

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1303001

Exhibits: WITN1303002-8

Dated: February 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 of GRO-B Hampshire, GRO-B. My date of birth is GRO-B 1955 and I am the widow of GRO-B: H. I have never remarried. I have a 33 year old daughter GRO-B who is engaged to be married soon.
2. I am an affected person in relation to my late husband who passed away as a result of receiving contaminated blood products. He was infected with HIV and Hepatitis C (HCV).
3. This witness statement has been prepared without the benefit of access to my husband's full medical records.

**Section 2. How Affected**

4. I first met my husband in the autumn of 1990. We started dating on GRO-B GRO-B 1991 and got engaged eleven days later. We were married in GRO-B 1992. My daughter, from a previous relationship, was born in

## ANONYMOUS

1985. When I met my husband, he was living in a rented flat as he was going through a divorce. His ex-wife had stayed in the house they jointly owned and he had moved out. He was already HIV positive when we met and he told me about his HIV status as soon as we started dating, and before we got engaged.

5. My husband had Haemophilia A. His condition was very unusual in that although his Factor VIII levels varied between 1% and 2% (on a few occasions they measured at 5%); he was classed as a severe Haemophiliac although he was occasionally described as mild. He only bled on rare occasions. He was repeatedly checked when we attended Haemophilia centres and the fact that his factor levels were so low without the associated bleeding, usually caused surprise amongst the medical professionals.
6. When I met my husband, he was already infected with HIV (and HCV although he did not know that at this time). He told me that he was one of the claimants in the earlier HIV litigation. He was anxious as he had been told he would be called to give evidence as his case was strong. The prejudice at the time extremely stressful and he was worried giving evidence might cost his job and friends.
7. The following information regarding events prior to my meeting my husband in 1990 is sourced from my husband's medical notes and correspondence. The notes and all supporting documentation are available. The same information was told to me by my husband himself save for that it was told to me in more general terms, so for example, when he told me about being given Factor VIII he did not give batch numbers.
8. My husband was treated on only three occasions prior to the admission that resulted in his infection:-

## ANONYMOUS

- a. In January 1968 he was treated at the Oxford Haemophilia Centre with 2 doses of AHG concentrate for a bitten lip.
  - b. In September 1970 he was treated with 2 doses of Factor VIII and Epsikapron after being hit by a motorbike.
  - c. In July 1971 he was treated with one dose of Factor VIII and Epsikapron for a tooth extraction.
9. My husband did not have any further treatment with Factor VIII or any other clotting agent until his admission to Frimley Park Hospital, Surrey, in December 1984.
10. On 16 December 1984, my husband went to the Accident and Emergency Department at Frimley Park Hospital where he was diagnosed with an iliopsoas bleed and was given DF118 and 10 units of Cryoprecipitate. He returned the following day due to ongoing pain and was admitted. It is clear from both the clinical notes and correspondence that treating doctors and nurses were aware he had not been treated since 1971. This would have put him outside of the risk window for HIV; he would not have previously been exposed to HIV.
11. The notes show that he was treated between the 17 December 1984 and 27 December 1984 with 4 batches of Factor VIII. The four batches were :
- a. NHS HLA 3128 on 17 December 1984
  - b. NHS HLA 3128 on 18 December 1984
  - c. NHS HLB 3195 on 18 December 1984
  - d. NHS HL 3208 on 19 December 1984
  - e. NHS Scottish 807 on 19 December 1984
  - f. NHS HL 3208 on 20, 21, 24, and 27 December 1984

## ANONYMOUS

12. My husband's consultant at the time was Dr Shirley (who it appears was a member of the UKHCDO). Furthermore, there are signatures on the prescriber entry for the Factor VIII of a Dr Butler and Dr Hindley.
13. **Exhibit WITN1303002** is a letter dated 4<sup>th</sup> September 1985 from Dr Rizza to Dr Shirley which states "*Thank you for your letter of 28<sup>th</sup> August 1985 giving details of [redacted] H [redacted] psoas muscle bleed in September 1984 and the treatment he received. I shall pass on the batch numbers of the NHS Factor VIII to John Craske for follow-up. In the meantime it will be interesting to see if the repeat HTLVIII antibody testing on a fresh sample of his serum gives the same result as his first one*".
14. **Exhibit WITN1303003** is a letter dated 21 October 1985 from Dr Shirley to Dr Rizza which states "*I am writing to let you know that repeat testing of [redacted] H [redacted] blood for HTLVIII antibody is again positive. If you have any further information on the follow-up of the batch numbers of NHS Factor VIII concentrate that he received I would be grateful to have this*". This seems to suggest that over 7 weeks after notifying Dr Rizza of the batch numbers, Dr Shirley had not been informed of the testing of the four batches.
15. **Exhibit WITN1303003A** is an extract from my husband's medical records which depicts the correct batch number.
16. By the time my husband was given the Scottish batch 807 in Frimley Park Hospital, a recall of unheated blood products had already taken place in Scotland. My husband was given unheated Factor VIII at a time when there was knowledge by medical professionals that HIV was transmitted through clotting factor. The treating medical professionals also knew that my husband had not been given any Factor VIII since 1971 and had therefore not been exposed to HIV. When he attended the Accident and Emergency Department the day before they should have been aware there was also a possibility that he may return to the hospital needing further Factor VIII and so source heat treated factor

## ANONYMOUS

V111. Medical professionals acted in contravention of the UKHCDO Policy of 14 December 1984.

17. Following the above treatment, my husband received no further Factor VIII or any other clotting agent for years and certainly was not treated again until after he was found to have seroconverted to become HIV positive.
18. In April 2003, Elspeth McIntosh wrote to Dr Gorman, National Blood Service (NBS) Brentwood, in relation to a query regarding Scottish Batch 807. This letter confirmed that Scottish National Blood Transfusion Service (SNBTS) did indeed have a Batch 807. It was confirmed that the material supplied to BPL was standard non-heat treated Factor VIII material. It was released for issue on 5 December 1983; a total of 635 vials were released of which 5 were sent to Glasgow on 16 December 1983 and 630 to BPL on 15 September 1984.
19. **Exhibit WITN1303004** is a letter dated 27 May 2008 from Dr Hay to me. This letter was written in response to my ongoing enquiries and states *"My interpretation of our record of your husband's treatment is that he had Oxford Factor VIII, which would have been an early concentrate in 1970. Epidemiological evidence published decades later would suggest that it is likely that he contracted Hepatitis C from his first exposure though I note that he developed jaundice in 1984 which suggests acute hepatitis at that point."*
20. **Exhibit WITN1303005** is a letter dated 22 July 2008 from Ernie Gascoigne, then Medical Affairs Manager at BPL to Dr Hay, then Chair of the UKHCDO, advising that the batches in question (not referring here to the Scottish batch) were all manufactured at BPL and that none were subject to any form of terminal heat treatment. The release dates from the QA departments were:
  - a. LA 3128 on 21 January 1984

## ANONYMOUS

- b. LB 3195 on 17 September 1984
- c. HL 3208 on 23 October 1984

21. Mr Gascoigne further stated that BPL only hold archive samples for one year after the expiry date and there was, therefore, no means of testing the batches in question. My husband was found to have seroconverted to HIV positive by the August of 1985. He was given the Factor VIII in December 1984. Even if he had been given the Factor VIII on the day that it was due to expire, there would still have been time to test the batches. Only three BPL batches were implicated so this would not have been a difficult task.
22. On 25 July 2016 I made a Freedom of Information Request (FOI) to BPL about the batches but was told that because BPL was not a health authority they did not have to respond to me and that my query had been passed to the legal team who would revert to me. To date I have had no further response.
23. In August 2016, I made a further FOI to the SNBTS about NHS Scottish Batch 807. The response I received was "*there is no record of any recipient seroconversions associated with FV111 (NY) 807. As SNBTS received no reports of any seroconversion associated with FVIII (NY) 807 no retrospective testing was carried out.*" From this, it would appear they were never notified of my husband's seroconversion from one of only four possible batches.
24. I made a further FOI to Frimley Park Hospital in August 2016, in which I asked which protocol was in place for treating PUPs or scarcely treated patients. I also asked which stocks of heat treated Factor VIII I were held between 17 December 1984 and 27 December 1984. In response to my FOI, I was told that this information had been destroyed in January 2015.

## ANONYMOUS

25. My husband was not warned of the risk of contracting HIV. He may have had some reference made to a risk of Non A non B hepatitis but I think this was implied to be a minor issue. I remember sitting with him at the Oxford Haemophilia Centre, which would have been at the earliest in mid 1991 maybe later, when he was told that non-A Non-B Hepatitis was not dangerous.
26. He contracted acute hepatitis soon after his treatment with the Factor V111 and was admitted to Frimley Park Hospital again. He was tested for a range of Hepatitis infections and I believe he knew this. He was given the results as they were available. He was tested for HTLV111 in August 1985 and I believe he did not know this. I believe he was not given the results until October 1985. He and his ex wife were trying for a baby at the time. Luckily she did not become infected.
27. My husband was told in person his HTLV111 result was positive and that it would need to be repeated. Subsequent test results were given by phone I believe.
28. My husband was not told that he had Hepatitis C until 1995 and **Exhibit WITN1303006** is a letter dated 5<sup>th</sup> April 1995 from Dr Giangrande to Dr Trowell confirming the same.

### Section 3. Other Infections

29. My husband was always given to understand he was Hepatitis B negative. His notes in March 1985 say he is HBsAG negative and several tests repeat this, however a letter from Dr Rizza to Dr Shirley dated 28 March 1983 says he was found to be HBsAB positive in 1971. A letter from Dr Ramage to my husband's GP, Dr **GRO-B** dated 12 August 1998 says he is both Hepatitis B core antibody positive and Hepatitis B surface antibody positive. On 16 September 1998 Dr **GRO-B** writing to Dr Sweetenham says that my husband is both Hepatitis B core antibody and surface antibody positive and says "This

## ANONYMOUS

was apparently recorded some years ago but [H] has never been informed of it". Another letter dated 30 June 1998 also states that my husband says he is not Hep b positive but had a surface antibody of >500 and was also core antibody positive. It says "on checking with Oxford, they have also measured him to be B antigen positive in the past although Mr [H] has never been informed of any of this". There is a similar letter dated just before he died. He was never made aware of this and it seems he went 27 years without being informed.

### Section 4. Consent

30. My husband was tested for HIV without his knowledge and therefore, impliedly, without his consent. A letter from Dr Cobb (SHO to Janet Shirley) dated 6 August 1985 says, (referring to his HTLV111 test), "This was not mentioned to him, purely that we were looking for some underlying viral infection". An entry in his notes dated April 1985 says 'yellow form for hepatitis survey for Oxford.' He was not aware of being part of a survey.

### Section 5. Impact

31. When I met my husband he was quite a long way through a divorce process; he had moved out of the family home and was living alone in a small rented flat. He was trying to rebuild his life. He told me that at one point he had been so low that he had contemplated suicide.

32. In the early years that we were together (1990 to 1994) my husband remained in fairly good physical health although the stress brought on by the need for secrecy as a result of the surrounding stigma re AIDS took its toll. He suffered from a range of complaints over this period, to include oral thrush, a swollen cyst in his neck and occasional night sweats. The fear of catching something when my husband was out and about was always a major issue and caused him no end of stress. As his health deteriorated he developed High Grade B cell lymphoma; in

## ANONYMOUS

1997, life threatening anaemia as a result of his treatment with AZT which required a blood transfusion and cirrhosis of the liver, in addition to an endless stream of minor illnesses.

33. My husband was put on Septrin in 1994 as a prophylactic against PCP pneumonia. Whether this medication caused the severe acne on his back or whether it was a coincidence I don't know. However, the acne lasted for months and he was extremely upset about this which meant that he always wore a t-shirt in bed.
34. When I met my husband he was living in Surrey and he then relocated to the South Coast to live with me. Shortly before my husband moved in, I attended a routine GP appointment with my daughter in relation to a childhood complaint. I asked the GP if my daughter could attend school and his shocking response was "*of course, it's not as though she's got AIDS*". I immediately realised that I was going to need to change my GP before my husband was living with me.
35. Whilst I was with my husband, I attended numerous hospital appointments with him. He was always stressed at these appointments. He would begin to get stressed a couple of days before the appointment was due to take place. This was exacerbated by the fact that he usually had to make up a reason for being off work as he could not disclose his HIV status. He did not like the interference with his life which, towards the end, became more and more intrusive. Moreover, he did not feel safe in hospitals and he had lost all trust in doctors.
36. It always appeared that the medical professionals were trying to find reasons for his stress and blamed anything and everything, rather than accepting the most obvious reason that he had been handed a life sentence by the NHS. He feared for his future, was in constant pain, could not work, could not tell people why he could not work and had financial problems. Over the years, the medical professionals have suggested various reasons as to why he was severely stressed to

## ANONYMOUS

include drinking too much, family problems and one occasion they wrote "*he hasn't helped himself because he is a vegetarian*".

37. In the spring of 1994, my husband was made redundant from his healthcare role. He took the matter to an employment tribunal who found that he had been unfairly dismissed but he wasn't awarded any compensation.

38. When my husband tried to find another job, he hit a major problem in that all of the application forms required him to declare whether he had been exposed to HIV. He was afraid of disclosing his HIV status so he had to take a self-employed role as a **GRO-B** which meant that he was not entitled to either sick pay or a pension. This meant that every time he had to attend a hospital appointment, he lost income. As time went on he had to have more and more time off due to his infections. This negatively impacted him in two ways. Firstly, it seriously reduced his income and secondly because he couldn't say why he had time off, he started to look unreliable. He loved his job and it was really important to him and it caused him a lot of distress to feel that he was being diminished in the eyes of his colleagues. After 1994 he never worked as an employee again. He remained self employed until he had to stop work altogether.

39. About a year earlier I had encountered a similar problem. I was also a healthcare worker. I was working as a bank worker for the NHS when a computer error removed me from the system. I was told that I would be put back onto the system but in order to do this I just had to complete a form; a mere formality. The difficulty was that this form included the question '*Could you have been exposed to HIV*' or words to that effect. Although I had had regular HIV tests and I was HIV negative and we had taken all of the necessary precautions, I still felt unable to complete the form. We lived in a fairly tight knit community and the risk of someone discovering my husband's HIV status was too great. I ended

## ANONYMOUS

up giving some absurd reason for leaving and had to become self-employed myself. I also encountered the same issues that my husband had with sick pay and pensions. This meant that there was no real financial security in our house in the face of illness and at a time when we needed it the most.

40. My husband and I wanted to have a child together. I already had my daughter (then about 9) who was desperate for a little brother or sister. We made enquiries with our GP and also at the Haemophilia Centre in Oxford. We had heard from another Haemophiliac's wife about a sperm washing procedure run by Professor Semprini in Italy.
41. My husband and I embarked upon the process which required a raft of tests for both of us. Our first hurdle occurred when we were advised by our Health Authority that they did not fund fertility treatment. We argued that we were not infertile and that it was needed to protect me from the disease that they had given to my husband. It was the start of a 15 to 18 month long struggle. We were pushed from pillar to post. We constantly had our hopes raised and then dashed and this went on throughout the process.
42. We paid privately for both uncomfortable and invasive tests. We were initially told that the programme was running at St Thomas's and that we would not need to travel to see Professor Semprini. This later changed, however, and we started to make plans to go abroad. Then we were told that it was in fact running at the Chelsea and Westminster Hospital. We therefore halted our efforts to go to abroad and started the tests needed for treatment in London. We were, by this time, over a year into the procedure. I was approaching 40 and my husband's CD4 count and sperm count were falling. I was due to have a hysterosalpingogram to test fallopian tube patency. I was going to have this procedure without anaesthetic to speed it up. However, the day before my procedure I telephoned to ensure that everything was going ahead and I was told that the programme had been cancelled.

## ANONYMOUS

43. If I hadn't checked I would have had to endure this painful test for nothing. No one had contacted us. At our last appointment at the Chelsea and Westminster Hospital we were told that we could not go ahead. I believe that the problem was one of ethical approval. So after almost 18 months of hospital visits, tests, waiting for results and fighting for funding it was all over without even one attempt. I recall that I picked up a newspaper just before we embarked on our journey home. A columnist (I think it was Littlejohn) had written "*Only dirty people with filthy habits get AIDS*". It was like being stabbed. We would not have a child together, we were filthy people. My husband and I did not speak all the way home; we were just too distraught.
44. By now it was the end of 1996 and my husband's health was deteriorating. He had been badly affected by the cancellation of the sperm washing programme. He was bitterly disappointed and his self esteem was hit hard when he received the news that his fertility had fallen to a sub-optimal level. He developed a number of symptoms and was subsequently referred to St Stephen's, London for a review of his liver.
45. He returned from this review absolutely shell shocked. He said that he had been told that he would probably get cirrhosis and that people die from this. He was told that he may be able to have treatment but that even if he did, it might not be successful. He was told that he could have a liver biopsy but that if he underwent this there was a risk that he might haemorrhage. He was then told to go home and decide what he would like to do.
46. He told me that he was never going back to that doctor. I do not know precisely what happened there but at the very best he experienced some shockingly bad communication.
47. Following this, my husband sought to have his liver care transferred elsewhere. He was supposed to see Dr Trowell at the Haemophilia

## ANONYMOUS

Centre in Oxford but she wrote to my husband advising that she had sent him 3 appointments; all of which he had failed to attend. In fact, he never received any correspondence regarding appointments and this accusation further distressed him. My husband and I then attended a Hepatitis C event at Treloars and his liver care was subsequently transferred there, which turned out to be a terrible decision. Somewhere in the correspondence or in the independent review there is a comment that my husband was offered a liver transplant. This is incorrect. My husband was never offered a liver transplant, in fact it was never even discussed until a few hours before he died.

48. By 1998, my husband had started to develop symptoms which turned out to be high grade B cell lymphoma, with a primary tumour in his nasal cavity. He was seen at various hospitals and was rapidly deteriorating. He had started to look as though he had cerebral palsy with his head pulled to one side and his arm twisted. He had pus continuously running from his nose. He had started to look so bad that my daughter was afraid to look at him. Shortly before this I had fallen down the stairs and was told I just had bruising but it turned out to be a wedge collapse fracture of my spine and I was trying to work whilst also looking after my husband and my own health.

49. My parents came to our house to give me a few hours break but I when I returned to the house I found my husband crying, he was far too ill to cope with this. He managed to tell me that my father had fallen and had gone to hospital with my mother. My father had broken his hip and also had cancer and my mother had to go to care for him so there was no one who was not struggling at this time. Looking back, I cannot believe that we came through it; although I sometimes doubt that I ever came through it.

50. My husband was finally admitted to Chelsea and Westminster Hospital and was put on massive doses of steroids. He started to unravel like a flower that was blooming and seemed, against the odds, to be

## ANONYMOUS

improving. He was a man of immense courage and determination and it still hurts that most people never knew how brave he was. I went to see him for 10 days in a row, whilst he was in hospital, by train with my still undiagnosed fractured spine. My father had surgery in our local hospital and was told to go alone to the toilet despite being an amputee with one leg and one fractured hip. This decision resulted in him falling and breaking his arm in two places. He ended up with breathing support and this was the same day that my husband was due to have bone marrow biopsy and a lumbar puncture. I had to decide who was least likely to survive that day as I couldn't visit them both. By this time, my daughter was staying, for days at a time with my friend who was her best friend's mother. All this had a negative impact on my daughter which has continued to the present day.

51. While all this was going on our income was obviously being depleted. My husband was discharged from hospital but still needed a great deal of care. As we were both self-employed (as a result of the HIV) claiming benefits was complex and we were initially awarded something absurd like £7.50 a week. On appeal, this was later increased to circa £50. We tried to claim for help with the mortgage but as the mortgage had been changed from one bank to another (I think) it was classed as a new mortgage. The rules had been changed so that you were supposed to take out mortgage protection but obviously my husband couldn't so we were penalised for not having the protection his HIV prevented him getting. We were disallowed this help for 6 months but my husband had just been given a 3 month terminal diagnosis. I cannot remember whether this was overturned or not.

52. My husband had chemotherapy at Chelsea and Westminster Hospital, London and then was discharged for care at GRO-B whilst at the same time undergoing radiotherapy on his nasal tumour. This left him drained. I think that he was also on triple therapy for his HIV by this time. Eventually he found it very hard to eat or speak. He was surviving on soft food and then later nutrient food supplement

## ANONYMOUS

drinks. He didn't eat solid food again for the six months leading up to his death. One of the most heart breaking things I found after he died was a list of things entitled '*yummy things to eat*' that he had written; he planned what he was going to eat when he was well enough to eat again. He never got to eat again.

53. My husband went into multi-organ failure and died on **GRO-B** 1998. The consultant later told me that this often happens with paracentesis, which was a procedure carried out on my husband. However, my husband was never given this information prior to the procedure being carried out. I think that because he was so uncomfortable, he may still have consented to the procedure but I am convinced that he would not have had it just before Christmas. He died **GRO-B** and my daughter's childhood died with him.

54. I have never remarried or had another long term relationship. Each Christmas when the decorations go up I feel a sense of loss that never lessens. I look at my married friends sharing their retirement holidays, birthdays, Sunday barbecues and I feel cheated and robbed. My daughter still misses my husband. She is getting married soon and he should be there to see it. This should also be the happiest of times but it is being overshadowed by the endless quest for justice.

55. My husband kept his infection secret from even his closest friends; with the exception of a Haemophiliac cousin **GRO-B** he didn't tell any of his wider family although they were quite close. This meant that neither he nor I received the support that people struggling with a potentially fatal illness usually get.

56. My husband had difficulty accessing dental treatment. This is supported by a letter dated 30 June 1989, from Janet Shirley to Mr Rippon the District Dental Officer in Frimley, saying his dentist will not treat him.

## ANONYMOUS

57. Due to the stigma surrounding HIV and HCV my husband and I had to effectively deal with matters alone. It created a life of deceit. We could not be open with friends or colleagues. When my husband had to go to hospital we could not say why, when friends had infections which we thought were too dangerous to be around, we could not say why. When my daughter wanted to bring home snotty children we could not say why. When we felt that we had no choice, we told my daughter and then she also had to hide. The secrecy makes you very afraid of being found out.

58. This fear was real because the consequences of being found out were dire. After the fear comes isolation. The secrecy means that you end up shutting people out. People never get to know you. Work colleagues think that you are unreliable, friends with their own worries think that your life is easy and your daughter thinks that you are being unfair and "*why can't you be more like her friend's parents*" (until you blow her life to pieces with the truth).

### Section 6. Treatment/Care/Support

59. My husband's lymphoma care was transferred to the wonderful Dr Sweetenham, then of Royal Hants Hospital, Southampton. Under his care, against all predictions, his lymphoma went into remission. For my husband there was no escaping, as his lymphoma improved, his liver got worse.

60. His admission to North Hampshire Hospital, Basingtoke on GRO-B GRO-B 1998 was the start of the worse 3 days of my life and the end of my husband's. The events of that admission were the subject of both an Independent Hospital Review and later an Ombudsman Inquiry. I have folders of contemporaneous notes, letters etc that I would like the Inquiry to see. I have never recovered from those 3 days and even recalling those events is leaving me feeling sick and giddy. My husband was under the care of Dr Ramage and his registrar Dr Sheen. It proved

## ANONYMOUS

difficult, if not impossible, to obtain any information from Dr Ramage. My husband ended up telephoning his secretary trying to get his test results and following this telephone call, my husband was called in for paracentesis without any explanation as to why. Later the hospital claimed he asked to go in but this was incorrect. My husband had wanted the results of his lymphoma tests, he was left to fret about it for days. He only found out his lymphoma had not returned a few hours before he died.

61. From Monday, **GRO-B** 1998 to Thursday **GRO-B** 1998 at 3.40am when he died, doctors at the North Hants Hospital drained 14.5 litres of fluid from my husband and failed to record properly the fluid balance charts and failed to notice that his abdomen was refilling. The drain leaked and he was left overnight in soaking wet clothes. These ascites encrusted clothes, complete with blood soiled dressings, were returned to me in a bag after he died ignoring any thought for my psychological welfare or cross infection.

62. He had withdrawn his consent for the drainage but it continued and even though in his notes a haematologist writes that my husband 'was concerned he hadn't consented,' the review accepted the doctor's account. About six hours before he died when his blood pressure was already critically low and he was having breathing difficulties, the registrar told me he thought my husband's problems were mainly psychological and I was the cause of it. I was told nothing was going to happen that night and I should go but an hour later I received a phone call at the hotel I had gone to, saying 'we need your consent for a CVP, you do realise your husband probably won't survive the night'. After my husband died, samples of his body were taken, not just without my consent but in the face of my presumed refusal for vCJD research. On objecting that I hadn't been asked I was told 'haemophiliacs make an excellent model for this kind of study'.

## ANONYMOUS

63. It was devastating to be told that the person you loved made excellent research material a few days after they had died. This caused many additional problems in coming to terms with our loss. Despite this, no one ever bothered to tell me the results of the vCJD testing on the samples of his body and it was left to me to track down the vCJD surveillance centre and learn he was not infected. Letter from CJD surveillance centre available.
64. I suffered flashbacks of the events in North Hants Hospital for years after my husband died. This was exacerbated by the fact that the North Hants Hospital, Hampshire behaved so badly in the next couple of years. I made a formal complaint regarding my husband's treatment which was handled extremely badly. The North Hants Hospital took months to reply and when they finally did reply, the letter arrived just before the first anniversary of his death which was the **GRO-B** 1999. This was repeated when the Independent Review was held in the run up to **GRO-B** again, the following year.
65. At the Independent Review stage, the hospital accepted that the staff managing the fluid balance were not properly trained. They apologised for the fact that my daughter had walked in on a scene that has left her distressed to this day. It took them months to send the apology after they had been told to do so. They accepted that more information should have been given about the procedure. The rest had to go to Ombudsmans' Inquiry. The Ombudsman held that the fluid balance charts were not properly kept and that they were wrong to take samples of my husband's body without my consent.
66. My husband did not want to speak to counsellors but towards the end of his life, he decided that he would like to speak to someone. Having followed this up, he received an answerphone message (we had expressly asked not to leave messages) inviting him to a memorial service for people who had died of AIDS. How that was supposed to

## ANONYMOUS

help him is impossible to fathom, especially as he didn't even know any of the people who had died.

67. In relation to counselling, a major problem with all psychological support has been that all the health professionals I have spoken to have been in denial about what happened. For example, in Hammersmith Hospital a doctor said to my husband "I see you've picked up HIV along the way" when it was pointed out to him that he hadn't picked it up he was given it, my husband was told, "it's the same thing". This attitude from the medical practitioners was unacceptable, upsetting and deeply worrying. I was asked if I would like counselling for my anger. My anger is not pathological. It is a rational response to an irrational situation. My anger does not need counselling it needs justice.

68. I did try counselling and the counsellor wrote to my GP saying I was suffering from complex bereavement as a result of what had happened.

69. I exhibit to this statement a letter from Christine Kalus, Consultant Clinical Psychologist to Dr GRO-B dated 29 July 1999. This is **Exhibit WITN1303007**.

### Section 7. Financial Assistance

70. My husband did receive help from the Macfarlane Trust (MFT) but everything had to be applied for with supporting evidence which caused a great deal of stress when we were already immersed in and dealing with a nightmarish situation.

71. The MFT paid for a new bed as ours smelt dreadfully of the pus caused by the cancer and the springs were hurting my fractured spine. In order to obtain a new bed we had to get supporting letters from the nurse who visited and it was suggested we might need occupational therapy backing which started to make the whole thing a major undertaking.

## ANONYMOUS

72. We were also granted some funding for help in the house for a couple of hours a week but again I think had to have someone come from Hampshire County Council in order to complete the application process.
73. The overriding outcome or effect of the MFT was that you lost all control over your own life, which seemed to become a parade of people turning up deciding what was best for you. Nothing was private or 'ours' anymore. It was as though our whole lives had become available for inspection.
74. I would describe the MFT as a form of "*patchy support*" which was absolutely erratic. Sometimes the support was good but sometimes it was appalling.
75. At the point when my husband was fighting for his life, I was caring for him and juggling work so we stopped paying attention to the MFT. With retrospect, I can see that the MFT was wholly irrational. For example, they would award funds for a therapeutic massage and reflexology, but not for necessities or things that would really help our lives such as sperm washing or debt problems that would escalate without help.
76. My husband used to receive monthly payments which increased when he became ill. However, he died having to worry about money through no fault of his own and nothing will ever correct that.
77. **Exhibit WITN1303008** is a hand written draft of a letter my husband wrote, planning to send to MFT, which shows his anguish at the scheme and its affect on him.
78. Currently, I am receiving the widow's top up payments. Initially the amount was topped up £15,000 and I don't think I qualified. Then it increased to be topped up to £18,000 and now it is topped up to £19,000. Unfortunately, this has never been a guaranteed source of income because the MFT review our applications on an annual basis.

## ANONYMOUS

79. I also received a loan from the MFT for a sum of £8,300 in or around 2003/2004. I have not yet paid this loan which was taken out for me to go to study. I was initially reluctant to take a loan as I feared being unable to pay it back if I could not get employment in the new career. The loan was set up by Ann Hithersay as an unsecured loan. After Ms Hithersay left, MFT wrote to me to ask if I would secure the loan on my property. It was a bizarre invitation. One of the terms of the loan was that I would not have to commence repayments until I started full time employment in my chosen career. The MFT has attempted multiple tactics in order for me to pay it back quicker and regrettably I think this behaviour was not uncommon for them.

80. The MFT was conclusively not fit for purpose. They came up with policies which were changed as and when it suited them and it was almost impossible to know the rules, which seemed to change on a whim. I found it completely unacceptable that at one time the level of financial assistance offered to me was dependent on my daughter's income because she was residing with me. I had a lengthy argument with the MFT through numerous emails. I questioned as to why my daughter was expected to support me and I presented the argument that the Trust was not acting in our good faith which was against their charitable objectives. Although they eventually retracted by then it had caused so much distress that my daughter had moved out.

81. The financial assistance did not meet our needs; but I also do not think that the MFT's purpose was ever actually defined.

82. My husband's estate received the Stage 1 and Stage 2 payments from the Skipton Fund and I used much of this money to pay off our debts.

### **Section 8. Other Issues**

83. While my husband was still living in Surrey he was asked to sign the waiver in relation to the previous HIV litigation. He didn't want to sign it

## ANONYMOUS

but he didn't think that he could afford to fight on alone, either practically or financially. In the end he gave in. He was afraid of what a court appearance would cost in terms of prejudice and stigma. He believed it could cost his job and friends. They had him over a barrel and he felt he had no choice but to sign it.

84. I spent the first three years after my husband died, fighting over his death in North Hants Hospital, rather than the issue of infection with HIV. It was my belief that the doctors caused his death. I went through the most hideous experience imaginable; the way the medical professionals acted was gut wrenching. This fight continued until about 2003. I then focused on the political campaign for a Public Inquiry. I was just turned 43 years old when my husband died and am 63 now, a third of my entire life has been spent fighting for justice. Summers have rolled into summers and I have missed them all, sat at a desk or computer writing, researching, fighting. No remorse has been shown ever and successive governments have piled on the misery.

85. I have been left with such a mistrust of doctors and hospitals that I am unable to fully access medical treatment. For example I had a CT scan but could not bring myself to have contrast put in my veins fearing what I might find out years later. The more I find out the less this seems like anxiety and more a reality based concern.

### Conclusion

86. This shocking scandal has robbed us of so much. My beautiful husband lost his chance to father children, to further his career, to enjoy a holiday, to have financial security, to have any kind of security, to be free of pain, to be free of fear, to wake up and not wonder how many mornings he would see or as I found out, when I found his diary after he died, not count down the days until the day he was expected to die. What else was there left to take? He would've have hoped my daughter and I might go on to live a normal life and if he could see this now, he would know that even that was to be taken.

## ANONYMOUS

87. If I could do one thing right now, it would be to stop campaigning, stop fighting, remember my husband rather than his tragedy. I want an end to the denial and cover up, recognition of what happened, recompense for the financial loss and for all the pain. After all this time, I want peace.

88. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my solicitors preparation of this statement does not cover investigative work. I would like to give evidence on such matters and am unable to do so in this statement.

### **Anonymity, disclosure and redaction**

89. I wish to apply for anonymity. I would like to give oral evidence to the Inquiry but I have family commitments until the end of 2019.

**Statement of Truth**

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

Signed GRO-B .....

Dated... 25.2.19 .....