GRO-C

Witness Name: J Cornes
Statement No: WITN1170001
Exhibits: WITN1170002-7
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MR JOHN CORNES

I, John Cornes, will say as follows:-

Section 1. Introduction

1. My name is John Cornes. My date of birth is GRO-C 1957 and I live alone at GRO-C GRO-C Birmingham, GRO-C This has been my home since 2011. I work for APCOA Parking Limited as an Administration Manager and I celebrated my 13th year with the business in September 2018.

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.

3. I was part of the biggest family of Haemophiliacs infected by contaminated blood GRO-C We were infected by contaminated blood products in the Queen Elizabeth Hospital in Birmingham. Four of my brothers have died as a result of being infected, leaving my brother GRO-C and I wondering who might be next.

4. We were known as *"the AIDS family"*, my brothers Gary, Roy and Gordon sadly died a terrible death from HIV. My brother Alan died in November 2017 from a stroke caused by stress related to being infected with the Hepatitis C virus.

5. My brother GRO-C is also infected with Hepatitis C. Thankfully; he has not developed cirrhosis of the liver and he is still alive.

6. When my brothers Gary and Roy were younger, they were in and out of hospital a lot more with bleeds related to Haemophilia. There is a 10 year difference between us. The older you get, the less you go in for treatment. But the problem is, when you are older, you have a lot more internal bleeds.

7. When we were younger, we were in bed all day every time we had a bleed there were no questions asked. I remember being at the hospital with my three brothers when the matron had told us off for being silly and laughing loudly together. There is nothing I would not give to be back with my brothers again.

8. **GRO-C**

9. This disease has impacted my life and the life of my whole family in a way I cannot quite describe. In life, you have a choice. You can either have your head down in the gutter, or keep your head high. I prefer to have my head high.

10. Life was different and so much easier when I was younger; it is far more problematic now than it ever was just having Haemophilia. Things happen now which would not have happened before, and age is not the only factor. Living with the effects of contaminated blood is very difficult.

Section 2. How Infected

11. I am a Haemophilia carrier A with low Factor VIII levels. My condition is classed as severe. I was infected with the Hepatitis C virus as a result of being given contaminated blood products.

12. I was infected in Queen Elizabeth Hospital, Birmingham. I was under the care of Dr Wilde at the time. He has recently retired. During my visits to the hospital, I spoke with Dr Wilde about my joints, but not really about being infected by Hepatitis C.

13. At the time when we were younger, my brothers and I went to a children's hospital until we were 15 years of age and then transferred to Queen Elizabeth Hospital for treatment. Gary and Roy went to Treloar school, but I am unsure whether they were infected there or not as there are no records of this.

14. I refer to exhibit WITN1170002 which is my treatment record and letter from University Hospital Birmingham containing a list of blood products, including their batch numbers, which I received between the years of 1979 and 1990. These include Lister, Factorate, BPL, 8Y and CRYO.

15. I was infected with Hepatitis C in approximately 1985. Although, I did not find out about this until approximately 10 years later in 1995.

Advice Given regarding the Risk of Infected Blood Products

16. Prior to being infected with Hepatitis C as a result of being given contaminated blood products, I was given no information or advice at all. CRYO and Factor VIII were seen as breakthrough treatments which helped my brothers and I get back to school and then work and avoid being in bed for weeks.

17. We were told that this was the new drug, but nothing was mentioned in relation to risks and dangers. I was never told about the lack of supplies within the UK and I was simply unaware and perhaps naïve not to ask questions.

18. The one word of caution which my brothers and I all heard when we were receiving blood products came from a family friend who was a Jehovah Witness. Perhaps I should have listened and not taken blood. I am a positive person, and I wanted to believe this form of treatment would help my brothers and me, perhaps even create a cure.

Discovery of Infection and Treatment resulting from the Infection:

19. I was first told about having been infected with the Hepatitis C virus in 1995. I remember receiving a very "*matter of fact*" letter to that effect. I was given no opportunity to discuss my condition further and I did not know about the effects it may have on my life.

20. After I received the letter notifying me I had been infected; I was given no further information or advice at all. I followed in my dad's footsteps; he had a Victorian attitude and he did not want us to feel sorry for ourselves as Haemophiliacs. I adopted his "*Get on with it!*" attitude when I found out about the Hepatitis C and did not ask questions following the emotionally-detached letter I received in 1995 which notified me of my Hepatitis C infection.

21. I was given no adequate information to try and help me understand or manage the infection. I did not have a chance to follow it up. The hospital had given me no advice nor invited me for an appointment to speak about it. I am quite methodical with things and if something was offered to me such as therapy or counselling, I would have taken it up.

22. I would have been asking a lot more questions had I been given the chance to. It is only in the past few years that things have developed to help people with the Hepatitis C virus.

23. I understand the pressure that Queen Elizabeth's Hospital was under and I was looking at things more openly, trying to see things from their side as well as considering my side of things. Nevertheless, I feel it would have been nice for the NHS to do a bit more for the community of the infected considering the vast number of us.

24. I remember that I was not given any information regarding the risks of others being infected as a result of my infection. I remember my partner, Helen, who was a medical scientist and was pregnant with Stacey (our daughter) at the time, had to ask all the relevant questions herself. She was aware about genetics and was able to get the information herself and prise the information out of them and she obtained lots of advice from her field. Yet, she had to ask the doctors herself and we feel that this information would not have been given to her freely.

25. This was similar to the situation which occurred with my ex wife GRO-C whom I call GRO-C GRO-C GRO-C GRO-C GRO-C

26. When I was given the Interferon treatment, I felt quite happy with how I was treated as the liver department were excellent. However, at the end of 2010 and beginning of 2011, my treatment failed and I had to wait a whole year to attempt the treatment again. The treatment involved taking 23 tablets per day and I felt like a junkie. Thankfully, I have now cleared the virus but damage has already been done.

Section 3. Other Infections.

27. I refer to exhibit WITN1170003, a letter from University Hospital Birmingham dated 29th January 2001, advising that *"it would appear"* I received a blood product from one of the CJD implicated blood batches.

28. I refer to exhibit WITN1170004, a letter from University Hospital Birmingham dated 24th September 2004, confirming I received UK source plasma derived Factor VIII between 1980 and 2001. This confirms I have received concentrate from a batch that had been contributed to by a blood donor who subsequently went on to develop CJD. I was told I was exposed to it, but I am still not sure how this is going to affect me. Again, this mirrors the way I had been notified of the Hepatitis C infection, this was a very matter of fact letter without any further information. I feel strongly that the NHS just does not want to know about infected people, they are not interested in the effects CJD may have on us. This could be another ticking time bomb.

Section 4. Consent.

29. To the best of my recollection, I do not think I was treated without my consent or without my knowledge.

Section 5. Impact

Mental and physical:

30. The mental effects of being infected with Hepatitis C are that my life has become mentally draining and sad. As a result of taking tablets to help clear the infection, I have become sick and I now suffer from depression for which I am also taking medication for.

31. After my brother Gary passed away in 1992 I split up with my wife GRO-C at the time. This was during my mid-30's; I had a mental breakdown and I went AWOL. I did not give a damn about things and I felt mentally detached. At the time, I was unaware about my own condition. If I was aware, I am not sure what further stupid thing I might have done.

32. I did not know what my other siblings were going through because we had not spoken about it at the time. I suffered from an emotional turmoil resulting from all of my brothers' conditions. Yet, the only way I felt I could survive was

to detach myself from reality. I decided to concentrate on everything else but the diseases which encroached into our family. I did not break away from this attitude and wanted to get rid of what was in my peripheral which was my suffering family.

33. Since 2010 and 2011 when I started acknowledging what was going on, it has been a tough life. I had a serious mental breakdown in 2011. Everything tumbled down. I had never acknowledged how I actually felt after my brothers' deaths, I never actually grieved. This was the turning point and the first time I was sent to a counsellor. I was scared of what I was going to do.

34. I am pleased I went to see the counsellor who was free of charge and provided by the NHS. I attended five visits, and he was brilliant. I like achieving things. I like to think that psychologically I am more open now. I believe you learn from things in life, I talk to people and it is important to talk about problems. I have been able to help others psychologically, and told others to look at life in a positive way; inevitably, only you can do something about it.

35. Unfortunately, I feel that the mental effects caused by mine and my brother's infections ruined both of my relationships and the relationships of others around me. My first wife, GRO-C who I have known since I was 12 years old, has a great personality. I still love GRO-C and we are great friends.

36. When I had the breakdown, my second partner, Helen, and I split up. This was in 2011, the year GRO-C split up with her partner, and my daughter, GRO-C also got a divorce.

37. When I was at the cemetery the other day, I was thinking how old my brother Roy would be, and I wonder what they all would be doing now. It is sad what happened. People learn from their mistakes. Hopefully, the hospitals have learnt theirs. It is sad, and there is nothing else I can say. I want lessons to be learned, nothing can bring them back. I want closure to this. Additionally, I feel that the infected and affected community should have compensation for

everything that has happened. Compensation for whatever life we have left, so that we would not have to struggle. Life really is a struggle.

38. I do not want to be a burden to people. I am proud of what I have achieved. I am not proud of how I have messed up my relationships, which I have been open about. After my second treatment of Interferon in 2011, the breakdown was a sign that it was all too much. What kept me from doing anything stupid was my youngest son Luke. He was young and I did not want him to think that I had taken the easy way out.

39. Following my breakdown, I am still on medication for my depression called Citalopram. Recently when the doctor asked if I could make the dosage smaller, I was tempted to try to wean myself off this medication but I decided against it.

40. I am a performer and to help with my mental health I get involved with amateur dramatics. This is how Helen and I met. Although she was a scientist, I did not feel I could speak to her about my condition. She knew about our family through the newspapers calling us "*Scum of the Earth*". Amateur dramatics is a way for me to get away from the real world, and I am lucky to have met Helen, and I am lucky that my daughter is a fan of what I do and is following her performing dreams.

41. In the recent years, I have started to look at the Tainted Blood websites and saw that I was not on my own. Although this was a way of trying to cope and look into it, sometimes I have to stop as it makes me depressed. Usually, I try to look for positive posts as a way of coping with things. I felt surprised at how many others were struggling and I also felt a huge sense of relief, not that others were struggling, but that others were going through what I was.

42. The infection has impacted upon my mental health as I have become a workaholic and I continuously feel afraid of when I might not be able to work; which in turn overlaps with the physical effects the infection has caused.

43. It is strange how your brain deals with things. People were surprised about me; first, a breakdown and then being a success at work.

44. The physical effects are that Hepatitis C has caused cirrhosis of my liver, and as a result of this I am regularly checked for cancer; every 3 months. I also suffer from diabetes and rheumatoid arthritis. Recently, I have been diagnosed with distended veins which can be life threatening. Now that I have been told by the consultant that I have distended veins, I feel as though I will have a heart attack. My heart is healthy, but mentally I constantly feel like this is a very real possibility. Moreover, tiredness is a real problem and I feel like I am fighting life all the time.

45. I refer to exhibit WITN1170005, a letter dated 16th August 2018, following my visit at the Gastroenterology Clinic, which confirmed that I have distended veins which are a life threatening condition in the context of Haemophilia. "*The gastroscopy showed distended veins in the gullet known as varices... It is important that we try and address this because bleeding of these varices may be life threatening, especially in the context of your Haemophilia A.*"

46. I have rheumatoid arthritis for which I have been taking the painkiller Diclofenac for a long time. My doctor advised me that this is affecting my liver negatively and I have recently been taken off this. The pain is a real every day struggle. All I was prescribed for my pain was Voltarol gel and Paracetamol which was simply not enough to ease the pain whilst walking. I could not walk. I have now been prescribed new medication; Carvedilol.

47. If I was to rate my pain out of 10; with 1 being low and 10 being high, it is generally a 3 when I am sat down, but a lot of the time it is a 10. This is an issue as although most of my job is carried out sitting down, my role involves managing staff and carrying out administration duties. After 13 years of service, I felt that I may not be able to work. But my employer has been fantastic and suggested I could work part-time with immediate effect in an attempt to alleviate my pain and make life at work manageable straight away.

In my head, I was crying and thinking *"I cannot do this, but I really want to"*. I felt lucky to be respected like this.

48. I love the film "*Chariots of Fire*". I have always thought that it was a fantastic gift to be able to run. The last time I ran was when I was a really young kid, but I kept getting bleeds and do not remember being able to run since. I generally cannot walk a lot because of the pain in my joints and in my feet. My whole body aches. I have always believed one's health is one's wealth, and when I watch the London marathon I absolutely love to see people achieving things physically. It is a great gift.

49. Mentally, I am able to control myself much better now and I am able to do things, but then my body takes over and this is out of my control. Last week, I went to the Queen Elizabeth Hospital with exhaustion. I had to have an infusion of iron due to my iron deficiency being so low. It gave me a little boost of energy. If I am tired, if I have a chance to lie down, I can go to sleep very easily.

50. At some point prior to 2007, I was diagnosed with diabetes. Although the hospital did not mention whether this was linked to having Hepatitis C, I do sometimes wonder.

51. I do not drink alcohol. I do not smoke. I currently take various medications such as Humulin, Metformin, Citalopram, Lansoprazole, and Carvedilol. I require iron infusions for my fatigue. I get the cirrhosis checked regularly and I have been put on beta-blockers following my recent diagnosis of distended veins. I will be on these for the rest of my life. I take Citalopram twice daily for my depression. The Lansoprazole helps regulate acidity levels in my stomach which has actually been caused by the number of tablets which I have to take. I also take Metformin 4 times daily for my diabetes. I also inject myself with Humulin every morning and every night and thankfully my diabetes is currently under control. I will now take Cocodamol as painkillers and Carvedilol which is a newly prescribed drug.

52. I have hospital visits mainly when I need a check up or when I get an internal bleed. I know when I get an internal bleed as it is very painful.

Educational effects:

53. The educational effect which Haemophilia has had on my life was missing approximately 50% of school time due to being hospitalised. Luckily, I have done well for myself. I completed an A-Level in Business Studies when I was much older. I decided to push myself and keep occupied. It felt great to achieve this.

Work-related effects:

54. In relation to work-related effects, I would describe myself as a successful professional. I worked in one business for 26 years, then I was self-employed for 6 years and now I have celebrated my 13th year with APCOA. When I filled out the application I disclosed that I was a Haemophiliac. When they questioned it, I was honest and told them what happened. The word *'blood'* made people react differently. I was personally not discriminated against and had an enjoyable career. However, after the Interferon treatment in 2011 which led to my breakdown, I ended up having three weeks off work. My area manager Mike was really understanding. I got on with him well. He advised that I could take as long as I needed. I felt I ought to have had longer than three weeks, but I am so conscientious about my work. Other than this, I have managed to work full-time throughout the years. It is only recently that I have had to start working part-time due to the diagnosis of a life threatening condition of distended veins in the gullet *"formed due to increased pressure within the veins that flow within the liver."*

55. I would like to work in the courts in the future. I find it fascinating and I am generally fascinated with people based work.

Impact on Family and Stigma:

56. We are the biggest family of Haemophiliacs infected with the Hepatitis C virus and we have had the most people die in our family compared to any others in the UK. There were seven boys; GRO-C of them were Haemophiliacs, and one girl.

57. I was never open about my condition at the beginning and in its early stages. The newspapers lied about who we were, what we said and what we had done. I never trusted the press. Really, right now I should be talking about how it affected me, and not drag my family into it. But in our family, everyone was affected.

58. My brother Gary contracted HIV and Hepatitis C and he died aged 26 in 1992, leaving behind a widow, Lee and his son, who he adored. I remember at the start when Gary told me he had HIV we went to his house, and we all thought it was just another type of cancer. He called us all around and told us. We had heard of it, but this was before people knew exactly what it was. We were not scared as we did not think we needed to be. There was no public knowledge, and this is why it was not scary.

59. Within a few months, my brother Roy was told he was also HIV positive. Unfortunately, Roy infected a 20 year old girl, Gina, who sadly passed away. This was publicised by the newspapers and this story was overly exaggerated as per exhibit WITN1170006 entitled "*A man accused of deliberately infecting four women with the Aids virus has died in hospital*". But the reality was that "*people made him out to be a monster, but Roy was a kind, caring and lovely man*". I remember we had reporters at the doors of our homes, we felt they were trying to rip the family apart accusing my brother of deliberately infecting girls. At the time, I remember thinking, Freddie Mercury passed away from AIDS, and I remember questioning why we were being targeted. Roy had not gone out promiscuously; he was infected by contaminated blood products. The truth is, we did not know much about the disease itself, the risks or the

dangers. Roy especially did not know the impact or how it could be passed as he was simply never told. Roy passed away in 1994.

60. My brother Gordon, also HIV positive, died eighteen months after Roy around Christmas time. When he was diagnosed with HIV, he told us about it but then retracted it. It was all psychological. Maybe this was his way of dealing with it.

61. I remember when Gary was dying; Roy and Gordon looked at each other, and I remember they both had a look on their face, contemplating who would be next. At Gary's funeral, after the papers had already been writing stories about our family; *"Scum of the Earth"* being one of the headlines. There was approximately 50 reporters at the cemetery behind the trees, taking photographs of the service. I remember our mother crying and not understanding the press.

62. This was the same when Roy died. People came to the cemetery to throw stones and even wrote *"Shit"* on his grave. I remember there being a comment *"Hurray! He is dead!"* As bad as this may sound, it felt better when we found out there were other families called the AIDS family. We were no longer alone.

63. In February 2000, Gary's wife Lee died after having contracted HIV from Gary, who was buried with him.

64. My brother Alan passed away in November 2017 as a result of his infection.

65. Our mother Audrey was previously a big, strong woman; a bit like the ones in Les Dawson sketches. She used to put on a tough outer shell to encourage us boys to be strong. When we were kids fighting in the streets, our mother would march up to us with her strong and good character and she would make you laugh. Our parents were the complete opposites, if mum knew how to embarrass you, she would! When she lost three of her sons, and knew that there might be two more, the shell crumbled. She became thin and gaunt, and in 2002 she died, too. I spent about five years grieving for my mum.

66. My family are buried at Lodge Hill cemetery. They are all buried together. Our mother is buried with Roy, Gary and Lee are also together, Gordon lies next to them and Alan's ashes have been scattered on the grounds.

67. My brother GRO-C suffers from Hepatitis C but has not developed cirrhosis. GRO-C GRO-C GRO-C

GRO-C

68. Our dad was the disciplinarian. He had a Victorian attitude and I followed my dad in his positive outlook on life. I feel that if there is a negative, people can always try to find a positive.

69. Being only aged 51, I have planned the details of my funeral. My brothers and I have had to do this at a young age, as we all knew our time would come sooner rather than later. I have chosen "*Tiptoe through the Tulips*" for my funeral service, and Polly was laughing at me because I like all the silly things. People plan their funerals, but not in the way we have had to.

70. GRO-C GRO-C My sister Merle nursed Gary, Roy, Gordon and then our mother Audrey. She was there helping every single day. GRO-C GRO-C She has become a loner and does not socialise. I am very close to my sister and try to take her out weekly; I feel this might help her cope. She also has her grandkids, but is very much an introvert now.

71. Life is too short to be angry.

72. The impact this virus has had on our family is that my ex-wife and I decided to legally change our older children's surnames. This was so that no one knew they were a part of "*the AIDS family*" and to avoid stigmatisation because it was really bad at the time. This caused my mother a lot of upset, but we wanted to protect our children from the "*Comes*" name, or rather our negative

reputation. This was when Hayley was 12 years old and was attending a GRO-C school at the time.

73. GRO-C

74. Following being labelled as *"the AIDS family"*, our house doors were labelled with messages such as *"scum"* and *"shit"*. We considered changing our family names entirely. But today, I am glad we did not.

75. My younger kids, Stacey (20), Elizabeth (15) and Luke (11) do not talk about medical things. I love them very much, and it is them who have kept me going. I am *"happy go lucky"* but there is a lot of stuff inside which makes life difficult. My older kids, Hayley (40) and Ryan (38) do talk about medical matters with me. They both want me to stop working and look after myself more. But I feel, even if I did not need the money, I would still want to work. It keeps me going. They are aware of the struggle our family has been through as Polly told them about my brothers and our family.

76. I would like to be around when my youngest becomes an adult. What an awful thought to have to think.

77. All my kids are involved in activities and have a busy life. This is a good thing. When we spend time together, we concentrate on the good. Elizabeth knows the basics but Luke is too young to understand. Stacey and I FaceTime twice a week and she's a busy actress. This infection has affected my nephews and nieces in different ways. I am very careful about who I may talk to in relation to my brothers. There was one reporter who actually apologised to our family. This was years ago. But I am still careful of the possible sensationalisation and how this may affect the younger generation.

Financial:

78. The financial effects of being infected with Hepatitis C are that I am now unable to work full-time. I have an understanding employer, and I would struggle a lot more if I was not this fortunate. If I did not work, I would not have any money. I am not sure what benefits there are. When the going gets tough, the tough get going.

79. Of course, holidays and travelling are not a possibility. As well as physically, this is a struggle financially. I take home £800 per month, and half of this goes to Helen as money for Elizabeth and Luke. Insurance is also a problem as in the eyes of an insurer although I am cleared of Hepatitis C, I am still a liability. I also feel scared to go away, in case something happens and my health deteriorates quickly.

Section 6. Treatment/Care/Support

80. In relation to psychological help, I now feel I should have been provided with this help as soon as it was discovered that I had been infected. I refer to paragraphs 34 and 35 of this witness statement.

Section 7. Financial Assistance

81. When I was first told of the infection, I received £20,000 from The Skipton Fund. Later, when I was diagnosed with cirrhosis, I received the Stage 2 payment of £50,000 in June 2011. This was not compensation as such, it was known as "*compassionate money*". I have been receiving £1100 per month and last April this increased to £1500 per month.

82. I used this money to put a deposit on a small, quaint apartment where I feel happy. It is my home. However, I only own 50% of it as due to my diagnosis of cirrhosis I am not allowed a mortgage. I wish I could own the other half. Financially, I think of things such as not putting the heating on to save money.

This really affects my joints, as the cold really affects them. It feels like a never ending cycle and I feel that compensation to alleviate problems as such is necessary.

83. The application for the money itself was really easy. I personally had no idea I was entitled to anything. It was during my appointment with Professor Mutimer at Queen Elizabeth's at the liver department that he told me about the £20,000 payment. He got the nurse to come in and we filled out the forms straight away. I had heard of other funds, but I have been working all of my life and did not think I was eligible and I never asked for money.

84. I believe compensation should be granted for the rest of our lives so that we can live without having to worry about finances. We already have enough to worry about. It would be nice to give my siblings some money due to also being negatively affected by all of this.

Section 8. Other Issues

85. Other than the issues I have already mentioned, there are no other issues to the best of my recollection.

Conclusion

86. When I was watching the opening hearings, I got so emotional I could not continue to watch them all. Going forward for young Haemophiliacs, I see what happened to our generation and the suffering we went through and I pray that lessons have been learned so that future generations are protected. I have 8 nephews who are Haemophiliacs and I believe that something good will come out of this tragedy provided that lessons have been learned.

Anonymity, disclosure and redaction

87. 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 would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.... GRO-C ..

Dated.....09.11.2018.....