

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1639001

Exhibits: WITN1639002-7

Dated: 16 March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B and I live at GRO-B
GRO-B
2. My husband GRO-B: H born on GRO-B, was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII) blood products. He died on GRO-B
GRO-B having developed Non Hodgkins Lymphoma, aged GRO-B
3. This witness statement has been prepared without the benefit of access to H's full medical records.

Section 2. How Affected

4. H had severe Haemophilia A from birth. H was initially treated with Cryoprecipitate and he was started on home treatment in 1977. According to his UKHCO notes (WITN1639002) he was treated with Kryobulin between 1977 and 1983. From 1983 onwards he was treated with Factorate, FIIIV (PFC), Hemofil and Profilate.

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5. He was treated at the **GRO-B** Haemophilia Centre at the **Royal Victoria** Hospital under the care of Dr Elizabeth Mayne. He spent a lot of time, as a child, in **GRO-B** Hospital in **GRO-B**, only attending the **GRO-B** in **GRO-B** if the bleed was serious. His main bleeds were into his elbows and ankles but he never had any severe haemophilic arthropathy problems as many others did.
6. **H** was informed that he had HIV sometime in 1989 but most of his notes are missing so I do not know exactly when he was told. It was however many years after had seroconverted which was 1983, and was apparently detected on a retrospective sample dated 11/02/1983. The UKHCDO notes record that he was diagnosed on 15 January 1984.
7. **H** was informed that he had HCV some time later. I believe it was sometime in 1992. The application for Disability Living Allowance, completed by Dr Mayne in June 1992 (WITN1639003), notes that he was positive for Hepatitis C (in addition to HIV).

Section 3. Other Infections

8. **H** was also infected with the Hepatitis B Virus (HBV) although I do not know when. Dr Mayne wrote to the **GRO-B** in **GRO-B** on **GRO-B** and mentioned that **H** had antibody to HBV at that time (WITN1639004).

Section 4. Consent

9. Samples of **H**'s blood were taken at his hospital appointments. I do not think **H** knew or consented to being tested for any particular infection. **H** may also have been the subject of research.

10. I believe that he was given Factor VIII without being warned of the dangers and if he knew he would not have consented. I also believe that he was re-infected multiple times with contaminated products.

Section 5. Impact of the Infection

11. I met **H** **GRO-B** whilst in my teens and we began dating. I knew that he was a haemophiliac and required treatment for his bleeds. His elbows and ankles were problematic. He couldn't work but he often helped his father **GRO-B** when he was able. He used to self-administer the FVIII concentrate treatment at home.

12. In about **GRO-B** **H** became withdrawn and I thought that he didn't love me anymore. He ended our relationship and said to me that he felt we would be better apart. He was reluctant to tell me why he felt that way and we did break up for a short time. However, we couldn't bear to be apart and a few months later we got back together and it was then that he told me that he had been infected with HIV. As we were both so young at the time it was very difficult to fully understand or to deal with such a diagnosis. I formed the impression that the hospital staff had not been particularly helpful in providing any explanation and/or advice to enable him to manage the infection.

13. **H** was a very private man and wanted to wipe the diagnosis from his memory. We did not discuss it often. It was his way of dealing with it. We only told my sister and one or two close friends. We were still able to socialise with other people because they did not know.

14. **H** was very worried about other people finding out that he had HIV. He hated collecting his medication from the local pharmacy and did not always give his hospital discharge letters to his GP. **H** was terrified that local people would find out and that he would become a source of gossip and be ostracised. He gave up smoking for a while but started smoking again through the stress of it all.

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15. We were so worried that [H] s status may get out. He burned all letters and leaflets from the hospital and didn't visit the GP very often as he did not want the staff to know. The government adverts which appeared on TV were very distressing and he changed channel if they came on the TV.
16. [H] and I married in [GRO-B] We had planned to marry in [GRO-B] but brought the wedding forward. At the time I went to the doctor with anxiety but couldn't tell anyone the real reason why. I was just so worried about the future, how long he would live and the dawning realisation that we would never have children.
17. We always had to be careful and [H] was terrified of infecting me which to me is very sad as it inevitably had an impact on our intimacy. I tested negative for HIV and HCV in November 1993 but it was always a worry for us.
18. We had to lie to friends and family that we were in no rush to become parents. We did see a social worker about having children and artificial insemination but nothing came of it as [H] became unwell shortly afterwards. I always regret that we did not have children together.
19. I remember that [H] was never fully well. He became tired, lethargic and quiet. He spent a lot of time in hospital during our marriage but we didn't tell many people in case they asked why he was there. Over time he was diagnosed with issues with his spleen, pancreas, liver damage, shingles, flu, thrush, ulcers, warts and high blood pressure.
20. In April [GRO-B] [H] despite his HIV infection was noted to have no clinical signs relative to HIV, had not at that time had any opportunistic infections and was not on any medication.
21. He began taking AZT in or around 1991
22. In 1992 [H] made an application for Disability Living Allowance (WITN1639003 above). Dr Mayne provided reasons why it should be granted and confirmed that [H] was HIV and HCV positive. At the time he was

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treated being with prophylactic pentamidine inhalations to combat possible infection with pneumocystis carinii pneumonia. His CD4 count was less than 200 and his platelet count had reached the thrombocytopenic range for which he was taking zidovudine tablets.

23. Dr Mayne also noted that [H] had persistently elevated liver function tests which was presumed to be caused by his HCV infection. She said that his prognosis was poor suggesting that 1-3 years would be optimistic.

24. In January [GRO-B] [H] was admitted to hospital with a 3 month history of a cough and an examination revealed evidence of oropharyngeal candidiasis but further investigation was not thought to be of use at that time. His AZT treatment was stopped because of his low CD4 count (WITN1639005).

25. On [GRO-B] [H] was out helping his dad [GRO-B] but he came home as he felt unwell. He felt dizzy and had a headache. That night he collapsed on the kitchen floor. I rang the hospital and was told to get him there immediately. It was 90 miles away but [H] was reluctant for me to call an ambulance because he did not want the paramedics to know that he had HIV.

26. My sister and I set off with him in the car but he had another seizure and collapsed onto me as I was driving on the on the motorway and I lost control of the car. Luckily the motorway was quiet or we could all have been injured. We had to call an ambulance after all.

27. He had come to by the time the ambulance arrived and he was able to give his details but he did not disclose his diagnosis, however, I did and I felt as if I had betrayed him but I thought that they should know.

28. [H] was diagnosed with cerebral lymphoma which is a form of Non Hodgkin's Lymphoma (WITN1639006). It was a direct consequence of the HIV infection. [H] was under the care of Dr [GRO-B] and was initially treated with Epanutin, Dexamethasone and Zantac [H] was thought to have responded well to steroid treatment but that response was short lived. Dr

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Mayne was keen for him to commence brain radiotherapy which he did in mid

GRO-B Initially he responded well but developed a chest infection.

29. I remember Dr Mayne took us into her office and told us that **H** could be treated but could not be cured and that maybe we should go on a nice holiday together and she would sort out relevant letters and documents to enable **H** to travel. We both knew that this was her way of telling us that he was not going to survive and we were both devastated.

30. He was discharged for the weekend and he wanted our families to go out for a meal together. It was **H**'s way of thanking everyone for all that they did. It was awful knowing that this was a farewell get together with us pretending that everything was ok but knowing that time was running out. There was only a few of us who knew the awful truth that night.

31. During this time, I gave up work to be with **H** and visited him every day. I drove him from **GRO-B** Hospital where he had his radiotherapy treatment.

32. I stayed in **GRO-B** near the hospital and my mum and sister took it in turns to stay with me. I didn't tell **GRO-B** about the HIV or Hep C and I feel guilty about that. It was awful living with this terrible secret and only telling close personal friends and my sister

33. On **GRO-B** **H** was noted to be very unsteady but Dr **GRO-B** felt that there was no alternative but to carry on with the treatment. The Dexamethasone steroid was increased for administration daily by the **GRO-B** **GRO-B** where he remained on **GRO-B**

34. **H** died at 10 pm on **GRO-B**
H **GRO-B**
GRO-B

35. I note that Dr Mayne, in her letter to **H**'s GP Dr **GRO-B** stated that **H** died peacefully. He did not. He suffered a painful and horrific death. His death

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certificate states that he died from Haemophilia A and pneumonia. It does not mention AIDS/HIV/HCV or Lymphoma (WITN1639007).

36. In **GRO-B** it is common practice for a person to be taken home before the burial and for the coffin to remain open for family and friends to visit and pay their respects. We had the wake at home but the lid had to be closed. A photo of **H** **GRO-B** was placed on the casket. Some of our friends questioned it as they knew that something was wrong, however, we had to keep the reason **H** had died a secret from everyone as HIV and AIDS was such a taboo subject. I told everyone that **H** had died from cancer and still tell people that to this day

37. Losing **H** was like losing my right arm. We had been together since I was **GRO-B** and **H** was **GRO-B**. We were very much in love. We were inseparable and the only time we spent apart during our marriage was when he was in hospital.

38. About 2 years after **H** died I rushed into a relationship as the loneliness of life without him was unbearable and I really wanted to have a family. We had a son together but unfortunately my partner was very violent and abusive and I finally got the courage to leave him in **GRO-B**

39. I still feel very isolated and have chosen to keep **H**'s diagnosis a secret. It is still the case that only a small number of close friends and relatives actually know what happened.

40. It has affected me in so many different ways and I have suffered bouts of depression over the years. I find it difficult listening to certain songs from the 1980's and 90's and deeply regret that we could not have children together.

41. I also feel guilty about the secrecy which meant that I was always lying to family and friends.

42. I often wonder what our lives would be like today and how many kids we would have had. I still grieve everyday for him and the life that I lost.

43. I have a new life now and a wonderful son but I will never get over the shock of finding out that [H] was infected or the impact that it had on him when he found out. I will never forget living with such a terrible secret for so many years and watching him suffer and pass away in such a painful way.

Section 6. Treatment/care/support

44. [H] was a private man and didn't want to talk about being infected. I do not know whether he was offered any counselling and support but I doubt it.

45. [H] shared very little with me about his treatment. I believe that he wanted to protect me. I do know that initially he refused the AZT treatment trial for HIV. He did eventually commence AZT in 1991 taking it intermittently and then a combination of AZT and DDI.

46. I was not offered counselling or psychological support during [H]'s illness or after his death. I was worried for the future and needed it. I did have some counselling privately in 2004 and have suffered with anxiety and depression on and off since [H]'s death.

47. This January I received a letter from the Belfast Trust offering support some 25 years later and I believe that this was only done because the Trust had to provide a statement to the Inquiry setting out what psychological support was on offer.

48. [H] received money from the Macfarlane Trust and I received £1000 towards his funeral.

49. I received no financial help since then until I heard about the Skipton fund in 2014.

50. Nick Fish at the Skipton fund was very helpful.

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51. I left work in May 1995 to care for [H] and did not return. I almost lost my home had my parents not helped me financially

Section 8. Other Issues

52. I try to live the best life I can but the Inquiry has brought to the surface many painful memories. I want answers as to what happened and why. I believe that there was a cover-up and would like those responsible to be held accountable for their actions. I do not want anyone else to suffer something like this ever again and believe that those in power should learn from this.

Anonymity

53. I wish to remain anonymous.

54. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-B

Dated.....16.3.2020.....