

Witness Name: Jane Campbell

Statement No: WITN0664001

Exhibits: nil

Dated: 03 June 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BARONESS JANE CAMPBELL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 January 2019.

I, Jane Campbell, will say as follows: -

Section 1. Introduction

1. My name is Jane Campbell. My date of birth is GRO-C 1959 and my address is known to the Inquiry. I am a campaigner and adviser on disability rights. I am severely disabled having been born with spinal muscular atrophy.
2. I intend to speak about my late husband Graham Armstrong born GRO-C 1959 and who died from AIDS in 1993.
3. In particular, I intend to speak about the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Affected

5. Graham had severe haemophilia A. He was a very active young man so he had to inject Factor VIII frequently. He also had blood transfusions after a car accident at Newcastle Infirmary in 1980 approximately.
6. I had known Graham since the age of 17. We met at Hereward College, in Coventry. This was a special college for young disabled people to further their education. It was a brand-new establishment based on having a student experience, which was a rather exciting prospect for those from cocooned special schools. We were both studying O and A levels.
7. I guess you could say that we were childhood sweethearts and he was my first true love. I did not want a disabled boyfriend, and Graham was as normal as they come. He was very able bodied, practical and extremely good at electronics, a typical craftsman. We dated for about three years before going our separate ways to study at university although we always remained friends and stayed in regular contact.
8. I went to Hertfordshire University for my degree and Graham went to a college in Scarborough for his higher national diploma. Like most people we both found partners when away, but deep down we both knew that we would end up together. We had a deep bond but understood that we were far too young to commit to marriage.
9. After achieving a 2.1 in my degree at Hertfordshire, I went to Sussex University for a master's degree and obtained a first. I have always been very academically minded. On completion of his electronics qualification, Graham started to look for jobs in the south of England, as he had enjoyed living there whilst we were dating.
10. Graham and his close friend GRO-A also a haemophiliac, rented a flat together in London. I was living close by with my parents at the time and

went to a party at Graham and [GRO-A]'s flat. I recall being shocked at how much he had changed and questioned why I had broken up with him. He was now a fully-grown man, and so mature. Graham was still looking for work at the time – being a haemophiliac made it extremely difficult. He eventually started working with my father as a trainee-heating engineer. Graham was a very good employee, yet my father took advantage of his haemophilia and paid him a pittance.

11. I started to see Graham frequently. We eventually started dating again and it was amazing; we were both so in love. After experiencing life apart, we decided to settle down and Graham proposed a year later. I was 26 at the time and we moved into a social housing flat on the ground floor. My parents approved as Graham was so good at looking after me.
12. It wasn't an easy life as we had only just started our careers but we both enjoyed working hard and building a home. Graham was a very talented craftsman, so he did all the refurbishments like a new kitchen and bathroom. In those days there was hardly any support for young disabled people living independently, so Graham also provided all of my care, at the same time as working and preparing our new home. Thankfully in those days I was more physically self-sufficient and worked in London at the GLC as a local government training officer.
13. At this point everything was going well with Graham's haemophilia treatment. He would self-administer the products after a bleed, and after a serious car incident carried factor VIII on him at all times. I remember looking at the bottles and the products looked English. Although Graham was a severe haemophiliac, he was very strong and used to pain – you would not know he was disabled until he had a bleed. There would be times when he would need to use a wheelchair for a couple of days, until the swelling went down.

14. We were married on 27 June 1987. Six weeks prior to the wedding, my father was killed in a car accident – it was a lovely day but it was not what it should have been; I did not have my father to give me away.
15. We were a very happy couple with strong family ties, so we felt the future was bright and we were blessed. During this time, we saw a television programme urging those that had a blood transfusion in the last couple of years, to be tested for HIV. Graham and I both thought it was directed at gay men, and it did not occur to us that the virus could be transmitted through blood products. Looking back something bad was in the air, but it was too unimaginable it could happen to us – I had only just lost my father, and our married life together had only just begun. Despite heavy media coverage on HIV/AIDs, we convinced ourselves that it was a 'gay plague' and did not believe it would affect us. Graham still looked well and we were so young.
16. That was until approximately 2 months before we were due to be married when we were asked to attend an appointment at the Haemophilia Clinic at St Thomas's Hospital, London. Graham was given the results of the blood test that all Haemophiliacs were given to test for the HIV virus. He was told that he had both HIV and Hepatitis C but "not to worry because it isn't the same dangerous strain that gay people were catching." We thought it odd but left it at that. We were not told how Graham had become infected other than it was as a result of taking Factor 8 which is made from blood. They did not seem concerned and, therefore, nor were we. Graham trusted his consultant Dr Savage (with whom he had a very good relationship). We were told absolutely nothing about the risk of passing on the infection and we were not given any advice on actions to take at that time, it was only later that we were given advice about staying safe.
17. I did recall that, whilst at Hereward College, Graham's best friend GRO-A GRO-A (also a Haemophiliac) had read an article about cheap American blood products being used by the NHS, which were possibly

contaminated because due to some of its sources (blood of prisoners who injected with dirty needles and buying blood from people in high-risk situations (homeless, poor, desperate), because the product was not subject to strict enough quality-control standards. [GRO-A] urged Graham to get tested, but Graham did not take the advice, as he trusted St Thomas's and his doctors. We just got on with our lives, in the same way that we had always minimised disabilities to have "a normal life". [GRO-A] is the only surviving Haemophiliac from Graham's friendship circle as far as I know; none of his blood products were imported. As far as I know [GRO-A] is still alive. Graham and [GRO-A] shared a flat in Croydon and was also a patient of St Thomas's. I remember that the only effective means of minimising [GRO-A]'s internal bleeding, was by using what he called "pig's blood". Whether it came from a pig or not, I cannot be entirely sure – but his treatment was definitely free from the risks that Graham faced. I saw him again at St Thomas's Hospital about five years ago. He would remember other things about Graham that I have forgotten as they shared a flat for two years and were very close when they were students at Hereward College in the late 70s.

18. I do not recall having any serious conversation about Graham's test results and thinking back we probably subconsciously did not want to research the implications of HIV at that point. As a couple we tried to believe it would not affect us – we were young and Graham looked well. It was only a year later when we were asked to attend an appointment at the Haemophilia Centre at St Thomas's where a new doctor had been appointed to look after Haemophiliacs who had contaminated HIV. The letter said it was important to attend. I remember Graham saying he had too much work on but something told me we needed to go, so I insisted that we attend and that I would go with him.
19. That day was probably the worst day of my life. I can remember the whole meeting very clearly. We were still under the impression that Haemophiliacs were somehow immune from the "AIDS virus" that was killing the gay population. The news that this was not the case and that

Graham would die within 5 years was a complete bombshell. As an intelligent woman I cannot believe I thought the virus was restricted to gay men. Graham asked about treatments and survival rates. The response was a deafening silence. We were told a trial drug AZT was available, which might prolong his life but the side effects were vomiting, lethargy and weight loss – similar to the symptoms of chemotherapy. This was the only drug offered to him. Graham asked when he might have been infected and they said it could have been as far back as 1980 when he was admitted to the Haemophiliac ward in Newcastle Infirmary following a car accident. I strongly believe Graham was infected by the transfusion he received then but have no evidence to prove it. Graham's brother Anthony must have also been infected there as he was still living at home in Yorkshire and that was his specialist hospital. I can't be sure but according to Dr Savage who treated Graham in St Thomas's, he inferred that once he heard rumours of the possibility of the blood products from America being contaminated, he stopped the unit ordering them. I can't say whether this was true or not, but Dr Savage appeared to be a very genuine Consultant who Graham trusted. Neither of us was able to talk after the appointment, and Graham was usually so talkative.

20. I do feel we should have been provided information earlier. It was as if they didn't know and if they did know, they kept it quiet. Possibly they felt it was in our "best interests" as that was the culture at that time towards disabled people. I remember Graham telling me that Dr Savage was struggling mentally as a result of his frustrations with the Government and NHS hierarchy. I'm not sure, but I think he volunteered, or was informed to move from/or leave the St Thomas's Haemophilia unit. We did not see or hear from him again when Graham started to become ill. I recall Graham telling me that Dr Savage said to him 'I am not killing any more of my boys'.
21. I felt the doctor (whose name I cannot remember) who told us of Graham's HIV status was extremely cold and offered information without support or counselling. Graham was told to approach the Haemophilia

Society instead who were setting up the Macfarlane Trust. We were told to use protection during sex and keep away from open wounds. We were told kissing was fine but Graham felt this was too risky. I remember thinking that it was rather odd that Graham did not receive a confirmation of his diagnosis in writing.

22. During a check-up the doctor also confirmed that Graham was HCV positive, it was almost 'oh you have this as well'. The virus was very much played down and I did not know what it is until recently. No advice was given about consuming alcohol, and Graham actually went through a period of time where he drank heavily.

Section 3. Other Infections

23. Graham was infected with HIV and Hepatitis C but no other infections that we were informed of.

Section 4. Consent

24. I do not believe Graham was tested without his knowledge or consent or for the purposes of research. The only information we ever received was about the test for HIV after he was infected.
25. I strongly believe those given AZT were treated as guinea pigs – the side effects of the drug were just as bad as HIV itself. So much so that Graham often considered coming off it. It was probably only due to my pleas, that he endured. This still haunts me and I certainly felt guilty about encouraging him to go through with it, especially as it may have even contributed to his agony.
26. I was offered an HIV test, which came back negative. Without going into too much detail, there is no way I could have contracted the virus because Graham kept his distance, which resulted in its own sad consequences as newlyweds.

Section 5. Impact

27. Graham was automatically prescribed AZT 3 months after our meeting at St Thomas's and soon succumbed to all the side effects. Graham began to deteriorate. He carried on working on and off for nearly 3 years but as time when on he became frail and thin and more and more depressed. We had no sexual intimacy from the day we received the news that he was HIV positive from the second "cold" Doctor. That inevitably destroyed the strong bond we had of sharing everything. He had always protected me and did not want to harm me; our physical marriage was over. I would have been quite happy to continue how we were before we knew his diagnosis, as I did not want to live without him in this new weirdly estranged way.
28. As far as I am aware, Graham was not treated for HCV and no biopsy was taken of his liver.
29. The infection completely changed Graham's positive, sunny, full of life attitude – in a word it destroyed him mentally as he was worried about what would happen to me after his death. He hardly ever complained about what was happening to him, he was simply deeply concerned about me, The more he came to rely on me, the worse he felt. Because of the cumulative effect of the illnesses associated with HIV, he was slowly unable to work, this meant he couldn't take out any form of insurance. We were refused a mortgage because we were both deemed to be too high a risk but, thankfully, my sister stepped in and agreed to guarantee a mortgage for us. I became the only breadwinner after about two years post diagnosis and we had no savings as a safety net because we were too young. As a proud Yorkshireman, this was crushing.
30. Physically, Graham was weak and exhausted and within three years he lost over half his body weight. He was a strong 14 stone man when I married him and he could hold me in the air with one hand. When he could no longer care for me it was very difficult to find help because of the

stigma surrounding HIV. I employed students from the local polytechnic to help me as my personal assistants, however many left when they found out about Graham. Towards the end when Graham was very poorly, it was a nightmare as Graham had a constant stream of strangers coming in to the house, along with doctors and Macmillan nurses etc. My mother remembers coming over and Graham could not even open the door as he intermittently lost his sight due to a tumour pressing on his optic nerve. The AZT or the disease progression, possibly brought this on. The mental and physical pressures on me became unbearable as not only could I not look after him, I had to work during the day to support us and then come home and cook/do domestic duties in the evening. Graham begged me not to send him into hospital and I completely honoured his wishes to the very end to keep him at home.

31. Since Graham could no longer look after me, I started to look into home care and any other services set up to help disabled people. Sometimes he would be too unwell to make a cup of tea, so we would sit for hours without a drink. Along with another disabled friend in the borough, I campaigned for social care direct payments and helped bring about a bill in Parliament which was successful. When I started to receive direct payments, I employed personal assistants in the home. I was unsure and scared to tell the PAs about Graham's HIV status, because of the terrible stigma associated. I did tell one or two, who I became very close to, and they continued to support us. I was truly grateful and still am for their support because there was nothing else offered.
32. At one stage Graham wanted to stop taking AZT but carried on for longer than he intended, as I did not want him to die sooner. When he finally stopped it was extremely hard to take. By that time we were both so worn out with the consequences of what we had been through – we were both at the stage of giving up. I'm thankful we didn't, as it's hard to bear the guilt of not being able to do more, even now. We endured five years of torture at such an early age – no one can imagine what that does to your

spirit and mental health. And it was so much worse Graham who bore it so bravely and with such grace.

33. The further medical complications from Graham's HIV infection, I think from memory (because we can't get hold of his medical records) included regular chest infections often leading to pneumonia, a brain tumour, skin disease, seizures, constant vomiting and headaches. His deterioration began with chest infections and progressed to serious pneumonia, weight loss and he eventually became confined to bed for the last 4 months of his life.
34. Graham had approximately 5 or 6 lengthy stays in St Thomas' Hospital. On one occasion I recall he was wrapped in tin foil, because he contracted sepsis after a bad chest infection. I was called at work to come to the hospital immediately. He was constantly throwing up and the doctors thought he was going to die. This was a year before he eventually did. After 10 days he was discharged in a desperately weak state. I questioned the staff and made it clear I would not be able to look after him due to my own disability. I wonder now whether they were in breach of their duty of care? It would have been obvious that I would not have been able to cope, and the hospital failed to acknowledge my situation. This was not the first time that nobody seemed to care that we were both severely disabled and in need of help.
35. Soon after the diagnosis, Graham resorted to drinking for escapism. He would be in the pub most evenings, but I could not be cross with him, I knew that if I was in his position, I would have done something similar. I became more and more lonelier as he withdrew into himself; we were basically sharing a house and strangers a lot of the time. He was not a man to share his pain or worries – as I said before he was a very loving proud Yorkshireman who put himself last.
36. AZT was the only treatment offered to Graham and it had dire side effects. Graham regretted going onto AZT – it may have prolonged his life

but he had no quality of life from the beginning of the treatment and throughout.

37. On one occasion in the early days, Graham experienced being refused treatment at our local general Hospital (Kingston) because of his HIV positive status. He had an accident at work which resulted in a nasty third-degree burn on his leg. Graham was told by the A&E doctor to go to the Haemophilia Centre at St Thomas's in London, even though he was in agony, unable to drive with an open acid burn wound on his leg. On another occasion he needed to go to the dentist for a nasty toothache, but because of his experience in Kingston Hospital he didn't go as he didn't want to be rejected again.

38. Few people came to visit Graham when it became known that he was ill with what most people by then called, "Aids". In the last few years of his life when he became very ill, there was only one of his friends who remained as solid support and that was [GRO-A]. As a fellow haemophiliac, Graham found it easier to open up with [GRO-A] and we never kept anything from him. We were never offered anything like access to a Peer Support Group, through the Haemophilia Society which I found astonishing.

39. Graham's infection impacted our family too. My mother described this time as a living hell. My mother was devastated and extremely worried for my future without Graham. She was getting too old to care for me and I did not want to return home.

40. After Graham's death, I began to have panic attacks and had to go on beta-blockers and antidepressants. I went straight back to work and campaigned for about 6 months about disability rights. Before I went to speak in front of an audience at a Trafalgar Square rally, I felt a rush of panic. I ran off in my wheelchair, hid behind a car, started breathing very quickly and shaking, this was the first panic attack. I later found out I was experiencing post-traumatic stress which resulted in me having to take 18

months off work. I was living on my own, deeply depressed and financially very poor during this time. There was no offer of support for the Widows of all the haemophiliacs who were dying at a rate of knots. My panic attacks came fast and furious, and I was very ill mentally, I could not sleep and was so scared. For a year I was unable to leave the house. The doctor prescribed medication and I paid for cognitive therapy.

41. My family helped financially during that time although they were not really in a position to do so as my father had been killed in a car crash six weeks before my wedding to Graham. My sister however had a reasonably good job and granted me a loan to help pay off my mortgage. She also contributed towards my treatment – without her I don't think I would have made it through the darkness. I also used the remainder of Graham's "blood money" (which was what we called the £30,000 ex-gratia payment from the government. We had already used about £20,000 of it to look after Graham at home which was very expensive.
42. I still have anxiety today, especially around the anniversary of Graham's death (19th December, 4 PM). Whilst I have learned to control the panic attacks and have had amazing support from my small family (just my mother and sister), second husband Roger and my many good friends, I have not been able to come off all the anxiety medication. I always believed I would have been the one to die young; My condition prognosis was that I would die by the age of 2 years old. I naturally thought Graham would always be there as my rock and would take care of me until the end. It's still hard to believe I'm alive 25 years after his death.
43. The stigma of HIV had enormous consequences e.g. one of my personal assistants left me on Christmas day, a few days after Graham's death, after an abusive confrontation about Graham's HIV status, which left me with no help except from my mother and sister. This increased my sense of isolation.

44. Graham's younger brother, Anthony, was also a haemophiliac. Anthony was married the year before Graham and I were married. Anthony had a little one-year-old girl. Soon after Graham's diagnosis we received a phone call from my mother in law. She told us Anthony was infected with HIV. Graham then told his mother that he was also infected and she went quiet. At that stage, Graham was under the impression, from what he had been told, that his infection was not as serious as the virus killing those in the gay community. My mother in law eventually lost her 2 youngest sons – my Graham and Anthony. She is still alive today, [GRO-C] [GRO-C] Her loss made her a very sad woman indeed.
45. Shortly after Graham found out he was infected, Anthony told him in a phone call that Graham was only at the beginning of the illness. Anthony had begun the symptoms of HIV a year earlier. He said to watch his deterioration as it would be the same for his brother. Graham was adamant that he was fine, but Anthony explained that he had recently had two chest infections and was losing weight. Anthony had been infected by Factor VIII treatments he had received from Newcastle Royal Infirmary. Graham watched his brother become progressively more ill, whilst knowing the same would happen to him in due course. The family told everyone that Anthony was dying of cancer because of the stigma surrounding HIV. We took a holiday in Yorkshire, so Graham could visit his brother. In hindsight it was not a good idea as Anthony looked like someone from a concentration camp, but it did provide the opportunity for Graham to talk with his brother alone which I hope gave him some comfort. A year before Graham's death, he buried his brother, the funeral was particularly hard for Graham as he was watching his future.
46. I now have feelings of great loss when I attend weddings. These couples have so much joy and hope for their lives together, exactly what I feel was taken away from me when I lost my childhood sweetheart. The contaminated blood scandal took away Graham's young adult life, and in many ways ruined mine. However, I have also been blessed by the experience, as I have learnt so much about true love and hope. A few

years after Graham died, I was very lucky to meet another man and as a result was given a second chance to experience all the things that were denied Graham and I after marriage. I also managed to return to work to pursue my career; I know Graham would be happy for me on both accounts. I met my second husband at a conference I spoke at, he thought my lecture was astounding and invited me out for a drink. We married three years later in 2000.

47. To begin with, Graham and I acted as though everything was fine, on the outside we could pretend, but we could not talk openly with anyone nor hardly with each other – the pain was too hard.
48. Graham was unable to work for the final 2 years of his life, which affected us financially. As the breadwinner, I worked extra hours to earn extra money but this took time away from home which grieves me even now and I often have moments of great regret. It was also easier at times to have an excuse to spend more and more time in the office as our situation at home was so difficult to bear at times. My career became an escape for me.
49. However I was able to earn enough money to buy Graham a computer, which he would use to occupy the long days at home. The “blood money” also enabled Graham to buy a comfortable car to go for rides which helped as a distraction from the illness. I encouraged Graham to go outdoors as much as possible because he was becoming so introverted. As Graham deteriorated, I employed a driver to take him out and to his appointments and drive him up to Yorkshire so he could see family. The driver was Andrew Hornby who I am still indebted to as he was such a wonderful support.
50. I supported Graham in every way I could, but I am still left with the feeling that I could have done so much more, perhaps I could have encouraged him to be more open, as he became so introverted and scared. I do not

know how we managed to cope at such an early age. I am thankful I have such a strong will, otherwise I would not be alive myself.

Section 6. Treatment/Care/Support

51. The only help we had was from a nurse at St Thomas's Haemophiliac Unit and our local GP, Doctor Judy Munby, from the Brunswick Medical Centre. They were both very supportive. Dr. Munby was involved with all of Graham's treatment, provided his prescriptions and was lovely.
52. Graham was offered counselling by the specialist nurse at St Thomas's Hospital, shortly after his diagnosis, but he did accept the offer. I do not recall the Haemophilia Society offering such a service but as we were not keen on charities because of their patronising ways, so we did not look to them in the beginning. I was never offered counselling or psychological support but the same lovely haemophiliac specialist nurse stayed with us during the 24 hours in which Graham died. Her name was Chris Harrington.
53. Chris Harrington, a nurse under Dr Savage, was the only person who really gave us appropriate support from the beginning. She acted very professionally and treated Graham and I as rounded human beings.

Section 7. Financial Assistance

54. We only found out through St Thomas's Hospital that we could make an application to the Macfarlane Trust which ran a relief fund but the paperwork was very bureaucratic and it felt like begging for charity or asking for benefits which neither of us had ever done. I don't remember the Macfarlane Trust giving us any more than approximately £500 in discretionary payments. The process was not made easy for someone so ill and no assistance was provided to facilitate the process. They did not take my needs into account, and it was a 'one size fits all' payment. The

procedure was comparable to applying for welfare state benefits, and for a proud Yorkshireman this was extremely difficult. There were numerous preconditions to receiving the money. The money offered was paltry. Additionally, we received the ex gratia payment of £30,000. The money was inadequate and too little too late.

55. There was no financial assistance from The Skipton Fund, despite Graham also being infected with HCV.

Section 8. Other Issues

56. We started litigation but we were told that if we went ahead we would not receive the £30,000 ex gratia payment. In the end we had no choice but to accept the £30,000 and even our lawyers advised us that we should take the money. The government completely had us, we had no money at the time, and I wanted Graham to be in comfort during his last years/months. I assured Graham that we would cope on my income and that he did not have to take the payment, but it was his decision to accept the money. I would have carried on to seek justice through the Courts but that's just my temperament. I am a "freedom fighter", Graham was not of that character – he was a mild gentleman who put up with a lot of discrimination and poor treatment without fuss.
57. The amount of money granted was an insult for a national health incident which killed people.
58. One of the consultants at Newcastle Royal Infirmary was absolutely vile. He admitted the NHS knew the blood was possibly infected, but believe he acted in "the best interests" of patients by concealing this from them. It is ethically wrong to decide for an adult patient without telling them the truth about their condition and its treatment. Graham was never given any choice. The contaminated blood products were automatically administered without his knowledge of the potential consequences.

59. After Graham died, I burnt a lot of his medical files, so that I could wipe the slate clean. I wanted mental peace and thought that that would help. I regret that now. When I first heard about the Inquiry, I did not know whether I could provide evidence, it would mean going back to that terrible place. I did not speak about the scandal for at least 10 years after Graham's death, the first time being on Radio 4 – a program called The Choice, presented by Michael Burke. I am still very angry towards the government and its cover up, but I have learnt to do something positive with my anger, and fight extremely hard for disabled people's rights in all areas where discrimination lies.
60. I have never wanted money, I just want equality of opportunity and the same rights as others. Disabled people are not born with the same choices as others, and we have to fight extremely hard for our rights, including the right to be alive. The contaminated blood scandal was a human rights catastrophe. This Inquiry is not just about a group of haemophiliacs and others who were given contaminated blood products, it is also about how the haemophiliacs were discriminated against as disabled people –Disabled People's health equalities record has always been in question and the haemophiliac scandal is a good example of that. I question why the government was not willing to spend money on screening blood when it first heard rumours of infection? Was it because it impacted only disabled people? I wonder. Haemophiliacs need to be heard and the Inquiry needs to give voice to those who have been ignored for so long.
61. Disablism is, like racism, a type of discrimination. There is an ingrained attitude that disabled people are flawed. That is the most disempowering and disrespectful way to treat any person. What needs to come through in the Inquiry is that disabled people were given-up on so quickly and easily. Our lives would have been so different if it was felt that patients deserved the necessary extra funds to heat treat the product when it was first known there was a risk. But the funding came too late and hundreds died as a consequence.

62. An apology from the government is not enough, there needs to be transparency as to what went wrong at every stage. Some people must take responsibility for their actions or inactions. Everyone involved should admit that a terrible error of judgement was made, and ensure it will never happen again. It also needs to be admitted that evidence was destroyed deliberately. This was a national scandal on the same level as Hillsborough and Grenfell.
63. Graham and I never liked The Haemophilia Society. It was run by people who were not haemophiliacs, acting in "the best interest of disabled people" when really it was in the best interests of themselves. The organisation was paying lip service to the government whilst representing itself as the voice of haemophiliacs. We met a number of haemophiliacs in the same situation who felt the same as us. There was a lot of resentment against the charity.
64. One man, a chemist, tried to work with the Haemophilia Society but said 'they were the most patronising group of people'. I have a feeling that the Society purposely gave little attention or support to our demand for a class action against the government. I do not have evidence, but I believe they did not want to rock the boat and preferred to preserve the status quo. As a couple we were not supported by the organisation. In many ways I would have felt less patronised if the financial support we did receive came from an anonymous government social security office, rather than a charity.
65. I am sorry that I do not remember the name of the man I refer to above. He was a member of the Birchgrove Group, the self-help group for the people with haemophilia and HIV. I saw him a couple of times after Graham died. I believe that he had become infected by HIV some years later than Graham and I was pleased that he still had a reasonable quality of life due to newer drugs that were coming online.

66. After the preliminary hearings of this Inquiry, I tried to obtain Graham's medical records. The hospital came back to say they did not have them. Graham's death certificate records bronchopneumonia as the cause of death.

Statement of Truth

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

Signed GRO-C _____

Dated 03/06/2019

