

ANONYMOUS

Witness Name

GRO-B

Statement No: WITN3960001

Exhibit: 0

Dated: December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF

GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1985 and I live at GRO-B with my partner GRO-B: P I am employed full-time as a GRO-B Solicitor.
2. This statement is made in relation to P who contracted Hepatitis C (HCV) and Human Immunodeficiency Virus (HIV) through contaminated blood products. I understand that P has also made a statement for the Inquiry.
3. This statement has been prepared without the benefit of access to P full medical records.

Section 2. How affected

4. [P] and I met in or about 2004 when we were both working at a local holiday park. At this time, I was 19 years of age and was employed as a Receptionist during my University Summer Holidays. [P] would have been 25 years of age and was working as a Maintenance Assistant/Handyman, a job he was relatively dispassionate about but which afforded him the opportunity to work near the beach, which he loved. We started a relationship in about 2005.
5. I had been in a relationship with [P] for a little while before I learned that he had Haemophilia. I recall seeing needle marks on his arm and asking him what they were from. I had heard about Haemophilia before as it is commonly studied at school as an example of an inherited condition. I was interested to hear about [P] experiences living with this condition (many of which flew in the face of general preconceptions) but it did not worry or concern me. [P] was always very emphatic that he did not wish to be defined by or limited by having a disability or for people to perceive him as 'weak'; as such, he did not openly discuss his condition very often. I have later learned that [P] was also worried about the associations or conclusions some people might draw about his wider health problems if they knew he had Haemophilia and so he felt a pressure to keep as much 'secret' as possible.
6. Whilst I was aware of the contaminated blood scandal and its connection to people with Haemophilia, it never occurred to me that [P] might have been affected. I thought of this tragedy as something that had happened a long time ago and that [P] was too young to have been placed at risk in this way.
7. It came as a profound shock to me to learn in or about 2006/2007 that [P] had been infected with Hepatitis C and HIV and had lived with these

conditions since he was a child. I had been moving a box of paperwork in the house we shared together when I came across some old letters from a hospital. The piece of paper I saw stated [P] name, CD4 Count and at the top stated that he had Hepatitis and was HIV Positive.

8. I recall looking at the piece of paper for a long time in our house on my own and thinking that it did not resonate with [P] he was not, in my mind, an 'ill' person (and certainly bore no resemblance to the images of people with HIV and AIDS I had grown up seeing in the 1980s and 1990s). I thought that it must be wrong and I even felt slightly foolish for 'misunderstanding' what I was seeing. At the same time, however, a lot of other things about [P] about his relationship with his past and his reticence to talk about certain subjects, started to make sense.
9. I waited for [P] to return from work but when he did I did not know what to say. I did not have the vocabulary. The phrases were too 'big', too menacing and too outside of my frame of reference. I managed to communicate that something was wrong and somehow [P] realised what I had discovered. We were both extremely upset but neither of us really knew what to say or do. I was perhaps 21 or 22 years of age and I felt like my world had been turned upside down by something that, at that time, I really did not understand.

Section 3. Other Infections

10. I am not aware of [P] contracting any other infections through his treatment with blood products. I do recall one day [P] opening a letter from the NHS which, in rather blasé fashion, announced they were just notifying him that some people who had received contaminated blood products might also have contracted CJD. We were both genuinely shocked that this could have been dealt with, with such bureaucratic insensitivity.

Section 4. Consent

11. I am not aware as to whether [P] was ever tested or treated without his or his parents' consent.

Section 5. Impact

12. The first time I spoke to [P] about his infections, and indeed on the many subsequent times we returned to the topic over the years, I recall him being very distressed and extremely, and overwhelmingly, ashamed about this aspect of his health. Certain things he said made it clear that he placed little value in himself, that he hated what he had and the perceived risk he posed to other people, that he hated what it potentially meant for his future and that he hated the fact that someone had done this to him and he felt impotent to do anything about it. It was an anger which had no outlet since it was a secret he felt he had to carry, more or less alone.

13. Whilst I was shocked when I learned [P] was HIV+, I now understand the huge chasm of fear and self-loathing preventing him from sharing this information about himself with anyone close to him; he had grown up in world where HIV and AIDS were, quite unjustifiably but nonetheless inextricably, linked with culpability and 'life-style' choices, with concepts of being 'unclean' and posing a threat to others and, through that lens, it was impossible for him to trust someone with this news and have faith that they could still want to be close to him, let alone love and care for him. Perhaps most alarmingly, [P] had never been offered or received any meaningful counselling with how to deal with these issues himself, let alone share something so momentous with someone else.

14. After I had learned about [P] conditions, [P] initially contacted Southampton Hospital (which is where he periodically saw an HIV

Consultant). The person he spoke to suggested we come to the hospital together to meet someone to give us both more information about the viruses. I had thought we might meet somewhere private but I recall being greeted by a lady (possibly a nurse) and invited to sit down in the canteen at the hospital with lots of people milling around; it was grossly inappropriate. Whilst the lady was kind and reassuring, I found the whole experience awkward and overwhelming. She gave us a leaflet and pointed out some 'helplines' printed on the back. Whilst she mooted the possibility of me having a blood test, it was a vague and non-committal suggestion that I was tremendously unlikely to follow up unless someone actually arranged it for me; I had not even been to a GP in years and had not the faintest idea how one even went about arranging such an appointment. Looking back now, I feel that we were let down even then by this totally unsatisfactory level of support.

15. In the beginning I did not want to upset [P] (and I suspect he felt likewise towards me) and so, as much as possible, [P] HIV was a subject we simply did not venture towards. For 8 or 9 months it preoccupied my thoughts every day, it kept me awake at night and, selfishly, I worried endlessly about the risk I had also now been infected. However, in truth I did not know what to do about it. Nobody else I could talk to knew and I felt that I could not betray [P] confidence. It was a secret that just festered, as I have no doubt it had done for [P] all his adult life.

16. Looking back at this period, it is clear that the news affected my life greatly. I felt like I had no help or support. Whilst we had each other I was unable to have a conversation with [P] about it; there were words I felt unable to say and questions I felt I could not ask. I experienced terrible flare ups of IBS and at times overwhelming feelings of panic and anxiety; at times I felt preoccupied with worries over 'germs' and I was scared I had signed myself up for a future with someone who might not be there to see it. I was working full-time and studying for a Graduate Diploma in law at this time; I tried as

hard as I could to bury myself so much in these commitments that I did not have the time to indulge my worries but, in hindsight, I think my own health and wellbeing suffered as a result.

17. Whenever I felt upset because I was thinking about it and [P] would ask if I was okay, I would always attribute my sadness to something else because I did not want to exacerbate the hurt and pain he already felt.

18. Eventually, about a year later, we did discuss me obtaining a test, which [P] arranged via his contacts at Southampton Hospital. We had to attend our local clinic for sexually transmitted diseases. I found this quite embarrassing; it was not a very pleasant place and was completely alien to me. After my tests, the nurses said that they would get in contact with me. I did not hear anything for a good two weeks (during which time I felt extremely anxious) and eventually I had to chase them up. Fortunately, the HIV test was clear but they had lost my Hep C blood sample/test. I was so relieved not to have HIV that I just 'let it go'. Ironically, the second Hep C test I had several years later also went missing and it was only in 2019 I got around to having one done via my GP (which came back clear). My experience was that the level of support or care surrounding all of this was all deeply inadequate and there was certainly no mention at any time of any counselling being offered (or recommended).

19. Back then, I did not have the where with all to start a conversation about asking for help. I would have expected the people who deal with this as part of their profession to signpost it; the fact they did not made me feel as though I would have been being a nuisance to ask. However, in our experience, the whole of [P] treatment with the HIV Doctors demonstrated (for many years – although not now) a lack of coherence and we found a rather 'laissez faire' attitude to be prevalent. You are dealing with people for whom it is easier in many ways not to engage with their health conditions. However,

P would tell me that no one ever told him what his test results were, that it was difficult to make an appointment and that even in this field, many Doctors seemed to have no knowledge of how his HIV had been contracted and frequently and visibly/audibly expressed surprise when he mentioned he had a female partner. I would hasten to add that P current consultant is excellent and has been fundamental in getting him access to treatments he requires but this has been a long time coming.

20. For many years I was scared to ask my GP for HIV tests as I was worried about these being on my medical records (which used to have to be produced for things like health insurance through my employer). However, I disclosed the situation to one of the GPs at our surgery a few years ago and she could not have been more helpful. The first time I mentioned the whole situation to her, she put me at ease and recommended regular tests. She will often ask me when I go into the surgery if I would like one done (especially if I am having something else done anyway) so it is less of a big deal. I am also older now so, as with many things, life experience and acceptance has made me feel less fearful about broaching the subject.

21. It would be impossible to say that P medical conditions have not impacted upon our relationship. Not all of that impact is negative and indeed we are probably extremely close because of what we have been through together. However, we have had to work at and through this. It has placed challenges upon us and forced us to have conversations and make decisions that many young people do not have to consider.

22. Over the years, we have talked and talked our way around this extremely emotive topic. Initially, tentatively. Over time, with greater acceptance. I was always aware that with P I was tip-toeing into emotionally uncharted territory and that one had to 'go gently' into what was a deep well of raw pain and visceral anger masked by many years of having to pretend to the world to

be 'okay'. [P] is the kindest, the strongest, the bravest and the most inspiring person I have ever encountered and I am utterly in awe of the fact he has achieved this despite what he has had to face up to in his life.

23. I think that [P] would probably say himself that, emotionally, he is a different person now to when we first met. Despite being very capable, educated and well-travelled, [P] had spent a number of years drifting aimlessly and, arguably, not achieving his full potential. [P] has been frank with me that in his late teens and early twenties, he had no regard for his own safety, for whether he lived or died. He would pursue his hobbies with an element of reckless disregard for his wellbeing because he thought he would die young anyway and would prefer to die living 'hard and fast' than wasting away with an AIDS related infection. He took unnecessary risks. He did not think there was any point studying for a profession he would die before he succeeded at or saving for a future he did not think he would have. His life lacked meaning because he invariably believed it would lack longevity.

24. Whilst [P] could be an extremely placid person, he would also be prone to getting disproportionately frustrated or angry at times. This anger was only ever directed at himself but it could unexpectedly put him in bad mood or make him feel overwhelmed by work or a household project. With hindsight, it is clear this was anger he felt over his situation but which he could not articulate.

25. [P] also used to smoke a lot of cannabis in the past, which I believe was a method of self-medication. He used cannabis to block out or cope with a trauma that was otherwise too significant to contemplate.

26. When [P] did open up about his feelings, some of the things he would say about himself would be heartbreaking. He said that he was worthless, that he should not be with other people because of the risks; that I should not be with

him because he would hurt me and that it would be better if he went away and lived on his own. He would say that he believed that if anyone found out that he would have no friends etc. and would have to move away and start again because of other people's overt or veiled prejudices.

27. Making this statement now is an altogether different exercise than it might have been years ago. In many ways, it is hard to revisit or remember how bleak things felt at some points when you are writing from a more positive place in time. [P] and have been together for 14 years. We are very happy in so many aspects of our lives. We have two beautiful dogs, we live in a beautiful area close to the beach and we have our health and each other. We know we are fortunate and because we know it is fragile we value it all the more.

28. I have not told and cannot tell any of my friends or my family about this. That has been made much harder by the news coverage of the Inquiry. It is not something I feel needs to be hidden but I have to respect [P] wish to keep this a secret. [P] and his brother (who is also a hemophiliac and co-infected) have both lived their lives through the terrible lens of prejudice and ignorance that was prevalent in the attitude towards HIV in the not that distant past and, understandably, that has made them very distrustful and scared of people finding out about their HIV. HIV is still a taboo subject now but it is nowhere near as bad as it used to be. Moreover, I feel strongly that any friend who took issue with it would not be a friend for much longer! However, this is [P] decision and I have to respect it.

29. [P] and I are not married and I do not think that [P] infections have affected this decision. It is possible they affected my/our views on having children. I have never been sure whether I want children or not. However, I found out about [P] infections when I was 20 or 21 and so, invariably, the perceived complications that having children might entail was, in my mind,

a barrier to letting me see this as a future option. Whether for self-preservation or otherwise, at an early point in my twenties I effectively removed the thought of a family from my expectations. I believe that at some stage, P would have liked to have children but that, likewise, he ruled it out as a possibility many years ago.

30. I am aware that it is now possible for us to have children through sperm washing (or, in circumstances where P viral load is undetectable, to risk conceiving naturally). Whilst I would not rule this out altogether, each option presents its own challenges and dilemmas. There was a period of time when a number of our friends were getting married and starting to think about having children. They were complaining that it was taking them a long time to get pregnant. Irrationally, and quite aside from my own views about having children, I recall at the time this dredging up confusing feelings of anger and resentment. Whilst I could not then (and perhaps cannot even now) articulate the reasons for this, I think it had something to do with not being able to express the sentiment that, in my mind, they were at least lucky to be able to try, to have that option open to them; it seemed so 'uncomplicated'.

31. I have also been affected by the stigma of HIV on different occasions. Since people are not aware of our situation, I sometimes find myself hearing people making inappropriate jokes or comments about AIDS and HIV. I am aware that there will be circumstances like this in the future. I often have to 'hold my tongue' so as not to appear too impassioned by the subject or to let on how much I know about it for fear of people questioning why that is the case. Also, *considering the nature of my job, I am sometimes reminded of it at work.* I have clients whose husbands, wives or partners have been unfaithful or have slept with prostitutes. They say with horror, as though it is the worst thing that they can imagine, "what if I've been exposed to AIDS". I have to resist the urge to roll my eyes. So many of these people would have, perhaps legitimately so, a complete breakdown if their ordered lives had been

shattered with such a brutal diagnosis. Even now; for [P] and many people affected by this Inquiry, that is a reality they have lived for a significant portion of their lives.

32. For many years, [P] was unable to visit his sister in America because of the travel restrictions on people with HIV. Even since the restrictions were lifted by the Obama government, [P] has been stopped at customs and has had to spend hours waiting to be interviewed because there is a marker on his passport (we have seen the screen – it says 'may have AIDS'). When this happens, I am left on my own in an unfamiliar country, often 'moved along' by officials and not knowing if and when they will let him out. Even now there are many places we cannot visit because of [P] HIV status.

33. [P] worked as a self-employed Carpet Fitter for about 10 years but made the decision to give up this work a couple of years ago. Aside from it being extremely punishing on his joints and causing a significant amount of pain, he got no joy, satisfaction or interest from it. At the time he also struggled to deal with any level of stress. Whilst I in no way wish to undermine the value of this as an occupation, I have no doubt whatsoever that it is not at all what [P] would have been doing with his life had he genuinely expected to live past 30. It was just a way to earn money. Had he not crashed out of university without finishing his degree (at the time struggling to cope with his HIV etc.) and had he had any confidence or self-belief in his own value to society, I suspect he would have qualified into a profession that he not only found more interesting but which was not dependent upon him doing manual work (which, for someone with Hemophilia, can be difficult at time due to bleeds and injuries etc.). He also felt he had to be self-employed in case any employer asked too many questions about his health or his absences.

34. [P] is much happier now he does not work as much. He has been able to focus on things that make him well, such as looking after his diet, exercising

and walking our dogs. I do not think that he would function as well if he was working.

35. [P] focus was, in the past, always short-term. He never thought he would have a future so he never thought of building up his career or pension. He is in good health now and he is positive about the future but I do think that he feels sad that he lived a big part of his life the way he did and that he wasted so many years.
36. At the moment [P] is fortunately well. However, there have been times when this has not been so. In the years before [P] started his anti-viral medication, he did suffer recurrent chest infections and, on one occasion, an infection that resulted in a large growth on his shoulder. On one occasion, his GP told him that ordinarily the GP would drain the growth in the surgery but he was not willing to do that for [P] because he represented an infection risk to other people. I remember [P] being hurt and angry by this. Rightly or wrongly, he was in so much pain he resorted to draining it at home himself with a syringe.
37. When [P] had the first set of medication to eradicate Hepatitis C, he became incredibly insular and quiet. In hindsight, [P] said he felt so tired all the time it was like being a zombie or his head being in cotton wool. We both said that whilst we did not realise it at the time, it was like he had lost his personality for about a year. He had to go to the hospital frequently and there is no way he could have done this had he not been self-employed without answering difficult questions.
38. Whilst he was on this medication, [P] also had two transient ischemic attacks (TIAs). These were incredibly worrying and frightening for us both. Fortunately, he had no lasting damage. He had to stop taking the medication before the HCV was cleared. It was not until a number of years later another Doctor told him that different medication was available with less side effects.

When he was eventually put on these drugs he, thankfully, did not seem to have any adverse reactions.

39. I believe that we are very fortunate in many ways, particularly compared to other people in a similar situation. [P] is a very strong person and I am convinced that many people would have crumbled in this scenario. However, *he has fought to be the best he can be. This also comes from him having a supportive family and that the fact that we have a strong relationship. We managed to create a resemblance of normality. This has not been the case for many people.*

Section 6. Treatment/Care/Support

40. I recall the first time that [P] came home from hospital after having been advised he ought to consider starting anti-viral medication. When [P] had been told his CD4 count he had been very shocked and in fact he did not know why he was not forewarned about it deteriorating earlier (we subsequently read the guidelines for starting medication are before a person's CD4 count gets near what [P] was as there is no need for that nowadays). [P] never felt he had a voice in the management of his condition at that time – just that he was expected to be 'in and out' of the appointment as quickly as possible. At the time, we were both very scared about whether he might react negatively to treatment and what this might mean for us. Fortunately, by and large he has coped very well with medication.

41. [P] recently participated in a trial for gene therapy for people with Haemophilia. He had hoped to receive this therapy upon completion of the first phase of the trial. Unfortunately, a patient in the US with HIV became very ill after receiving gene therapy and so, sensibly, the doctors want to make sure the treatment is safe for people on anti-viral medication before

offering it to them more widely. [P] is left wondering now, however, that perhaps if he did not have HIV he might also have been 'cured' of Haemophilia.

Section 7. Financial Assistance

42. I am aware that [P] receives payments from the EIBSS (and previously from the MFT). For many years, these payments were unsatisfactory and were only in 2019 increased to a more meaningful level.

Section 8. Other Issues

43. It is difficult to say what exactly I would like to see from the Inquiry. In truth, it all seems so little so late. Neither [P] nor I have any interest in raking over the details of the past or harboring anger or bitterness. One only has to 'dip one's toe' into the testimonies and issues surrounding the Inquiry to feel a small sense of the pain and tragedy that has ravaged the lives of those involved; we have been slightly fearful of wandering too deep into that quagmire for fear of what it might bring up.

44. I believe that the Inquiry is a good opportunity for those affected to have a voice to share their stories and maybe see some sense of 'justice' done. That said, however do you even begin to think about compensating people in any meaningful way for the traumas that have been inflicted on them year upon year, where successive governments have failed to take responsibility for the actions of those who held positions of trust and responsibility and where, even having caused this harm, people were left so entirely without support to give them the tools to deal with the impact of this trauma on them and their families. You cannot give someone back the teenage years they spent in angst over what they regarded as a life sentence, the relationships they did not have, the opportunities they did not take, the dreams they could not fulfil.

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You cannot give people back the hope they lost many years ago and erase every time they felt scared they would die a horrific, painful death (or cause a loved one close to them to risk the same ends) or when they listened to other people judge or pour scorn on someone with these diseases. I worry any attempt to make amends will be unsatisfactory, derisory and, if so, yet another wound inflicted on people who have already suffered so much.

45. I am aware that there is a narrative surrounding this tragedy which suggests that these people had a medical condition, that the NHS did its best and that they would have died without the treatment. We now know that this was not the case. We feel it is important that this is recognised by the Inquiry. We believe the Hemophiliacs were the victims of a gamble taken willfully, recklessly, uncompassionately and callously by people who played God with their lives, who turned a blind eye despite knowing the risks they were putting patients in and who could and should have done more to protect them and done so sooner. Then, having allowed this tragedy to happen, subsequent governments have deprived people of the emotional, psychological, financial and practical support they deserved and which might have prevented the depth of emotional harm that has been felt. If the Inquiry is to be regarded as a positive step in a sense, all of these things cannot and should not be minimised.

Anonymity, disclosure and redaction

46. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

47. I would be happy to be called to give oral evidence.

Statement of Truth

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

Signature.....

GRO-B

Dated.....

23. 02. 2020