

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1722001

Exhibits:

Dated: NOVEMBER 2018

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 My date of birth is GRO-B and I live at GRO-B
GRO-B with my husband, GRO-B: H
H I am by occupation a retired GRO-B
2. H has given a Statement to the Inquiry (Witness Number GRO-B on
GRO-B

Section 2: How Affected

3. H suffers with severe Haemophilia A. He was diagnosed as a Haemophiliac at around 1 year old. H became infected with HIV and Hepatitis C as a result of receiving contaminated blood products, Factor VIII (FVIII).

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4. [H] was told of his HIV diagnosis in August 1985 and was then told that he had Hepatitis C some time between 1989 and 1992. He attends the Oxford Haemophilia Centre at the Churchill Hospital, Oxford and it was there he was told that he was HIV positive and later, Hepatitis C positive. [H] does not know exactly when he became infected as the doctors have been unclear. He received FVIII on a number of occasions including when he had surgery more than 10 years before he was told he had HIV.
5. I met [H] in the late Summer of 1985 when he moved to the area where I lived. We had had a few dates together and started to become close. [H] told me that he had HIV in or around October 1985. We met for a drink and he told me his news. I could tell from his face just how difficult it was for him to have that conversation with me and I recall we sat for much of the time in silence. He was very insistent that we should split up because there was no future for us. He had just two years to live and there would be no children.
6. Our relationship hung in the balance. When he told me, I felt that our relationship was on the cusp of developing into something serious. Over the course of the next week or so we spoke to one another over the telephone. I thought 'I actually really like him' and did not want to split up. The fact we stayed together re-affirmed our commitment to each other. We married in [GRO-B].
7. I remember being tested for HIV before we married. A nurse came out to our flat to make sure I was 'OK' and I remember being impressed at that time, thinking 'this is good'. With hindsight, I believe it suited the hospital and that they were looking to absolve themselves from their responsibility in infecting [H] with contaminated blood if I had HIV (as they could have argued that I was the source of the infection).

8. As we had been warned not to have children we followed that advice. [H] had been given just two years to live. It is one of my biggest regrets that we remained childless but at that time [H]'s life expectancy was grim and remained that way until newer treatments came on to the market.
9. Some time between 1989 and 1992, after attending a hospital appointment, [H] came home and told me he had just been informed that he had Hepatitis C as well. At that time (and right up until 2002 when he began to experience serious health issues), [H] attended medical appointments on his own.

Section 3: Other Infections

10. [H] has also received notification that he is at risk of vCJD.

Section 4: Consent

11. [H] had no prior knowledge of being tested for HIV and Hepatitis C. Moreover there was little known about either virus so there was very little information/advice available to us. We would talk here and there after [H]'s hospital appointments trying to work out between us what everything meant. I recall [H] coming home on one occasion and telling me that they thought his life expectancy was now around 10 years. This was sometime after his HIV diagnosis.

Section 5: Impact

12. As stated, my biggest regret is that we were unable to become parents. I have a maternal nature and would have loved to be a mother. When I met [H] my twin sister had two children. My younger sister went on to have two of her own (with whom I have a close relationship). It is a sadness that I have had to reconcile with my gratitude that my husband is still with me.

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13. To live with [H]'s infections, has been like living under a continual 'black cloud' of uncertainty. Every time [H] has been seriously unwell, I have thought 'is it now? Is this the end?'
14. [H] started treatment for his Hepatitis C in September 2002 with Interferon injections and Ribavirin. He returned from a hospital appointment just before Christmas 2002 and told me his white blood cell count was apparently 'all over the place'. He went down like a pack of cards soon after that and ended up in hospital over Christmas with sepsis. It was not until a nurse stopped me on my way in to visit him and told me that my husband had turned a corner and was 'stabilised' that I realised how close to death he was. I remember how frightened I was and how close to despair I felt. [H] had been so close to death and I had not known. No-one had told me. We were told that infection was a possible side effect of the treatment but we did not know what that meant. I was totally flawed and knew that I would never be the same (psychologically) from that time. The treatment that was supposed to eradicate Hepatitis C almost killed my husband. He was weakened by it to the extent that he was never physically the same again.
15. My sister took me in to the hospital on a daily basis up until February 2003 when [H] was discharged. He could do nothing with his left hand or his right knee. He came out on crutches needing 24/7 care. I worked full time and had to give up work. He had re-learn how to walk and how to draw.
16. He could not work for a whole year. I did not return to work for three months and when I did it was on a part time/flexible working arrangement basis to fit in with caring for [H]. I initially worked over an extended lunch hour period 12 noon to 3 pm. My boss was delighted to have me back on any basis workable for me.
17. Unfortunately when the [GRO-B] at which I worked changed hands in 2004, and I was pushed out (within months). I showed my new employer the ropes and

taught her all I know about running the [GRO-B] service. I believe I was in effect constructively dismissed because of my inability to work full time. I was accused of turning up late and balled out in front of customers at the [GRO-B] for arriving at 10.15 am. I was not in fact due to start until 10.30 am that morning. I was left devastated. I had worked there for 14 years and enjoyed my job. As stated, my previous employer had been very good about time adjustments needed to enable me to care for [H]

18. The cascade of physical problems [H] has suffered arising from his weakened state has had an enormous impact upon me, to include the brain haemorrhage he had in 2007 resulting in paralysis. I am no longer as emotionally resilient. I have become a deep-seated worrier.
19. Another psychological burden to me has been that of the attitude of the medical profession. I have accompanied [H] to all his hospital appointments since 2002. I have been made to feel that as I am not the patient my presence and any questions I have raised in relation to [H]'s care and treatment are unwelcome. I recall one doctor commenting sarcastically "You are here too Mrs [H]? – always a pleasure." I have noticed a small degree of change in this within the last 9 months or so, a more welcoming approach when I accompany [H] to his medical appointments.
20. In terms of stigma, [H] and I have (with the exception of lately confiding in a few of our closest friends) always known the importance of keeping [H]'s health status including his haemophilia strictly to ourselves and not to mention it to anyone.

Section 6: Treatment/Care/Support

21. [H] and I have been co-reliant upon one another for support.

Section 7: Financial Assistance

22. It has been unnecessarily onerous for [H] to apply for financial assistance. It has placed a terrible strain upon us to be made to feel like you have to beg for every scrap of help.

Section 8: Other Issues

23. There are no other issues.

Anonymity, disclosure and redaction

24. I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed..... [GRO-B]

Dated 28-11-2018 ,