Witness Name: GRO-B
Statement No.: WITN6387001
Exhibits: none
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 05 January 2022.

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

Section 1. Introduction

1. My name is GRO-B, my date of birth is GRO-B 1965 and my address is known to the Inquiry.

2. I am a mild haemophiliac with haemophilia B (otherwise known as Christmas Disease). I intend to speak about my infection with hepatitis C ("HCV") that I got as a result of receiving blood and blood products. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life and especially, my family.

3. I am a stonemason by trade and run my own business. I have a wife named GRO-B and three children who are 30, 27 and 24 years old. I

also have a brother who was infected with hepatitis C around the same time as me.

4. I am not legally represented, and I am happy to give my statement to the Inquiry, and I wish to be anonymous.

5. The Inquiry Investigator has explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

6. I wish to acknowledge that as time passes, memories fade and so I have provided my witness statement to the best of my knowledge.

Section 2. How Infected

7. I inherited Christmas Disease from my mother. As a child, me and my brother would go to The Heath Hospital (also known as University Hospital of Wales) for treatment relatively infrequently. We would go around once or twice a year. It was only really required when we injured ourselves. I may have also received blood during an operation too. Although I do not definitively know when I received the infected batch of blood, I assume I contracted it when I was around thirteen or fourteen years old (or as late as sixteen years old). Dr GRO-D ran my clinic at that time.

8. I played rugby at school. There were about five or six times that I received treatment using blood products after playing rugby and getting injured. Had I known the risks of the treatment I was receiving, I would not have played rugby and exposed myself to that kind of risk.

9. As I only had a mild condition, I think a lot of the times I was treated, I didn't need it. Dr GRO-D and his colleagues played God. They should have at least given us the choice about whether to use potentially

infected blood. I sometimes think the treatment was experimental and that they were too blasé when administering treatment.

10. I found out about my HCV infection when I was 26 years old. I read about people being infected through blood somewhere and later either my hospital contacted me or I had contacted them in order to do an HCV test. Eventually, the hospital got in contact to let me know that I had hepatitis C. It was a very difficult time following being diagnosed, as I had a young family at the time. It was also made much worse by the fact that my diagnosis wasn't explained very well to me and I was not given sufficient information on the diagnosis. They tried to minimise it and were also quite vague about it.

Section 3. Other Infections

11. I do not believe that I was infected with any other infections other than HCV as a result of my treatment with blood and blood products.

Section 4. Consent

12. I did not consent to the treatment I was given with blood products. It was just given to me. In retrospect, there was far from enough research done on it. Given that they knew the risks, they let it be administered far too easily. I understand that scientific understanding of it all was in its infancy, but if any of it was motivated by financial reasons, then that is unacceptable. The research should have been done far more diligently instead of administering it to us like guinea pigs.

13. I believe that I was tested for other infections but I think a lot of it was done under the radar. I think they took my blood and tested it without telling me what it was being tested for. This was during Dr GRO-D's period (but not latterly – my current hospital, The Heath have been brilliant).

14. My biggest fear was being diagnosed with HIV. I knew they were testing for it at the same time as my test for hepatitis C. Although I was not told, but I became aware of this possibility through the news and read about it.

Section 5. Impact

15. Looking back on everything, I realise that I first suffered symptoms from my hepatitis C infection about twenty years ago in my mid-thirties. I started getting very tired easily. The lethargy meant that I couldn't concentrate properly. I think brain fog is the best way to describe it. That affected my business and career. As I was functioning below par, I wasn't able to achieve what I otherwise could have. You soldier on because you have to – there's no other choice. But I wasn't working at full capacity so my work would take me twice as long. There were also times that I didn't work at all, so my infection did affect us financially too. It's only with hindsight, now that I am better, that I am able to appreciate the full extent to which HCV negatively affected me.

16. The impact wasn't just physical. Mentally, I spiralled downwards. I went off the rails: I was drinking more than I should have. All the pressures led to me splitting up with my wife for six to seven years. The diagnosis of HCV and the treatment that followed it played a significant part in that. I was not myself for a long time. It's only for about the last six years that I have been myself again. My wife firmly believes that me leaving the marital home was down to the HCV treatment's medication. With my kids, you learned to keep a bit of distance from them because you're afraid of passing it on. I was so afraid of cutting myself and the inevitable transmission risks that would cause. HCV impacted my whole family. For me to leave the marital home, in their formative years, was terrible. It also affected my social life. When you're spiralling downwards, your relationships with so many people are affected.

17. My brother's treatment for hepatitis C worked straight away as he had a different genotype. As it wasn't working for me initially (as I will explain later), it made me feel like the end was nigh. I think, in some ways, my brother suffered more than me as he was younger. He found it more difficult to cope with than me. Like me, he also suffered terrible general side-effects from the treatment of hepatitis C.

18. My family were told to be tested for hepatitis C. That was traumatic. Knowing that I could have potentially infected my family was horrible. It was tough particularly because there were so many years that I didn't know I had hepatitis C so wouldn't have been taking any precautions. Luckily, none of them have tested positive for it.

19. I didn't tell anybody about my hepatitis C infection because of the fear of stigma. I dealt with it by myself. The day I was told I was so distraught because I thought it was the end of the road for me. Even to this day, my closest friends still don't know about my HCV infection. It's not a conversation that I've had with them – it's not something that I would wish to disclose because there's still stigma attached to it.

20. During dental appointments, I didn't experience stigma from the dentist directly. However, I was personally affected because I didn't want to go to them as I was worried that they would say 'no' to treating me. That would have just reinforced that I was being stigmatised and so, I wanted to avoid a scenario like that.

21. When I left my wife and moved in with somebody else, I told my new partner about my hepatitis C infection. I felt as if I was stigmatised by her in that it was always lurking in the picture. When I finally got cleared, it was a huge weight off my mind and I felt that I could integrate more with others instead of holding back.

22. I have cirrhosis. Although my liver is damaged, I don't dwell on it. I try to keep positive: my take on it is that I can't be that bad if I'm feeling well.

My Fibro Scan results have also shown signs of improvement. I'm not at death's door. Things have gone in the right direction. I make a conscious effort to look after myself by not drinking much alcohol and eating well.

Section 6. Treatment/Care/Support

23. I was given three rounds of treatment. The first two sets of treatment didn't work but the third one did. The first treatment was by far the worst - it knocked me back quite severely. I went through a lot of mental anguish, including leading to a split with my wife for a long time (which I have explained in more detail earlier on in this statement). The treatment made me incredibly lethargic which meant that it was difficult to work. I could just about continue, despite the fatigue, but that was mainly because I had no other option: there was no money coming in from anywhere else.

24. They then wrongly told me I was clear of hepatitis C on the second round of treatment but it later transpired that I wasn't. I was angry and distraught about that. When the second treatment didn't work, I thought to myself that I could be dead this time next year. Fortunately, the doctors were diligent and administered a successful third treatment. I think they felt obliged to push through the third round of treatment as soon as possible after that (given that they had wrongly told me I was clear of hepatitis C).

25. I had my third (and successful) round of treatment about six years ago. This treatment worked brilliantly. The Heath Hospital pulled out all the stops. I now have check-ups every six months which can include Fibro Scans, ultrasounds, blood tests and a consultation with the liver specialist. I can only sing praises of The Heath. They have done such a good job with me (after getting the HCV infection).

26. However, I am disappointed that I wasn't properly informed of how to manage the transmission risks of hepatitis C when I was initially diagnosed. I was really worried about the risk of passing it on to others. I

should note that once things were more known about hepatitis C, I was better informed about its risks.

27. I was offered the help of a social worker that I saw once. But because I had put up with hepatitis C for so long, I just got on with it and didn't feel the need for it.

Section 7. Financial Assistance

28. I received both a Stage 1 and Stage 2 payment from the Skipton Fund. I also receive payments from the Welsh Infected Blood Support Scheme. Accessing these schemes have been a relatively straightforward process. I think they even back-dated some of the payments.

29. Having that extra money from the support schemes is so important to me. I am anxious about whether those payments will continue - I need a guarantee that it will so that I can plan my future properly and with certainty.

Section 8. Other Issues

30. I feel disappointed and angry about everything that's happened. I think we were treated as guinea pigs. No amount of compensation is adequate for those who lost loved ones. I look with trepidation towards the future.

31. They might have had the best of intentions but there's no getting away from the fact that they should have fully explored the consequences of their decisions. In particular, getting blood from American prisons seems to be inherently risky. It's unforgivable to be giving patients something worse than the ailment or disease they are being treated for in the first place.

32. I would like someone to be held to account for what happened and for them to publicly apologise. I want provisions and mechanisms to be put in place so that something like this never happens again.

Statement of Truth

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

Signed GRO-B

Dated 14,3,2022

Please note a wish to Remain anonymous! Many Thanks.

GRO-B