

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1032001

Dated: 16/04/2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, **GRO-B** will say as follows: -

1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is known to the Inquiry. I was married at the time of my diagnosis and had a young family. I intend to discuss my infection of hepatitis C which I was diagnosed with in **GRO-B** I do not know the exact year I became infected only that it was between the years of **GRO-B** I am going to be writing about the impact this had upon myself, my work and my relationships

2. How Infected

1. I have Type A mild haemophilia and used injections of Factor VIII to treat this, whenever I had an internal bleed. I got infected by the

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injections of Factor VIII between [GRO-B] in [GRO-B]
[GRO-B] I was diagnosed with hepatitis C and B in [GRO-B] at the
[GRO-B]

2. The initial signs of infection were recognised due to my liver function going up and down. I think these tests were being done due to the possibility of me receiving infected blood. I was also having ongoing tests for HIV. However, I was eventually diagnosed as having active Hepatitis C via PCR testing, and I was aware at this point about the infected blood and that they were testing for hepatitis C. I can't remember how I was told that I had active hepatitis C.
3. After I was diagnosed, a doctor at the [GRO-B] fully informed me about what the diagnosis entailed, and I knew it was due to the Factor VIII treatment for my haemophilia. I do not remember the names of the doctors who treated me at [GRO-B]

3. Other infections

1. I was also diagnosed with hepatitis B, which my body had cleared successfully, however the main impact of infection has come from the hepatitis C.

4. Consent

1. As an adult, my consent for treatment would have been presumed (not actually asked for) for the Factor VIII injections, as I had need from injury or surgery, and I was not told of the risks of hepatitis C or other infective agents. My parents are deceased, so I don't know whether they gave active consent or whether that was also presumed through my need for treatment as a child. Neither do I know whether they were informed of the risks of blood-borne infections associated with the treatment.

2. I was aware of the risks associated with my treatment for hepatitis C and have not been treated without my consent. As far as I am aware I have not had any treatment for the purposes of research.

5. Impact

1. I have suffered mental and physical side effects as a result of the infected blood. Mentally I have never fully recovered.
2. Initially I was very stressed that my diagnosis would impact upon my career, as I was in the middle of a GRO-B when I was diagnosed. I started treatment on completion of the course, after reassurance from the Doctors that it would not have an impact on my ability to do my job or create a risk to my clients. However, I found it very difficult to concentrate on my GRO-B after my diagnosis.
3. Physically, the treatment was awful. I had to endure a year of 3 x injections per week and regular oral medication. The physical side effects were hypersensitivity. I had more allergies and my skin was excessively itchy. I would often scratch my skin until it bled. I had appetite loss and lost 2-3 stone as a result. I also suffered anaemia and have insomnia.
4. Mentally, I suffered with marked depression, which to this day, has never truly left me. I stopped medication for it a year ago. I found it very difficult to communicate with my family as to how I was feeling, which was difficult for me and them. As a result, I felt very isolated from family and friends and felt short tempered and anxious a lot of the time.
5. I remember going on holiday to GRO-B with my family. I had paranoia, convinced I would get arrested taking my treatment needles

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through customs. I knew this was irrational, but this helps describes the extent that my paranoia and depression were at this point. It was so difficult to pretend to be enjoying myself during the 2 weeks I was there. On a personal level, it was a very difficult holiday.

6. Financially I had to keep working, as I had a wife and young family to support. My other symptoms of feeling utterly exhausted and flu-like for the entire year of treatment, were exacerbated by this necessary situation, and I would have taken time off if I had been given the opportunity. Having had Hepatitis C also made it more difficult to obtain holiday and life insurance which makes you think twice about getting insurance at all.
7. My wife as far as I recall, was offered to take a test for infection. As far as I am aware she has not done this. I was informed there was virtually no risk of passing on the infection. I am no longer married, and find it a barrier to new relationships, explaining previous infections. My children were unaware until recently that I was infected.

6. Treatment/Care Support

1. I was offered counselling which I accepted and completed I have received counselling twice. I have also paid for further Cognitive Behavioural Therapy myself.
2. For the hepatitis C infection I had to administer 3 injections per week for a year and oral medication. I received treatment of Interferon and Ribavirin.

7. Financial Assistance

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1. I received a £20,000 one off payment from the Skipton fund. In order to receive this money, I had to sign a disclaimer stating I would not take action over infection from contaminated blood.
2. I also recently received a lump sum back payment from the GRO-B of approximately £11,000. This amount consisted of three back dated payments with regular future payments being awarded of approximately £4,000. I would have claimed sooner, but it was poorly advertised, and I was unaware that I was entitled. I was informed about this scheme by a person from the Haemophilia Society. I didn't think the entitlement to financial assistance was clear or well advertised for my particular circumstance. This annual payment has recently been increased for my particular circumstance.

8. Other Issues

1. After starting my first job, I did training/away workshops. I coincidentally worked with a man in approximately GRO-B who also had haemophilia, but more severely so than I. He informed me he had had hepatitis a few times and that he had been told by medics that this was because we had been obtaining pooled blood from America from paid donors (sometimes alcoholics/needle users/prison inmates who presumably needed the payment more than most) greatly increasing the risk of infection. His hepatitis infection was discovered in I think around GRO-B. He later was diagnosed and died of HIV/AIDS. However, what I fail to understand is why wasn't I informed of these known risks? And why did they not test the blood and implement heat treatment back then? The medical profession clearly knew the risks were present so why didn't they tell and test everyone?
2. I also lost my brother to HIV from infected blood in GRO-B he was GRO-B. At the time of diagnosis, he was offered very little information (according to my sister). I don't know if counselling was offered to him at the point

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of diagnosis (circa **GRO-B**), but he attempted suicide shortly after. This was very shocking and sad for my family. The information about hepatitis C (known at the time as non-A/non-B Hepatitis) was not discovered until later.

3. I have had regular tests for HIV infection from **GRO-B** or earlier, but never knowingly for hepatitis until I began attending **GRO-B** in **GRO-B**. Was I tested for hepatitis without my knowledge? Or didn't they bother even though they knew I was at high risk?

Statement of Truth

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

GRO-B

Signed.....

GRO-B

16-4-19

Dated.....14/04/19..

16-4-19