clear. It just felt like another generic blood letter and did not come across to me as important because I felt like it had been sent to everyone.

25. I have no knowledge of Hepatitis B being tested but in Exhibit W1577002, the letter states I was tested in 1978 and also in 1979. I must have had these tests but I do not know anything of them. The letter even states '*he was not told what the diagnosis was*' regarding my Hepatitis. I was never made aware of the Hepatitis B and I was not told of Hepatitis C until 1993 so the HIV came first in my eyes. The Hepatitis may well have preceded it by four or five years. That's why the Department of Health added Hepatitis to the waiver that brought the 1991 HIV litigation to an end because they had already made the link that we were going to have hepatitis. There was a general consensus amongst doctors that a percentage of those who had received contaminated blood products would be HIV positive but, 100% would be positive for Hepatitis.

26. When I was given interferon I felt like I was a guinea pig in a trial. The interferon was considered a magic drug but should not have been given to anyone who was HIV positive (as stated in Exhibit W1577002). However I did not know I had Hepatitis C and was one of these contraindicated co-infected. Those that were administering it should have known that the outcome would be fruitless as research had indicated as much I refer to Exhibit W1577008, a letter from Dr Wensley, The Royal Infirmary Manchester, dated 25th October 1990 states '*he will probably participate in a study of Interferon that Dr Warne's is carrying out at present*'.

Section 5. Impact

Mental and physical effects:

27. The Hepatitis C has crippled me. I am constantly tired as my liver does not work properly. I am on fourteen tablets a day for the HIV and other health issues caused by the infections. I also take about ten painkillers a day including co-codamol, oramorph and temgesic which is because of the bleeds and arthritis along with Zopiclone to help me sleep. I have problems with my left shoulder, elbow and knee. I am waiting for a shoulder transplant for my left shoulder, but I said no because my bleeding is so severe. I also have Factor 8 every other day which I do at home due to something not being right with my liver clotting. I still bleed (tissue based), for example if I lean on something I would have an internal bleed. I have to be so careful. The drugs I have to take make me feel sluggish; I used to be sharper. Before, I presented in front of 30-40 trainees and would not think twice, whereas now I find it a challenge to converse with my wife.

Further medical complications:

28. Due to the Infection I have suffered from compensated hepatic cirrhosis secondary to HCV infection. My cirrhosis is classified under the Child-Turcotte-Pugh classification system as grade A. I suffer from osteopenia, as

shown on the DEXA scan, together with Gastric Antral Vascular Ectasia, where the liver cannot manage pressure of blood so diverts to stomach making it bleed constantly, leaving me anaemic and requiring blood and iron transfusions. This is a direct consequence of the Hepatitis. I refer to Exhibit W157707, a letter from Dr Bell, Leicester Royal Infirmary dated 28.03.2017, summarising my current condition.

29. In 2006 I also developed type III cryoglobulinemia which is secondary to Hepatitis C infection. Thanks to this when I get a cold it takes a long time to warm up and my whole body seized up and I constantly ache, so I always put the heating on, even in summer. This is also shown in Exhibit W1577007.

30. HIV drugs come in different styles but they can have a bad affect due to the Haemophilia. Only a small percent are suitable to me due to the combination of me having Haemophilia and allergies to some drugs. Therefore I am very limited to what treatment I can take. I was allergic to Nevirapine (hepatotoxicity) which they gave to me and I did not sleep for seven weeks. I have also been given HIV drugs which increase bleeding times. Drugs I have had problems with include protease inhibitors (including bleeding and haemarthrosis), Co-trimoxazole (allergy), Efavirenz (intolerance due to hallucinations).

31. I also have had to take water tablets because my liver does not work, these are called Furosemide. I was also on Spironolactone which had "man boobs" as a major side effect. This was so painful and uncomfortable, not to mention embarrassing..

32. In 1995 I had an AZT for HIV. This gave me bad headaches; I was in bed because the headaches wouldn't stop. There was no option though, I had to carry on. The treatment came out in August or September. If it had come out sooner my brother would be alive, or at least have had a chance of being so. I took the AZT in August or September. It was monotherapy, tackling HIV with one medication. As experience grew, that was when they realized you needed triple therapy, which is three medication's working together in combination.

This was for everyone who had HIV. At this point in time I was working from 1989 onwards as a librarian. It was a real struggle because the more time I put into work the less time I had for my body to recover. I could not get the rest my body needed so I was just relapsing all the time. I would just get used to the medication regime when it needed to be changed and I would have to go through the whole cycle again to settle with a completely new regime.

33. Whatever journey you have it gets you to a point where you need to feel comfortable and I have got there. The more stress you put on yourself means more that you have to handle.

34. I finally had interferon treatment for Hepatitis C. That worked but the damage already caused left me with liver cirrhosis. Every six months, I have to have ultrasound scans to check for tumours and cancers. With regard to the Hepatitis B there is no treatment, but I have had vaccinations later on in life, 3 or 4 years ago.

35. There were not really any other treatments which I consider ought to have been made available to me, I did not ask for much and that is what they delivered. My expectations were not high from the start so they met them. They did what they could.

Mental and physical effects of the treatments:

36. In 1990 I was given the first Interferon for the Hepatitis C. It was an injection but it did not suit me. I went down to seven stone and could not work. I could not stand up.

37. The second interferon was in 2007. It was an injection, both Interferon and Ribavirin. I went half way through and my haemoglobin went down to about three and I fainted. My blood platelets also went down to almost zero. That's when they thought it was too dangerous to carry on so they stopped that. During one particular week I had to have twenty units of blood, as I was bleeding uncontrollably. My spleen was growing to a level where I couldn't

stand or breathe. It was massive (5kg). So in 2008 I then had my spleen removed.

38. Following my splenectomy and the state of my enlarged liver I was placed on the liver transplant list. I could not have a liver transplant at the same time as my splenectomy as I would not be strong enough to cope. I have been waiting for a liver transplant since 2008 and I am about half way up the list. I could only go on the list once I had my spleen removed.

39. I was started on Interferon again in 2008 after I had my spleen removed. This was again Interferon and Ribavirin but they had to stop this again because I was loosing so much blood from my back passage. So they did banding on the varices in my back passage as my blood vessels were blowing up like balloons. My haemoglobin levels then went down which meant regular blood and iron transfusions.

40. The second and third time and to some extent the fourth I suffered from pancytopenia (when platelet levels fall very low) but they said I had a 80% chance of clearing it, so I felt I had to keep going. I am Genotype 3A.

41. They started the fourth Interferon treatment in 2010 and I then cleared Hepatitis C in 2011. I have been clear ever since, but the damage done to my liver is irreparable.

42. One of the side affects is that you suffer memory loss, feel suicidal and suffer from depression. They wanted to start me on anti-depressants before I started my medication but I did not want to do this because I was already taking so many drugs that made me fuzzy-headed that the anti-depressants would have added to this mix and made matters worse. I would have been walking around like a zombie.

43. Part way through my Hepatitis C treatment, I suffered from memory loss. I knew my wife, mum and dad but I would forget who other people were or the connection I had with them. This lasted about a year but my mind did not get

back to normal and I would argue with my wife because I could not remember if I had agreed to something. It was getting very worrying and about a year ago I saw a psychologist who said I had memory loss from the Hepatitis C treatment. HIV treatments are also known to cause memory loss. My bad memory was one of the things I could not get to grips with. I am still not as sharp as I used to be. I also have an aneurism in the brain which does not help. This is managed but I am not having treatment because of my Haemophilia. I have regular MRI scans to check if it gets bigger. I understand if something goes wrong I come out worse than I went in.

44. As I mentioned above, when I was having an allergic reaction to Nevirapine I couldn't sleep for seven weeks. I just watched television. I lost my taste buds so it did not matter what I was eating so I did not feel like eating. When it was nearly 22.00pm I would start panicking because I would have to face the night by myself. Half way through the night my thoughts would wander and that would be a dark and lonely place to be. Would the lives of the people around me be better off if I wasn't around? Who would look after my family if I was no longer around? These were scary times because there is nothing worse than being helpless and being a burden on someone's life.

45. With the Hepatitis C I was so physically ill I could not feel anything. As soon as I had the hepatitis C treatment injections a headache would start within two hours after which I would be bed-ridden. I would re-surface in time for the next injection All I remember during all my hepatitis treatments is being confined to a bed, the dread of the treatment and the never ending trips to the hospital, never certain whether you'd be back home or kept in as an inpatient.

46. I could not have any mental effects from the Hepatitis C at the time because physically I was so ill and so drained. It was just an awful time because all I can remember is getting up going to the toilet, going to the hospital, and fainting. One day I woke up and my stomach was so big. I got up and did not feel like I had enough room in my stomach. I went to the hospital for a transfusion and do not know how I got up. My parents were watching as I went down hill. My brother had died and all they could see was me dying in

front of their eyes and they felt helpless. That was absolutely soul-destroying for me.

Impact upon treatment, medical and/or dental care:

47. Some dentist's would not take on HIV positive clients because they thought it was a risk of infection and their equipment would not be cleaned enough. They would just say they were full but there would be places for other people so I knew it was just an excuse.

The impact of being infected on your private, family and social life:

48. This has absolutely ruined my life and the life of thousands of people. The viruses I was infected with have not only taken away my immediate happiness but also my future happiness.

49. I met my wife Rekha in 1988 and got married in 1989. We met at a religious function in Leicester. We were all there at the same time and she noticed me. I had all this baggage so marriage was not top of my list because I felt I needed to handle my troubles on my own. If it wasn't for her I don't think I would be alive. It is a lot to take on board. It was only when we were married that I had to have all my liver problems.

50. Before our wedding, the doctors said I would only have a short time to live, so the marriage was difficult. From an Asian point of view you look for the perfect suitor. The stigma is also worse in the Asian community as illness is seen as karma because of what you have done in a previous life. If anything had happened to me and Rekha was left on her own she would be told she had made her bed so she has to lie in it. I am thankful Rekha said she would rather have a year of me then a boring life. She never read the small print.

51. I have been robbed of the chance of having a family. Rekha and I were advised by doctors not to have children. At one point Rekha became pregnant but we had to make the heartbreaking decision to have a termination as my

health was so precarious. The doctors gave us a choice, but it was not really a choice as they encouraged us to abort our child. My health was deteriorating so much and Rekha could not have looked after me and a baby, especially if the baby had health problems too. That was a very difficult decision as you look forward to the prospect of a family, but it was not meant to be. So it is just me, my wife, my mum and our little dog Milo.

52. As well as missing out on the joys of parenthood, the prospect of growing old is bleak. At the moment, my wife and I look after my mother. Parents are there for their children and then children are there for their parents. However, when you have no children, who is going to be there for you? As my wife and I get older, we will have no kids to fall back on. We don't have that cushion as it's been taken away from us.

53. How I manage my life is now different. When my friend, Antonio Russell, had to go into hospital with a head bleed, he found that none of the nurses or doctors were okay with handling someone with haemophilia let alone Hepatitis C and HIV as well. They were trying to find a vein but when they realised he had all these problems they left the room. It left me, my wife and a doctor to treat him. It opens up how you start thinking of things. Will I have people managing me or will it just be Rekha? That was only six or seven years ago and there are still pockets of the country that are not dealing with it how they should. It makes me think, when my time comes will there be doctors who know about me?

54. Some friends of mine have gone abroad and are able to behave care-free. I don't have that luxury, through no fault of my own. The infections impact upon my lifestyle. All this has impacted on my life massively because I don't have the same number of friends or amount support and it is hard to have faith that anyone will pick up the pieces because there are a lot of pieces to pick up.

55. With the vCJD I had a camera with my own name on for my endoscopies and sigmoidoscopies. There have been times I went in for my check up and they said they didn't have my camera because they had transferred it in another

hospital. I was told that one of the cameras was destroyed as they were not confident of cross-infection and these cameras cost around £40,000. You start feeling bad because they will not use a different camera in case you pass something on. So I am not surprised that the attitude of the public is tainted regarding cross-infection when the doctors themselves cannot be sure.

56. We started off with one-thousand two-hundred co-infected haemophiliacs who were infected with both HIV and Hepatitis C by contaminated blood but now there are approximately two hundred of us left. I have been to around ninety funerals in total but there was one heavy year where I attended 70 funerals of people who were part of the Haemophilia community, one of them being my own brother's. I was very close to my brother; he was like my right hand man. The heartache was too difficult to cope with. There came a point when I was going to so many funerals, you automatically start thinking you are going to be next. It is like playing Russian roulette and after a certain amount of time; you know the bullet is going to come for you. Every week there was somebody passing away, one after the other, and then another and another.

57. The Haemophilia support network was like one big family so it was not just me who went to a lot of funerals. In the mid-90s, we decided that we would just go to the funerals of our nearest and dearest in the future because the personal devastation was too much.

Stigma associated:

58. Stigma has been the worst part of the whole thing. If you have epilepsy or heart disease, you could talk openly about it but as soon as you mentioned HIV, it would clear a room. Stigma is also much worse in the Asian community. It is not something people would talk about in the family or extended family. There was already a taboo in the Asian community as they would link HIV with the gay community. It got to a point where you couldn't even mention haemophilia as people would put two and two together and we couldn't share any aspect of my health. This increased the level of isolation

we already felt and knocked both our confidence drastically. Even now in 2018, you still cannot talk about it. As far as the Asian community is concerned, it is a case of burying their heads in the sand and hoping it will just go away.

59. The government actively encouraged a sub group within the Haemophilia community so the co-infected couldn't be open with the Haemophilia community at large because many did not want to be contaminated. So there was a rift within the Haemophilia family. The uninfected were afraid of the mono-infected, who were themselves afraid of the co-infected. The money resulting from the compensation schemes caused a rift. If you had the whole community fighting for one cause we would have got to the point of having an inquiry much sooner. There was never one central voice. I do not know how this has come about but now we are all singing from the same hymn sheet, and hopefully the outcome will be amicable to all concerned because we have all suffered

Educational effects:

60. When I was at school, I would be called up on stage and the rest of the children were told I was a 'special boy' who they could not play with or touch. At playtime, I had to sit in the classroom and was not allowed to play outside in case I got hurt. When Factor 8 came in, it was like a magic potion which changed my life. Before Factor 8, if I fell down and hurt myself, I would be in bed for a month. However, with Factor 8, within three or four days of a bleed, I would be back to normal. Factor 8 gave me greater freedom and I thought it was great. As I mentioned above I went to Hereward College in Coventry to do my O Levels and A Levels. It was during this time I started experiencing health problems, as detailed above.

61. I went to do a degree in Birmingham and it was during this time that I was diagnosed with HIV. The Haemophilia affected my university education but the HIV did not. During my third attempt at my final year, the first two attempts

having been disrupted by periods in hospital, my problems with my knee caused the university to award me an aegrotat degree.

Work-related effects:

62. I had to give up work in 2004 because of my health issues. I would have loved to have carried on working but I could not cope. It was a difficult time because of the Hepatitis C and HIV. My Haemophilia was under control except for the protease inhibitors being used to treat my Hepatitis C and HIV, which increase bleeding. The Hepatitis C treatment that I had in 1991 made me weaker and I could not get back on track. Back then my liver was getting bigger as was my spleen, There was a point when the doctor said I was always anaemic so I should not give my 100% at work as if I did I was not recovering.

63. I wasn't happy but was relieved to give up work because I knew I could not cope, both physically and mentally. I would be delivering a speech to a group and I would just start dripping with sweat, and saying the wrong things because of the side effects of my treatment. I would have to stop and just sit down. The worst bit was that it was embarrassing. My shirt would be drenched and people would ask if I was alright but I would not want anyone to touch me. I could not tell them why.

64. When I left Preston I cut of all past ties, which is why I did a public article about my experience in my name openly. My workplace only found out about my illness when I released the article. I felt sad in a way because all of the staff would have been supportive but it is a lot to share with someone and you do not know how anyone is going to take it.

Financial effects:

65. If I had carried on working I would have had more money coming in but there comes a cut off point where only so much money will give you a certain level of life style. More money would not have added to my day to day life. What I

have coming in now is comfortable enough to live on. When we first got the payments in 1991 we were given three to six months to live but I still had a responsibility to my parents, brother and wife, whereas some individuals thought they were only going to be around for a short amount of time so they spent it.

Section 6. Treatment/Care/Support

66. I have never felt any need for therapy.

Section 7. Financial Assistance

67. In terms of one off payments from the trust I first got £20,000 in or around 1991. For the Hepatitis C I first got £20,000 or £25,000 and then when I reached stage 2 I got another £25,000

68. Every month I get £1,500 a month for Hepatitis C plus £1,500 for the HIV.

69. With regard to the process of applying for financial assistance there were too many hurdles and hoops for sick people. It was also the ones who shouted the loudest that got the most. Every step of the way I said what I needed help with as I was articulate enough and well enough to send letters but I know that others did not because the process was so complicated. When the trust needs so much information but when you are not well you cannot focus to send everything in, and besides you just don't have the energy. They would tell you that you have missed meeting so you would have to try again next month.

70. The trusts were generally helpful but could have been better. The Skipton Trust was more difficult than the McFarlane Trust. The last thing you need to do is jump through hoops when you are not well.

71. If you could understand the system the trusts used and you could understand what they wanted you were able to get the money far quicker. But most of my friends, because of the illness, did not go to college so their education was not up to a level where they could make their own case. Sadly these are the ones who needed it the most. So when I received some money I would feel guilty, especially when we all had similar needs. It was a really hard battle.

72. Just over a year ago I made an application to the Macfarlane Trust while it was winding down in order to get our garden done. I asked for £10,000.00 and was given £8,500.00. They also offered price match funding but this was not very helpful as if I could match the price I would not be asking for money in the first place.

Section 8. Other issues

Birchgrove:

73. One of the most gratifying moments in our lives has been the The Woodland Project which was a sponsored Birchgrove Group project of the planting of 1200 trees, creating a living, lasting and peaceful tribute to the lives of haemophiliacs infected with HIV via contaminated products. The grove of trees is not only a memorial to those who have sadly died but also shows the resilience and strength of those who are still affected and living with HIV. Working for a campaign group gives you the confidence to fight in other areas. We started Birchgrove north in 1995 which was based in Lancashire. The aim was to have us report back to say how the co-infected were getting on but we were dying at such a rate. With Birchgrove North we are able to try to get funding from the local government. At the end of each year they would have extra funding so we would try to get these extra funds to go away for a Christmas weekend or have a nice meal. Everyone could get everything of their chest and live a happier life. If you did not understand anything you could ask a friendly face. It gave everyone a chance to be themselves and be open but it needs time, energy and funding.

74. My wife was in charge of the hotels, GRO-C was in charge of getting freebees from companies and my job was to get the funding and write reports so we could get more money. I do not actively do it anymore; it stopped when I moved in around 2007/2008 because I could not physically cope with it.

75. Birchgrove North was brilliant when the American litigation was taking place.

Tainted Blood:

76. Today I support Tainted Blood. I am not as active with them at the moment because of my energy levels. The people in the group are amazing and fight tirelessly; it is incredible what they have achieved because Tainted blood has made sure people are not isolated and are aware of all that is happening. This is crucial as being alone can be worse than the illness you are suffering. They are up to date and current all the time..

Conclusion:

77. I believe the Department of Health was knowingly giving patients these blood products even though they were aware they were causing viruses. They carried on importing the products because the demand was so high. The Department of Health should have been honest with patients and at least told them there was a risk. Everyone trusts their doctor, but Haemophiliacs are born with their condition so I saw my doctor as a second parent and trusted them to do the best for me. It wasn't the doctors who were dealing with me who were at fault as most of them did not know there was anything wrong with the blood products.

Anonymity, disclosure and redaction

I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I want 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..... 30th NOVEMBER 2018

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Significant entries from medical records

29.07.1962	Born and diagnosed with severe Haemophilia A.
1979-1983	Infected with Hepatitis C and HIV.
04.1979	First tested positive for Hepatitis B.
17.01.1980	First mention of Hepatitis non-A / non-B.
21.01.1980	Confirmed Hepatitis non-A / non-B.
1979-1983	Administered the contaminated Factor 8.
01.1980	Suffered a bleed and jaundice.
02.06.1983	Letter stating I need to go for a blood test for HIV.
1990	First tested positive for HIV and Hepatitis C.
1990	First interferon injection.
19.11.1991	Manchester Royal Infirmary note indicating active Hepatitis.
1995	Had an AZT for HIV.
16.05.2003	Letter about vCJD.

2006	Type III cryoglobulinemia.
2007	Second Interferon.
2008	Spleen removed.
2008	Third Interferon.
2010	Fourth Interferon.
2011	Cleared Hepatitis C.
23.03.18	Saw a psychologist who confirmed memory loss was from Hepatitis C treatment.