

ANONYMOUS

Witness Name **GRO-B**
Statement No: WITN0364001
Exhibits: WITN0364002 - 009
Dated: May 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** says as follows:

Section 1: Introduction

1. I make this Statement for the benefit and assistance of the Infected Blood Inquiry relating to my infection and the circumstances surrounding the death of my brother **GRO-B: B** who died on **GRO-B** 1987.
2. It all started when my brother was diagnosed with HIV and then AIDS. I was not sure of the date that he found out about his status, I had thought it was in early 1986 however with the benefit of reviewing of his medical records, it would seem he tested positive on 12 December 1984. **WITN0364002**
3. I was not diagnosed with HIV, so I have always put my brothers contamination down to a treatment he received while he was in hospital for one of his bleeds, as from the time we were using home treatment around 1977/78, we both availed of the same stock of medication at home.
4. From the time that **B** was diagnosed he had a number of illnesses and infections and thus spent a good portion of his time in Sheffield hospital until the infection moved on to his brain. He spent the last few months of his life in hospital.

Section 2: How infected

5. I am a severe Haemophilia A sufferer with a factor deficiency of 1%, as was [B] Prior to the introduction of home treatment in 1977, I was treated with bags of Cryoprecipitate. **WITN0364003.**
6. I suffered with haemophilic arthropathy and my elbows were the worst affected. I had recurrent bleeds in my right elbow especially which usually responded well to treatment. The bleeds increased in frequency and so it was thought that I might benefit from a arthroscopic synovectomy.

Section 3: Other Infections

7. By way of letter in November 2004, I was notified that as I received UK NHS clotting factor concentrates that is was possible that a plasma donation from a donor who developed vCJD, may have contributed to the plasma pool between 1980-2001. There, I was now at risk of vCJD. I have attached a copy of this letter marked with the letters **WITN0364004.**

Section 4: Consent

Section 5: Impact

8. My parents would travel to Sheffield two or three times a week during [B]'s last months, then in the latter weeks of his life they would spend the whole time with [B] at the hospital.
9. At the time of [B] death, my own father was 59. He had a strong bond with [B] and they did everything together, from playing soccer to fixing cars. Following his death, my father was never same. He never worked again. He was not the same after our loss, he became irritable and was unwilling to get involved in anything until he passed away on [GRO-B] 2001, aged 73.

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10. My mother was 57 at the time of [B] death. She too gave in to the grief and never left the chair in the sitting room. Slowly she got more unable to walk and succumbed to numerous illnesses and died aged 77 on [GRO-B] 2007.
11. In 1988, I met my [GRO-B] This was a time of hope and fear combined for me. Hope that he finally met his life partner yet coupled with the fear of having to open up and explain to her what had happened to my brother. I was afraid of how she might react, would this be the dream I had my future shattered? I had been there before and had always shied away from serious relationships out of fear of getting too close.
12. But with [GRO-B] I was willing to take the risk, I felt she had to know without question but til this day, no one but her knows how much of stressful time it was for me to open up and tell her about my condition, the potential risks that there could be for her too and the details of what happened to [B]
13. In my mind I was convinced that lightening could strike twice and coupled with the sense of guilt that I was alive an he wasn't just added to the stress of it all.
14. Thankfully, [GRO-B] was not fazed about my condition nor the details of what happened to my brother. Even on leaving her that evening after the revelation, I was convinced she would feel differently the next day and I would get the inevitable phone call ending things.
15. Over 30 years later, she didn't leave me and we married in [GRO-B]
16. With the benefit of my medical records, it is noted that due to my deranged and abnormal liver function tests, it represented chronic hepatitis since 1984. Please see **WITN0364005**.
17. I note that as I was taking out life insurance, the company sought my records. I would seem that I was tested for HIV in June of 1988 and the antibody test came back negative. I do not recall having this test. Please see **WITN0364006**.

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18. From the late 80's to late 90's, due to my abnormal liver function tests, many liver biopsies were carried out **WITN0364007**.
19. From review of my medical notes, I can see now that I was Hepatitis C positive in 1993 which was treated with interferon, yet the diagnosis came much later. Please see **WITN0364008**.
20. Then in 2002/2003 I was diagnosed with Hepatitis C. This was a bolt from the blue to say the least. I had got away with not being infected with HIV and AIDS but now found I had another challenge that could have as much of an impact on my future as I had feared from the previous threat.
21. Due to the stigma attached to carrying a blood-borne viruses at the time, when I was told of my HCV infection, I told no one outside of my immediate family.
22. I had two cycles of treatment before I cleared the virus.
23. I was treated with Interferon Monotherapy for six months. During the treatment my liver function tests returned to normal but as soon as the treatment stopped, my liver abnormality returned.
24. Whilst receiving the treatment, I lost weight and struggled through work, I was constantly tired. At the time I was holding down a job with numerous responsibilities as a workshop Manager.
25. My concentration was poor and it didn't take much to make me lose my temper. While at work I would try not to take it out on the workforce, I would do my best to bottle it up. However, inevitably and unfortunately I would take it home where I would easily lose my temper at the slightest thing. I wouldn't really discuss work with GRO-B I would either fall asleep through sheer exhaustion or shout at her for any small reason.
26. I was not myself at all.

27. **GRO-B** was trying to advance her own career and seemed to be doing well. I felt that I would be letting her down if I didn't keep up.
28. Even my condition had never caused me this amount of grief, but here I was and I didn't recognise the person I had become.
29. In 2004, my Hep C was treated with Pegylated Interferon Ribavirin for 12 months and again, during this treatment my liver function returned to normal and fortunately, after the treatment they remained normal, **WITN0364009**.
30. Again, I suffered awful side effects with this treatment. I lost an extreme amount of weight. The tiredness was overwhelming and **GRO-B** reminded me that I had told her one evening that I had fallen asleep at work at my desk – not for long and thankfully no one noticed it, or rather no one ever mentioned it if they did.
31. If I was to do anything remotely physical whilst on treatment, then I would develop flu like symptoms – begin shaking and sweating and would have to go off to bed.
32. I lost a whole year during that treatment. Although this treatment in 2004 was successful, I had been left with a feeling that "it may come back" as this is what happened on the previous occasion. This resulted in a chronic low level anxiety.
33. It got so bad I just could not cope with working life and ended up leaving work later that year. I did eventually secure another job and had worked there ever since until I took early retirement on 1 July 2018.
34. Then I was faced with the biggest test in my marriage. It is very hard for me to put this into words, but our marriage came very close to ending. **GRO-B** was struggling to understand what was up with me. We both knew that the treatment wasn't going to be easy but we were hopeful that the benefits would outweigh the emotional sacrifice that went with it.

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35. This was hard to bear on so many levels and without putting too finer point on it, I did consider ending my life. Thankfully I can say that sense prevailed.
36. **GRO-B** is aware of this, I could not pretend anymore and it was getting the better of me. Coupled with the financial strain I had felt I had put us both under after quitting my job.
37. Although we had thought that children may be part of our marriage, we made a joint decision in the end not to have kids. We didn't want the risk of contaminating a child.
38. I went to see my GP about an another issue and I thought at the time I had discussed with him what I was feeling but either I did not explain this to him clearly I does not appear on any of my GP notes. Admittedly, it took me all my time to remember my name some days.
39. The question of the possibility that I was suffering with depression never entered my head, despite what I was considered doing. I felt depression was for others, not for me. I had fought tooth and nail to lives as near normal al life that I could. This was just another hurdle I would have to get over.
40. It was only by chance that **GRO-B** had been listening to a programme on Radio 4 relating to treatment of Hepatitis C and the regime people had gone through. It appeared that there was a range of sufferers, from Haemophiliac to others that had been infected either through infected blood products or from other sources that the disease could be contracted.
41. The one recurring factor that kept coming up in all interviews that were conducted were that individuals either couldn't continue the treatment as they couldn't handle the side effects and most of them were planned to be on it for 6 months but were only able to endure it for a few weeks and for those who managed to carry o, the majority of those were treated for depression.
42. I had tolerated the treatment for 12 months as planned and I had never felt so wretched and in fear for my future. In a bid to get it over and done with, I

decided against seeking further help from the medical professionals regarding my mental health as I was nearing the end of his treatment.

43. The penny dropped and the real horror of the true nature of this treatment was now unravelling.

44. It is that English stiff upper lip, it does you no favours.

Section 6: Treatment/Care/Support

45. GRO-B and I received counselling after B HIV diagnosis and then in 2004 we were counselled in respect of my HCV treatment, side effects and ways to help relieve the symptoms.

Section 7: Financial Assistance

46. Following the death of my brother, my parents received help with his funeral costs and some monetary assistance from the McFarlane Trust. They also received a payment of compensation from the Skipton fund, in or around 1992.

47. I recall that my parents had to sign a document, I believe may have been a disclaimer. As we lived in fear of the stigma that this illness brought, my parents were very private, B illness was never discussed openly outside of the immediate family.

48. In 2011, I was notified by the Haemophilia Centre at Sheffield Hallamshire that a further claim in the amount of £20,000 could be made.

49. Since August 2018, I have received the EIBSS scheme payment and continue to receive some financial help from the Mobility assistance on a monthly basis.

Section 8: Other Issues

50. We have suffered at the hands of treatments given in the dark past of the NHS but nothing in my mind has been hidden, that we were treated as second class citizens by them.
51. It has been over 15 years since I cleared the HCV infection and the fatigue has persisted. This has impacted significantly on my ability to carry out normal daily activities.
52. I have to say that the Sheffield Hallamshire Haemophilia Centre have always had my best interests at heart. I believe that I have always known what is happening, I am kept fully informed and supported, whether that be medically or relating to help with the EIBSS scheme.
53. I, wherever possible offer my assistance to help them where I can because they have tried to make my life more bearable.
54. Due to psychological stress and trauma my wife and I have endured, I wish my identity to remain confidential and I would like to fully exercise my right to anonymity and therefore would not be willing to deliver evidence at the Inquiry hearings.

Statement of Truth:

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

Dated the 17th day of MAY 2021

Signed: _____

GRO-B

GRO-B