

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN6423001

Exhibits: WITN6423002

Dated: JULY 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My full name is GRO-B I was born on GRO-B 1971 and I live at GRO-B
2. I was infected with the Hepatitis C Virus (HCV) through contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How Infected

4. I have moderate Haemophilia A with a current factor level (and it has varied widely) of 6% and was formerly classified as severe. I was treated at the

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Leeds Haemophilia Centre at St James University Hospital (SJUH) under the care of Dr B A McVerry initially. In the early 1990s I moved haemophilia centre to Bradford then Bangor and then in the mid-1990s I switched again to the Leicester Royal Infirmary. On Leaving Leicester, I transferred my care to Nottingham, then most recently back to Leeds.

5. I was treated with Cryoprecipitate from diagnosis in the 1970s on a fairly regular basis. I then went on to Factor VIII (FVIII) concentrate as a self-administered home treatment. I refer to Exhibit WITN6423002 being a copy of my UKHCDO patient record. I was given a variety of products to include BPL and Factorate before they became heat treated and safe.
6. I was informed that I had been infected with HCV (then known as Non-A Non-B Hepatitis) when I was in my late teens (in 1990 I believe) by letter sent from SJUH. My grandfather was infected with HIV at the SJUH and had died of AIDS the previous year, so I had first-hand experience of what it meant to be infected with a virus and that exacerbated my distress. I had no support from Dr McVerry or his team. I remember clearly him telling me at a later appointment that there was a high likelihood that I would have passed it on to my past sexual partners and a high likelihood that I would pass it on to future sexual partners. For a young fellow like me, it was a very big deal and I was worried. There was no treatment and no counselling offered to me. I was, apparently, asymptomatic and was not referred to a hepatologist.
7. It was at Leicester Royal Infirmary under the care of Dr [GRO-D] a decade later that I was told they had concerns about my liver readings and I would be eligible for the compensation just announced and that I should expect a lump sum and regular payment. I was then informed by a Senior Nurse at my next review that that was not the case because I was PCR negative and had not had any Interferon treatment. She also said that the spike in my liver readings could be attributed to my alcohol intake. I made a complaint about that nurse to Dr [GRO-D] as I thought her unprofessional. Dr [GRO-D] rebuffed my complaint and told me that the nurse had lost her own son to HCV. I think she was very anti drink for that reason and had an axe to grind.

Section 3. Other Infections

8. I wasn't infected with anything other than HCV although I was notified of the risk that I may have also been exposed to vCJD.

Section 4. Consent

9. I was tested for infection without my knowledge and consent. In the mid-1980s, I was regularly tested for HIV without my permission by SJUH. I had appointments every three months and the build up to each one was terrifying. When I went on to heat treated FVIII, I was told and assured that it was safe, but then I saw on my notes that they were continuing to test me, and I had it out with Dr McVerry. I said 'you need to stop that because I haven't given you my consent'. Dr McVerry's behaviour and my loss of trust in him were, in part, reasons for my move to the centre at Bradford.

Section 5. Impact of the Infection

10. I have tried not to let haemophilia rule my life and I have tried to pursue a normal life. I am very active and enjoy scuba diving, rock climbing, cycling, hiking and jogging. People look at me dumbfounded if I choose to tell them that I have haemophilia and there are so many preconceptions about it. I get asked 'If you cut yourself, do you bleed to death?' I don't generally tell people that I have haemophilia unless I feel that they need to know. In the 1980s there were terrifying ads on the TV about AIDS. It was known as the 'gay disease' and it was also associated with dirty, promiscuous people and those associations then extended to haemophiliacs.
11. To learn that I had been infected with HCV was something I tried to bury. I internalised it. It was a burden I carried alone. I have carried a massive sense of guilt all my life that I might have infected others. It has had a huge

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psychological impact on me. I still feel very scared about it. I suffered with that guilt for most of my life and that guilt had an affect on the quality of my sex life (and I always told my partners to include my now wife as I wanted them to be fully aware of what they were involving themselves with).

12. There is also the issue of never knowing for years if and when HCV will re-emerge and begin to affect my liver, as it can lie dormant. The more I researched it, the more I came to fear that at any point in time the HCV infection could just kill me. My parents were worried sick about me, particularly after what had happened to my Granddad. They were really stressed. They were never advised or prewarned of any risk of infection to me through the use of blood products.

13. I suffered with a bout of psoriatic arthropathy in my knees, ankles and toes that came and went between the years 1993 and 1995, although I didn't associate it as being linked to HCV at the time. I was working as a lab technician at the time and I remember that I could barely get up and down the stairs at my place of work.

14. HCV is something I have always had to disclose to dentists. Having moved from area to area, I have used a few different practices. I am always seen at the last appointment slot of the day, to minimise the risk of cross contamination.

15. Thinking back over the years, I didn't have the same experience as everyone else. It definitely affected the way my life panned out and my life experiences. Psychologically, I struggled a lot. Nowadays mental health issues have come out of the closet and are taken far more seriously. I was a young Yorkshire man from a working-class background, and I had massive guilt issues that I internalised all my life and carried alone. I was so scared that I may have infected someone, or that anyone I may have liked could have ended up infected and it was just horrible to live with.

Section 6. Treatment/care/support

16. I have had no treatment, care or support.

17. Despite everything I consider myself one of the 'lucky ones' as I am still here, and I have been able to lead a very active life. As a haemophiliac, I understand the importance of taking care of your joints and taking your treatment. I was asked by SJUH to speak in the auditorium to parents of haemophiliac children which I did and my message to the parents new to haemophilia was the importance of keeping their children active (on a risk managed basis).

Section 7. Financial Assistance

18. I was told by the Senior Nurse at Leicester that I was 'a lucky man' (as I was PCR negative), but I would not qualify for any compensation. I was a young man and was, in effect, fobbed off. I was recently told by a Senior Nurse at SJUH that the HCV infection is more likely to cause a spike in my liver function test results rather than alcohol consumption which would have elicited a prolonged reading.

19. My cousin has haemophilia A and is antibody positive for HCV. He recently told me that he received the Skipton Fund lump sum payment that I was told I couldn't pursue and has also been the recipient of a significant regular payment. After all these years, I feel I need to take action for my family, if not for me. I have been told that a lot of my medical notes and records are missing to include my liver function test results, but the SJUH are helping me by contacting my previous centres and asking them to look for their paper files etc.

Anonymity, disclosure and redaction

20. I am seeking anonymity and understand that my redacted Statement will be published by the Inquiry.

Statement of Truth

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

Signed..... **GRO-B**

Dated..... 30th July 2021