

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1766001

Exhibits: WITN1766002 - 019

Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I **GRO-B** will say as follows:-

Section 1. Introduction

1. My name is **GRO-B** I was born on the **GRO-B** and I live at **GRO-B** **GRO-B**
2. I make this statement on behalf of my late father, **GRO-B: F** who was born on the **GRO-B** and died on the **GRO-B** 1991 as a result of receiving contaminated commercial blood products intended to treat his haemophilia. He was infected with HIV/AIDS, Hepatitis B (Hep B) and Hepatitis C (Hep C). Whilst it seems unlikely, having reviewed his medical notes it appears possible that he may also have been infected with Creutzfeldt-Jakob disease ('vCJD') or a different neurological condition for reasons explained below, although I am not sure about this. I also wish to make points on behalf of my mother who was infected with HIV when my father inadvertently passed the infection on to her as a result of their intimate physical relationship.
3. I live with my wife and **GRO-B** children, **GRO-B** and **GRO-B** years old. I am currently working as a **GRO-B**

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4. I would like to make it clear at the outset that I believe that the vast majority of those in the medical profession are good and honest people providing an excellent service in difficult circumstances. Despite the fact that both my father and mother were tragically infected with HIV as a consequence of this disaster, my mother can give some fantastic examples of excellent medical treatment throughout her life. I have never previously been part of any campaigning groups (although completely understand why others have felt compelled to do so) and only requested my father's medical records when I heard about the public inquiry. If I'm honest I didn't expect to find anything out of the ordinary and certainly did not approach the task of reviewing my father's medical records with a cynical mind. However, unfortunately I made some surprising findings when reviewing the notes which until explained are rather suspicious and this is why I now feel it is necessary, on behalf of my late father, to raise questions in a 'leaving no stone unturned' approach. I hope that the doctors in question will understand that there is no implied criticism in what is essentially a task of trying to establish the facts both before and after my father's death.
5. This witness statement has been prepared without the benefit of access to my late father's full medical records. Whilst I was provided with a relatively large bundle of records in January 2019 that I had requested from the Royal Victoria Infirmary Hospital (RVI) in Newcastle where my father received treatment for his haemophilia, it appears that some records may be missing. For example there are no notes detailing significant consultations that I know took place, such as when my father was told he was HIV positive. Other documents have been heavily redacted and I can't understand why as it is clear that some of the redactions, that I will refer to in more detail below, could not possibly have been made to remove reference to third parties. The notes also appear to indicate that it was known/believed that my father was infected with HIV from at least 1982, possibly much earlier. He was not told of his HIV infection until 1985. The precise dates of infection with Hep B and Hep C are not clear. He was however described as 'jaundiced' following his first self-administered home treatment with FVIII when he was 13 years old. I have not

requested GP records and assume they no longer exist. The entries that I consider to be most relevant are exhibited and attached to this statement.

Section 2. How Affected

6. My father was diagnosed with severe Haemophilia A from the age of 9 months.
7. He received Factor VIII concentrates (FVIII) to treat his bleeds from being a young child up until his death on the **GRO-B** 1991. The medical records show that he regularly self-administered FVIII at home and also received FVIII at the RVI very regularly throughout his life. He started self-administering FVIII at home when he was 13 years of age. He also had numerous blood transfusions throughout his life and there is reference for example to a blood transfusion following a tonsillectomy when he was 14 years of age. There is also reference to a severe allergic reaction to Cryoprecipitate when he was 16 years of age. His treatment included but was not limited to Hemofil,, Koate, Factorate, Profilate, NHS products and Humanate and the batch numbers for all of the products are recorded although the treatment record appears to be incomplete.
8. The medical notes that I have received reveal that my father had a blood test on the **GRO-B** 1984 which produced the first *documented* positive test for HIV in **GRO-B** 1985. My mother and father were told of this first *documented* test and positive result shortly thereafter early in the year of 1985. The limited medical records that I have do not include any earlier HIV tests (positive or negative) but for reasons documented below it now appears that the true date of infection was much earlier. The medical records indicate that my father's treating Consultants may have known or suspected that my father had HIV several years before he was eventually advised, which I will explain in more detail below.
9. The medical notes were provided to me earlier this year with a covering letter from a Consultant Haematologist at the RVI which is exhibited at 'WITN1766002'. In this covering letter, the Consultant points out that earlier

HIV tests were filed separately from individual patient records. The Consultant explains that a copy of a cumulative list which refers to my father cannot be provided as it contains other patient's names. I found this letter to be a little odd for two reasons. Firstly, I had made a straightforward public access request for my father's medical records. Whilst I had indicated on the standard form that must be completed that the reason for the request related to the pending Public Inquiry, I did not ask any questions about HIV testing or the date of infection. I would have expected that a request for medical records would be a straightforward administrative task that would not necessitate a review/interpretation of the notes by a Consultant Haematologist. It was clear that the notes provided to me were not originals and I later clarified this with the subject access team at the hospital, who confirmed in an email to me dated GROUP January 2019 that the original notes had been destroyed after being scanned into a computer system some time ago, although I don't know when this occurred. On this basis, I would have expected that the task of providing me with notes would simply involve printing from a computer, at an administrative level, and then redacting to remove reference to third parties prior to posting. I would therefore be interested to find out, if possible, why the notes were reviewed by a Consultant Haematologist. I acknowledge that there may be a perfectly reasonable explanation and I mean no discourtesy to the Consultant when raising this question, but hopefully it will be clear to anyone reading this statement in full, given some of the findings and peculiar redactions within the medical records discussed below, why I now wish to know more about how the notes were redacted and handled generally.

10. The second reason why I found this covering letter to be strange concerned the content itself. I was a little surprised by the suggestion that a cumulative list existed which related to my father which could not be provided to me. I would have expected that any cumulative lists could simply be reacted, heavily if necessary, to remove reference to third parties. Also, the reference to there being 'variability' in results in relation to some of the earlier testing seemed a little strange. I inferred from this that the Consultant was hinting that my father may have been tested at an earlier stage (i.e. before the first *documented* test in December 1984 / January 1985) but that there was some

uncertainty and thus these results were perhaps not disclosed to him or included within his own medical records. It seems clear to me that if an earlier warning could have been provided to my father, even if it related to inconclusive results, then it ought to have been, especially in light of the fact that my father went on to inadvertently pass on the infection to my mother as explained further below. If there was a policy in the 1980's against sharing full information with patients about HIV testing and results, even if those results were inconclusive, then I would not criticise the consultants in question but would suggest that the policy was clearly dangerous and inappropriate. I would also add that if a policy exists today which led to the hospital deciding against sharing the notes (those referred to as being 'filed separately' in the covering letter) which would evidence the earlier results with me, so as not to allow me to share them with the public inquiry, then in my view this is also an inappropriate policy.

11. In summary, it felt to me as though the covering letter was almost attempting to explain an omission or perhaps address a criticism which hadn't been raised. I wish to make it clear again at this stage that I acknowledge that there could be a perfectly good reason for this covering letter and I mean no discourtesy at all to the Consultant who was responsible for drafting it when asking these questions. It may be that they were simply trying to assist my understanding of the case. However if there is a policy which requires Consultants to cast an eye over medical notes in cases of this nature, to not disclose notes 'filed separately' and to then draft covering letters seeking to explain the omission of certain material then whilst I would have no criticism of the doctor's concerned, I would be suspicious as to why the policy was considered necessary.

12. I found the redaction of some documents within the medical records to be extremely strange. Whilst I understand the need to comply with data protection laws and remove references to third parties, there are countless examples within the notes of redactions that clearly were not made to conceal personal data or references to other parties. Letters to my father are heavily redacted with several paragraphs removed. Whilst it is possible that my

mother was referred to in places, it seems highly unlikely that all of the redacted paragraphs related to her. However, one example of redaction that it would appear could not possibly have related to a third party is a prescription sheet, a copy which is exhibited at 'WITN1766003'. This medical record quite clearly relates to my father, [GRO-B]. There is no reason why any third party would be mentioned on it and it's clear that the redacted entries concern medications provided to him. One of the 'regular prescriptions' has a black line through it so is completely redacted. Two 'one only and premedication drugs' have lines through them and cannot be read. It is clear from the unredacted entries that this concerned the month of January 1990. This was a long time after my father was officially told that he was HIV positive in 1985 and just over a year before he died in [GRO-B] 1991. I exhibit another example of a heavily redacted prescription sheet at 'WITN1766004'. This prescription sheet clearly relates to medication provided in May 1988. Whilst there may be a perfectly legitimate explanation, I cannot think of any logical reason to remove the ability of those reviewing the medical notes in the future to ascertain precisely what treatment an individual received. If the redactions were made to hide information from my father or anyone looking at the case subsequently, I am genuinely baffled as to what they related to or why it may have been considered necessary. I could speculate that the drugs could have related to treating Hep C, perhaps prior to my father being told he had it but the truth is I really don't know.

13. If it is something that the Inquiry can establish, I would be interested to know exactly when the notes were redacted. Shortly after initially receiving the medical records I emailed a [GRO-B] at the subject access team at the RVI to ask whether the original notes had been destroyed, as it was clear that the notes I had were photocopies or printed from a computer system. He replied to confirm that the original notes had been destroyed (although did not confirm when this took place) and that prior to destruction they had been scanned to the archive database. I am therefore curious to know whether the notes were redacted prior to being scanned onto the computer system and destroyed (whenever that was), or if alternatively, were the notes only redacted at the point of requesting copies towards the end of the year 2018

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after being printed? I noticed that one of the documents within my father's records had been redacted on two separate occasions. I could tell that this was the case because most of the redactions on the page were printed redactions (only visible on one side of the page) whereas another line had been redacted in pen and could still be seen clearly even when the page was reversed. This suggests to me that the original notes may have been redacted at a much earlier date, prior to being scanned onto the database and destroyed, with there perhaps then being additional redaction when printed and reviewed further to my request towards the end of the year 2018. If this is correct, I would be interested to know whether there is any explanation for the redaction of notes that were simply being scanned to the archive database. I would have expected that redactions should only occur at the point of notes being requested by a third party. Redaction of the notes at any time before I requested them would raise suspicion if unexplained. No-one else had requested my father's notes before I did towards the end of the year 2018.

14. One of the documents within the medical notes reads *"This confidential file has been created to provide... patients health status" "In most cases, results of HTLV111 will be known to patients concerned. However please be circumspect in your approach; if you are unsure of how to Counsel please refer immediately to Haemophilia / Haematology staff on call."* I exhibit a copy of this document at WITN1766005

15. This use of the word "most" appears to indicate that not all patients were advised of their HIV status immediately, something my mother tells me that my father always suspected. This document suggests that this was an adopted policy as the document is clearly intended as a reminder/memo to medical staff to be "circumspect" in their approach – in other words, not to mention the positive HIV status to a patient without first checking with the Haemophilia staff that the patient in question was actually aware. It could be suggested that this may be appropriate in the case of children, but if this policy only concerned children why wouldn't the document refer specifically to children or those under a certain age? The presence of this within my father's medical notes would indicate that the policy was adopted in relation to adults

also as it would appear that it was a cover sheet for a separate 'confidential file.'

16. After receiving the strange covering letter and reviewing the medical notes, I sent an email to the subject access team on 7 January 2019 with numerous questions. I asked whether there had been any earlier HIV tests concerning my father, whether there were any other medical notes relating to my father that had not been disclosed and questions in relation to the redaction process as mentioned above. I exhibit a copy of the email correspondence at 'WITN1766006'. GRO-B at the subject access team at the RVI replied that same day to explain that redactions are applied for GDPR purposes, but he did not clarify when the redaction process took place in relation to my father's medical records. He confirmed that he would pass on my other questions to the relevant department and would respond in the "near future." I did not receive a response so chased this with an email on 12 May 2019 but still have not received a reply. The exhibited email correspondence covers my initial request on 7 December 2018 through to my chaser email on 12 May 2019.

17. My mother recalls attending a meeting in Newcastle with my father when all haemophiliacs in the Newcastle area were told by Consultant, Peter Jones that there was a risk to haemophiliacs of being infected with HIV via FVIII. My mother explained that my father said to her immediately following that meeting that he suspected that those treating him probably already knew which of the haemophiliacs were infected.

18. I do not know what led him to believe this at the time, but sadly there are documents within his medical records which appear to indicate that he may have been correct. Whilst my mother is not sure of the precise date of the meeting referred to above, it was definitely prior to 1985, when my father was officially told by Dr Jones that he was HIV positive for the first time. There is no record of this consultation within my father's medical records.

19. I exhibit at 'WITN1766007' a documented headed "Newcastle Health Authority" which contains an entry dated 02.05.88. This is a few years after

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my father was first told he was HIV positive in 1985. The document notes that my father is aged GRO-B which makes sense as the document relates to May 1988. Significantly, it reads as follows:

1. SEV Haemophiliac A
2. HIV Positive (triangle) ix 1982

20. A triangle is a medical abbreviation for 'diagnosed' and 'ix' could be a medical abbreviation for investigation. Either way, it seems clear that whoever wrote this knew or had reason to believe, in 1988, that my father had been HIV positive since 1982. This is a rather shocking revelation as my father was not told of his positive HIV status until after the first 'documented' positive test result in January 1985. If my father was known to be HIV positive in 1982, he could have been advised. Alternatively, if subsequent investigation (perhaps with reference to batch numbers of the blood products given to my father) had established that the true date of infection was 1982, then he should have been advised of this in 1988 which is when this document was produced, or whenever this information was first known if this had been established earlier. It was clearly apparent to whoever made these notes and should have been shared with my father. The year 1982 was 2 years before he started a relationship with my mother and of course the HIV infection was subsequently transferred to her.

21. I believe that the reference to 1982 as the date of infection with HIV is likely to be accurate. This document appears to be a scientific and faithful record of what was known at the time. For example, whoever wrote this was aware that my father was allergic to Cryoprecipitate as a teenager (sadly I note that this was overlooked when he was given Cryoprecipitate in hospital only a few months before he died, although I wouldn't suggest that this mistake contributed to his death given how ill he was at the time). It seems therefore that whoever made these notes had the 'full picture' and was aware in 1988, that my father had HIV from 1982. This should have been shared with my mother and father. Other reasons for me believing that my father was infected with HIV in 1982 are set out below.

22. My mother confirms that my father always suspected that his seroconversion took place when unexpectedly he collapsed in a GRO-B This incident does not appear within the medical notes so my mother cannot be precise with dates but believes it was around the year 1982.
23. Dr Jones, who treated my father at the RVI, contributed to a Radio 4 program in the year 2016 concerning the contaminated blood disaster entitled 'the reunion' which is still available to access online. In the programme he commented that "the first patients were identified as being HIV positive in 1982" and they subsequently "tested everyone." This would be consistent with my father's HIV infection occurring or being known about in the year 1982.
24. There are Haemophilia Patient Monitoring Records dated 13/10/83 and 28/06/84 which I exhibit at **'WITN1766008'** which refers to abnormal findings on general examination. The words 'No lymphadenopathy' appear in a column that usually doesn't contain any comments on other examples. This is something you would look for if you thought that a patient may be immunocompromised and so this may indicate that they were aware of or concerned about his HIV status at this time, well in advance of the first 'official' positive test result in January 1985, from a sample taken in December 1984.
25. I refer to exhibit **'WITN1766009'** which shows that on 28/02/84, in his review of my father, Consultant Haematologist, Peter Hamilton sends a request to the Clinical Biochemistry Lab at the RVI for testing of blood with the comment 'Auto a/b's and immunoglobulin please.' It may be that 'auto a/b's' refers to autoantibodies, which are found in autoimmune diseases so again this may indicate testing for HIV, although I am not sure if this is correct. This is several months before my father started a relationship with my mother and again well in advance of the 'official' first positive test result in January 1985.
26. On 28/06/1983, a year and a half prior to my father being advised he was HIV positive, Dr Jones makes a request for "T Cells please" on a blood test form, which I exhibit at **'WITN1766010'**. The handwritten notes to the left of the box on the right-hand side and above were made by my mother and can be

ignored. I understand that T cells are monitored in HIV positive patients. An earlier test was done in 1982 and a copy of this is exhibited at **'WITN1766010'**.

27. My father's medical notes detail an incomplete yet comprehensive record of the batch numbers of FVIII products that he self-administered and was provided with by the RVI during his lifetime. Internet research surrounding the different FVIII products and batch numbers led me to a timeline on the website taintedblood.co.uk. This timeline links to a document dated 10/09/1984 which I exhibit at **'WITN1766011'**. In this document the Public Health Authority ('PHA') present tables concerning the number of patients who have received 18 different batch numbers, which it was known had been provided to two haemophiliacs in Cardiff and Bristol who had died of AIDS. Of the 18 batch numbers listed in that 1984 document, a cross reference with my father's medical notes revealed that he received three of the products mentioned in the PHA document. The first was batch number '110477P1' which it would appear was 'Hemofil' and administered on the 01/11/1978. I exhibit a copy of the batch number at **'WITN1766012'**. The second was 'A12710' which is described as an 'NHS' product and was administered on 10/04/1981. I exhibit a copy of the batch number record at **'WITN1766013'**. The third was A12780 which on the attached cumulative list of products given to my father between March 81 and October 83, which I exhibit at **'WITN1766014'** dated 06.08.1981. The fact that my father definitely received three of the 18 products that were flagged up by PHA on 1984 suggests there is a good chance that he was infected with HIV with one or more of the products. This document was not made available to those affected or to the general public at the time. The fact that the PHA were able to specify within exhibit **'WITN1766011'** the precise number of patients who had received one or more of the batch numbers of concern, evidences that they kept full records of which patients had received the different batch numbers and therefore were in a position to advise patients of the heightened risk of infection with HIV. It is alarming that this information was not immediately communicated to my father in 1984, especially when one considers that my mother was infected with HIV by my father well after this date. The failure to advise patients when this

information was available was clearly a significant error. It is analogous to a car manufacturer, aware of a problem affecting brakes which has already killed two drivers and in possession of the contact details of a group who are also likely to be similarly affected, deciding against notifying the relevant parties to warn them of the danger. Even this analogy doesn't quite do justice to the failure to act given that a problematic braking issue would at least be confined to a limited number of vehicles, but this was not the case with HIV infection which could, and would, be passed on to others.

28. My father's medical notes confirm that he was infected with Hep B (exhibit **'WITN1766010'**, 2nd document) and my mother has confirmed that he was aware of this. It is also clear from my father's medical notes that he was also infected with Hep C. There is a reference within my father's medical records to him being 'jaundiced' when a teenager following his first treatment with FVIII. In addition, there is a blood test record dated 27/03/1990 confirming a positive Hep C result. A copy is exhibited at **'WITN1766015'**. A letter dated 17/12/1990 from Consultant Peter Hamilton to my father's GP refers to his liver being enlarged by "several fingers" in the years leading up to his death. It now appears however that the Hep B and / or Hep C may have played a significant role in my father's decline and ultimately his death. In a letter from Dr Hamilton to my father's GP dated 31/08/1990, which I exhibit **'WITN1766016'**, 9 months before my father's death, he states that "we know that he is almost certainly Hepatitis C antibody positive" and comments, "I just wonder whether some of the problems that he is having are not those of a chronic grumbling hepatitis." In summary, my mother and I have always believed that HIV/AIDS was responsible for my father's death but now it appears that Hep C together with other infections may have played a significant role. My mother states that my father was advised at some stage between 1990 and his death in **GRO-B** 1991 that he was believed to have Hep C, but it was presented as being insignificant. My mother states that although it is clear from the medical notes that my father's treating consultants were considering treating him with Interferon, that this was never mentioned to him at the time.

Section 3. Other Infections

29. Whilst there is no reference to vCJD in my father's medical records and it was not something that was ever discussed as a possibility with my mother and father whilst he was alive, I do now wonder whether he may also have been infected with this or something similar which affected his brain / central nervous system. I am aware that others were infected with vCJD at the RVI with contaminated blood products to treat their haemophilia. My mother recalls seeing another haemophiliac patient at the RVI who had been given contaminated blood products who was shaking and unable to walk. My mother confirms that my father was extremely unsteady on his feet within the last years of his life, falling repeatedly. It is documented within my father's medical notes that he commented that his feet felt "like jelly" and that he felt like his feet were 'flapping' and he was sleeping all of the time. It appears that there was a neurological condition in the background which was investigated with a brain scan showing abnormalities that were unexplained, with there being speculation about tuberculosis being a possible cause. I exhibit at **'WITN1766017'** handwritten entries concerning my father's treatment in **GRO-B** 1991, just two months before he died. The notes confirm that an MRI scan was undertaken which shows 'multiple lesions' to his brain. Unfortunately, the remainder of the sentence was crossed out and is unreadable. The notes confirm he was to have a lumbar puncture which I understand can be done to diagnose disorders serious infections and disorders of the central nervous system. I exhibit at **'WITN1766018'** a report from a Radiologist dated 13/03/1991 discussing the MRI scan. It is clear that the abnormalities observed are not explained solely by the HIV infection. My mother recalls being advised by his treating consultants that they were 'stumped' as to what was causing him to be so ill in the months leading up to his death. I exhibit at **'WITN1766019'** a letter dated 17/12/1990 from Dr Hamilton to my father's GP. In this letter he details how my father had advised him that "if he is running for a bus he feels his feet flap". In 2004 due to concerns raised in relation to vCJD and contaminated blood, the Government banned all those who had received a blood transfusion since the 1980s from giving blood. This would have included my father if he was still

alive as he received blood transfusions and FVIII throughout the 1980s and up until his death. This suggests there is some uncertainty on the part of the Government as to whether those receiving blood products in the 1980's were in fact infected with vCJD. In the year 2004 the Public Health England published a list of 14 batch numbers which were considered to be vCJD implicated. I understand that only those who had been given the relevant blood products who were still alive were notified, so my mother and I would not have been notified if the Government believed my father had been affected. I did not find any of those batch numbers when cross referencing them with my father's medical records although my father was given FHC0278 which appears close in number to one of the implicated batches, namely, FHC0289, but I do not know whether a similarity in batch numbers tells you anything about the date of production. My father was such a heavy user of the FVIII products that I feel there was a good chance he would have been infected with anything contaminating the products in the 1970s and 1980s. I have no idea whether it is plausible that my father could have been infected with vCJD as it seems from my research that it is believed that vCJD related deaths only occurred in England after my father had died in 1991, but I wonder whether this only refers to the first 'known' cases and maybe earlier victims, who passed away before testing for this condition became routine, were not therefore identified? Even if the possibility of vCJD infection can be ruled out by experts when dates are considered however, it appears that my father had some form of undiagnosed neurological condition which it appears may not have been explained by the presence of HIV/AIDS.

Section 4. Consent

30. I do believe that my father may have been treated and tested without his knowledge and consent. For the reasons explained above including the redaction of prescription sheets, reference to HIV diagnosis in 1982 and possible examples of earlier testing for HIV, well in advance of the first 'official' test in January 1985, it does appear that he was tested without his consent and that information was withheld from him. There may be an explanation for the redaction to the prescription sheets but if not, then it

appears that he may have been treated without his consent as I cannot otherwise think of any good reason to remove reference to treatment history from medical notes.

Section 5. Impact of the Infection

31. Whilst I will address the impact that this disaster has had on me briefly, I wish to stress that I would probably not have felt it necessary to provide a statement dealing with the impact on me personally as luckily thanks to an amazing mother and fantastic upbringing I have always been extremely happy in life. I am acutely aware of the fact that my own experience pales in comparison to the experience of many others affected, especially those who tragically lost children.
32. The main reason that I wish to contribute to the Inquiry therefore is to do so on my father's behalf as he is not here to explain how it affected him and whilst my mother is providing a statement separately, I also wish to make points on her behalf as it may be that I recognise ways in which this has affected her that she may overlook. I will then also briefly cover the main ways in which the disaster affected my life.
33. I cannot begin to imagine the emotional turmoil that my father must have suffered as a result of his infection with HIV. My father was a young professional [GRO-B] and had moved in with my mother who was also starting her professional career. My father by all accounts had a fantastic social life with some very good friends. My mother and father [GRO-B] [GRO-B] when my father was given the devastating news that he was infected with HIV. As a result, my father must have known at the age of [GRO-B] that he was almost certainly going to die young and suffer a painful death. Aside from losing a child, being told you are going to die young must be one of the hardest things any person has to deal with in life. One of the few comforts available to most parents in this situation is that their spouse and child/children will go on to live long and happy lives. Unfortunately for my father, within a few years of being told he was HIV positive, he was told by his

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treating consultant that his wife and the mother of his [GRO-B] year old son was also HIV positive.

34. As a father of [GRO-B] young children myself, I cannot imagine how hard it must have been for my father to be told firstly that the HIV had progressed to AIDS and he was close to death and secondly that his wife also had HIV meaning that their [GRO-B] year old son now seemed destined to lose both parents. Thankfully and perhaps miraculously, my mother has proven to be incredibly resilient to the HIV infection and remains in good health, despite now having to receive treatment. It is desperately sad that my father died not knowing that this would be the case.

35. My mother has explained that my father suffered terribly in the years leading up to his death with a range of embarrassing, painful and debilitating conditions. His medication on [GRO-B] 1991, just 2-3 weeks before he died included the following:

GRO-B

GRO-B

36. My father suffered with

GRO-B

GRO-B

GRO-B

AS

stated above, there is also reference within his notes to an interpretation of an MRI scan in [GRO-B] 1991, [GRO-B] before he died, which comments upon low density areas and some mass effect in the brain. The radiologist does not appear to know the cause commenting that, "the pathology is uncertain" and they also state "even TB should be considered."

37. My mother told me how she used to start at my father's head and work downwards when providing him with his medication and treatment towards the latter stages of his life. Treatment included but was not limited to

GRO-B

GRO-B

GRO-B

This was a man in his late

twenties who had only a few years previously taken part in the

GRO-B

GRO-B

38. It is desperately sad to contemplate both the physical and psychological pain that he must have endured as a result of this disaster. I am extremely proud to hear from my mother about how brave he was and how determined he was to carry on with life despite all of the above and this is also clear when reviewing his notes.

39. My father was given treatment for HIV which included AZT and Zidovudine. He also took part in

GRO-B

Given the huge number of ailments that he suffered with it is difficult to ascertain which may have produced side effects, although it is noted within the records that he was 'intolerant' to Zidovudine.

40. I would also like to briefly touch upon how I believe this has affected my mother. She was a recent graduate from university in the 1980s when she met my father, who she would go on to marry. At a very early stage in their relationship, she had to take on board the news that he was HIV positive. I was born approximately 9 months later and when I was

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that she had the courage to do so. She really is an inspirational woman who despite the most horrendous circumstances has maintained a **GRO-B** **GRO-B** has helped others throughout her life and has been a fantastic mother.

41. After my father passed away in **GRO-B** 1991 when I was **GRO-B** years of age, my mother was later taken advantage of by a man who was only introduced into our lives via his role at **GRO-B** because of the circumstances involving my father's death. Unfortunately, this man was highly manipulative and abused my mother both physically and emotionally. My mother has always kept her HIV status a secret and still does due to the stigma that is unfortunately associated to it. This man threatened to tell others about her condition in order to trap her in the relationship. We lived with this man for several years until he moved out when I was **GRO-B** years old.

42. When I was a teenager my mother met a lovely man who treated her well. My mother became pregnant with my younger sibling when I was **GRO-B** years of age. My mother was advised of the relatively small risk of the infection being passed onto the baby if she received treatment during her pregnancy so decided to proceed and thankfully this advice proved accurate as my younger sibling was tested and it was confirmed that he/she was not infected. My younger sibling is **GRO-B** and is generally happy and extremely well rounded but I have no doubt that finding out that our mother was HIV positive when he/she was a teenager must have been incredibly hard for him/her. Whilst the pregnancy was obviously good news, in terms of how this disaster affected my mother, it is undoubtedly the case that she was extremely anxious throughout this pregnancy. She also had to start treatment for HIV, when up until that date it had not been considered necessary. She reacted badly to one of the drugs which caused her to become extremely unwell and as a result she was in hospital for around a week.

43. Luckily my mother has lived for over 30 years now since being told of her infection with HIV. However, she has lived with great uncertainty and until more recently has never dared to plan more than a few years ahead. Whilst her situation is much improved from when she was first given the devastating

news, she still doesn't know how or when the infection could affect her future. She has to take medication on a daily basis and due to the stigma that still exists albeit to a lesser extent, she often has to do so in secret. She does a great job of protecting her children from seeing the impact that this has on her and she is the most positive person I know but it is clear that it has had a significant impact upon her daily life.

44. Whilst my mother has had a successful career and is highly regarded by her colleagues, I have no doubt that the infection has affected her work. She definitely feels gratitude simply for being employed despite her infection and therefore in my opinion works harder than she ought to. She isn't as quick to fight her own corner when it comes to her own terms and conditions as she would be if she didn't feel so lucky just to be employed. This is just an example of one of a huge number of ways that the infection has affected her life.

45. I believe the infection has affected her social life for example how she interacts with other people who are not close family members. Whilst thankfully this is no longer the case, when she was first diagnosed with HIV, for a number of years and after watching my father die a horrendous death, she must also have feared that she was to suffer the same fate and that she would die leaving her young boy of primary school age without parents. It is amazing that she was able to remain resilient and positive about life in these circumstances and she truly deserves all of the happiness in the world for what she has had to put up with.

46. I don't wish to dwell too much upon how the disaster affected me as I have genuinely had a very happy life and ultimately feel very lucky to have had such a fantastic role model in my mother. I have no doubt also that my father was a huge positive influence during the first ^{GRO-B} years of my life before he passed away. Obviously losing a father at a young age is difficult for anyone, whatever the circumstances. However, I think a significant feature of this disaster is the stigma that is associated with HIV which still exists today but was appalling at the time in the 1980s and early 1990s. As a result of this the 'affect' of losing a father was almost certainly exaggerated.

47. The man that my mother met after my father died used my mother's infected status in order to control her. We moved in with this man which involved moving home to a new area and to a new primary school. Despite my mother's best efforts, he was able to limit the contact I could have with my father's side of the family, although my mother made sure I still saw them as much as possible. My mother made me aware of the issues with this man and told me why she felt trapped, which I understood. We had to do things in secret quite often to avoid my mother being abused by him as he was so controlling that she wasn't 'allowed' to do many things that most women would consider to be ordinary daily activities. It's difficult to comment upon the extent of the affect that this would have had upon me as a child but I suspect it made me more nervous, anxious and reserved than may otherwise have been the case. If my father had died of cancer as opposed to HIV/AIDS, I have no doubt that my mother would have left this relationship at a much earlier stage, but she felt trapped by his threats to tell others of her HIV status.

48. When I was GRO-B I found out that my mother had HIV. She had hidden it from me, understandably, when I was younger and had been waiting for the right time to tell me. She did not realise that I had worked it out. I can't remember how long I kept this to myself. When I ultimately built up the courage to ask her the question she was able to reassure me a great deal. However, the day that I worked it out was obviously incredibly difficult. I remember attending a school trip that day and just trying to make it through the day without crying in front of others. The internet was available and naturally my research when I got home about the life expectancy with someone who has HIV only made things worse, as I knew my mother must have had it since before my father died in 1991. In the weeks that followed I was thinking the worst and was wondering whether my mother might only have a couple of years to live. Thankfully that wasn't the case at all. However, I mention this just to further illustrate that this condition, due to the stigma attached, is worse than many other similar illnesses in terms of the affect it has on others. If I'd found out my mother had cancer, I could have discussed that with friends or teachers, but in this case, I knew the importance of not telling others because I'd always

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known to keep the true cause of my father's death a secret, as I'd been told about his HIV status from a young age and trusted not to tell others.

49. A childminder once refused to continue to look after me, despite me being very well behaved, after my mother decided to tell her about her life history and her infection with HIV.

50. When my mother became pregnant with my younger sibling, I understood that the risks of her passing the infection to the baby were low and I encouraged her to go ahead with it but it was nonetheless a difficult time as far as my own anxiety regarding my mother's health was concerned. My mother did not require treatment for HIV until this stage. However, the pregnancy meant she had to start treatment to afford maximum protection to the baby. I was worried about this as naturally you take the view that 'if it isn't broken, don't fix it' and the last thing I wanted was for my mother to take medication that would directly affect the disease which until that stage appeared to have effectively laid dormant. She reacted badly to one of the first drugs that she was given during the pregnancy, which ruled it out as a possibility in the future should her HIV levels increase. This was incredibly worrying. My mother was also admitted into hospital during the pregnancy for around a **GRO-B** with severe **GRO-B**. There was obviously concern for both her and the baby, together with the usual anxiety about whether others may find out about the underlying condition when hearing that she was in hospital in these circumstances.

51. When my younger sibling was born, we could not be given a guarantee that he/she did not contract the infection. We had to wait approximately 3 or 6 months for the results. This obviously added a degree of stress and anxiety to what would otherwise ordinarily have been only an extremely happy period.

52. Eight years after my younger sibling was born my mother was advised that she should start taking treatment to suppress her HIV levels which had risen. This was obviously unwelcome news as it felt like things were progressing to the next stage. Thankfully it appears that these concerns were misplaced and there is now no reason why my mother cannot live a long life with treatment. It is nonetheless still there in the background and it is not possible to completely

ignore it and the fact that it could have an impact in the future. The infection will always have an 'affect' on all of us, but clearly this is much worse for my mother than it is for my younger sibling and I as she has to live with it and take treatment on a daily basis. There is a constant reminder for her.

53. It goes without saying that my father's death at such a young age also had a devastating impact upon his parents and other family members.

Section 6. Treatment/care/support

54. I do not believe that my father faced any difficulties or obstacles in obtaining treatment, care and support as a result of being infected.

55. Counselling or psychological support was offered to my parents. I have not directly been offered counselling or psychological support but thankfully do not feel that I need it.

Section 7. Financial Assistance

56. My parents were involved in the 1991 litigation and received ex gratia payments. I believe they had to sign a waiver in order to receive the payment. My father received a letter confirming that we were going to receive the money shortly before he died, which hopefully gave him some limited comfort that there would be some additional support for his family. Shortly after my father died, my mother received a payment which was in the region of £60,000 due to both my father and mother being infected / affected by the infected blood disaster. A sum of £16,250 was provided to my father on the basis that he had a child so my mother earmarked and invested this money for me, which I received when I was 18.

57. My mother receives monthly payments from the Government. The amount has recently been increased, on the basis that she is an infected family member of someone infected with contaminated blood.

58. We have been fortunate in that we have never struggled financially. However this was mainly due to luck and fact that both of my parents continued working

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for as long as physically possible, even in challenging circumstances, as opposed to being the result of proper support from the Government and on this basis I have enormous sympathy with some of the other people who have given evidence to the Inquiry who have been unable to work or have struggled having lost the support of their loved ones.

59. Luckily, my mother and father had an insurance policy that resulted in the mortgage on the home they owned being paid off. We were also fortunate that my mother has always been able to work. If my parents had not had adequate life insurance and my mother's health had deteriorated as rapidly as my father's, things would have been very different.

Anonymity, disclosure and redaction

60. I would prefer not to give oral evidence to the Inquiry if there is any risk of my mother's identity being disclosed and would therefore be happy for an anonymised version of my statement to be read out if this is possible. If it is believed that it is important for me to give oral evidence and I can do so anonymously, then I would consider doing so.

Statement of Truth

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

Signed.

GRO-B

Dated 13.09.19.