Witness Name: Tony Going
Statement No: WITN4924001
Exhibits; WITN4924002-3
Dated;

# INFECTED BLOOD INQUIRY

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# WRITTEN STATEMENT OF TONY GOING

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 March 2021.

I, Tony Going, will say as follows: -

## Section 1. Introduction

1. My name is Tony Going and my date of birth is GRO-C 1965. My address is known to the Inquiry. I am married and have three children, as well as three grandchildren. I work as a security guard for Northampton University.

2. I intend to speak about my infection with hepatitis C (HCV), transmitted via a blood transfusion. In particular, how I came to be infected, the nature of my illness, the treatment I have subsequently received and the impact it has had on my life.

3. I am happy for the Inquiry team to take my account and I can confirm that I am not legally represented and that the provisions of the anonymity

measures have been explained to me and I am happy for my story to be in the public domain.

## Section 2. How Infected

4. In 1984, I was out in Northampton with a few friends. The town is a regular stop off point for football fans travelling down to games in London and we ended up getting chased by a group of lads that I believe were on their way to a game.

5. We ran towards the main shopping centre in Northampton, which has big glass doors at the entrance. To me, it felt like I was pushed, but it's possible I could have tripped or something, as I went full-force through a glass panel in one of these doors.

6. We were still being chased and I was in fear, so I got up and kept running. But then I looked down at my right hand and saw that the skin around my wrist was completely cut open, flapping from side to side. I could see that there was a trail of blood behind me. I ran into a Radio Rentals shop to get away and get help and the staff in there had me lie down whilst they called an ambulance.

7. I was taken to Northampton General Hospital. I don't remember much about travelling to the hospital or getting there, so I may have passed out. When I came around, I had my arm up in some sort of sling, connected to a blood bag. I was told I had needed to have over 100 stitches and had also damaged my tendons and nerves. The discharge note is exhibited here at **WITN4924002**.

8. I was in hospital for about 24 hours. After I was discharged, I got called to the little police box they had on Becketts Park and asked to do an interview with them. During this they told me that I had suffered something like 60% blood loss. The police were threatening to charge me with criminal damage for the door – it seemed like they were just trying to get out of doing anything about the guys that were chasing us.

I think that they did actually catch them in the end, but nothing ever came of it.

9. Many years later, in around 2011, I was suffering from terrible backaches and was very tired a lot of the time. These problems had been going on for a good few years already but it was getting to the stage where it was affecting every area of my life. My GP, Dr Williams at the Mount Surgery, was running some tests to try and get to the bottom of it. I was sent for a full blood count.

10. He called me in not long after and told me that I had tested positive for hepatitis C. He didn't really tell me much more about it; there was hardly any information on what it was or anything, certainly no precautions to take or what it meant for the future.

11. I thought it was like HIV at the time. I didn't know the difference. I remember getting into my car and bursting into tears. I was absolutely devastated. I wondered if it was fatal and what it would mean for my family. Of course, I would have understood better if I had a bit more information on what the virus was and what it meant for me.

## **Section 3. Other Infections**

12. As far as I know, there is no suggestion that I was infected with anything other than HCV from the treatment. I do not recall if I was tested for HIV or if I was, being given a result of that test. The blood transfusion in 1984 is the only transfusion I have ever received.

13. I am faithful to my wife, have never been an intravenous drug user and have never been treated abroad. I have a small tattoo on my hand that I did myself whilst at school. But I sterilised the equipment before and didn't share it with anyone else.

## Section 4. Consent

14. I did not give consent to being treated with a blood transfusion, but I was not fully conscious and so wouldn't have been able to do so anyway. Nothing was explained to me after the procedure either.

15. I do not recall giving my specific consent for an HCV test and do not believe that I was even informed that the test was being carried out. I did consent to all the treatment that I have received for my HCV infection.

## Section 5. Treatment/Care/Support

16. Not long after my diagnosis I was referred to Dr GRO-D at Northampton General Hospital. I was still trying to blank the whole thing out and I remember him telling me that I was not taking it seriously but I was really still in a bit of shock at the diagnosis. The tiredness and fatigue were still getting worse over this period and I was stressed out a lot, with really bad back pain. I was also experiencing periods of jaundic because of the infection. I had seen my GP and he had prescribed medication for stress and anxiety.

17. Dr GRO-D had mentioned that there was a treatment available that involved regular injections, but I remember him saying that he didn't think I could cope with it. maybe it was the fact I was being treated for stress – I don't know. I had heard from a few people I knew that the treatment was really terrible, but I'm not sure why Dr GRO-D didn't at least explain it to me and allow me to make that decision for myself. It kind of felt to me like he wasn't that interested in helping me get rid of my infection.

18. After seeing Dr GRO-D for a while, he eventually told me about a trial that was being set up at a hospital in Birmingham, I think the Queen Elizabeth. This was around 2014 and up until that time I had been monitored through blood tests. I believe that the trial was run by the hospital itself and was actually trialling three different drugs, including

pills and injection. I was on the pills and some of my blood was taken for further research as well, which I consented to.

19. Even this had complications as after I went for the tests and assessment, I was initially told that I had not been successful. The trial, which was to cost around £30,000 per person wanted different levels of infection to treat. I was disappointed to say the least and it felt a bit like a kick in the teeth considering I had not been offered the chance of treatment when it was available on a prior occasion. However, I was lucky in that about 6 months later I had a call out of the blue saying a place was available. It seems that someone else was too ill to take part and I was given their place.

20. The trial lasted for 13 weeks. I'd take eight tablets in total each day – two tablets at a time, four times a day. I had to travel between Birmingham and Northampton once a week and the hospital paid for my train fare. I can't remember the names of any of the doctors that were in charge. I had one particular nurse that I would see each time.

21. I don't really recall having any major side effects from the treatment itself. I was ill anyway though, so it would probably have been hard to notice them. My fatigue was horrendous by this time and my back pain made me nauseous and I also suffered from headaches and difficulty concentrating. It was also around this time that the depression surfaced and I ended up on medication. I had already been treated for anxiety but it seemed to get worse at this point probably because of a number of factors, the treatment, home life pressures and losing friends through an inability to face getting out and about.

22. The only lasting thing I can really think of is that my eyesight has gradually got worse in the years since the trial began. I had perfect eyesight before but now I need glasses to read. I did mention this to them towards the end of the trial but they said it wasn't to do with the drugs. I thought it was a little odd that they claimed to be sure of this when it was a trial for a new drug.

23. At the end of the trial, they told me that I was 99.8% cleared of the virus. I had a biopsy at Northampton General not long after and this confirmed that I had liver scarring and cirrhosis. I don't remember the biopsy being painful or anything. They told me that I needed to stop drinking and advised me to stop smoking as well. I do remember them being surprised as my liver readings were still quite high at the end of the treatment but they seemed to have calmed down with time.

24. I still see Dr GRO-D once a year when I go for annual scans. The last one was just the same as usual – the virus remains dormant and my liver is no better, no worse.

## Section 6. Impact

25. The initial diagnosis had a really big impact on me, particularly mentally. I lost all of my confidence. A lot of people just don't really understand anything about Hepatitis C at all and that makes you just feel ashamed about it. I tried to blank it out for a long time, just tried my hardest not to think about it at all.

26. The antidepressants I was put on made my head really blurry and I couldn't think straight at all. I feel like I just lost a lot of my energy around the time of my HCV and never got it back. I find it hard to push myself to get up and leave the house; I am still so tired a lot of the time. I wasn't offered any counselling or psychological support after my diagnosis.

27. One of the biggest impacts was on my work life. I was working at a Sainsburys warehouse around the time of my diagnosis and, as noted, had been struggling with back pain a lot during this period. If I ever raised it, they would just put me on pointless cleaning duties. There were lots of office jobs that would have been much more suitable for me, but they didn't seem that interested in helping me out.

28. After my diagnosis, I told some people in HR. I was given a load of pamphlets and books about HCV from the hospital as well and I decided

to give these to someone in HR so that they could understand what I was going through. They were lying still there on their desk on the day I left, untouched and unread. They were so unhelpful and not at all understanding. Several times I'd get to work in my car, sit in the car park and then turn around and leave to go home – I just could not face it. Mentally I was not up to it and being infected consumes you, it's all you can think about never mind having to do a day's work.

29. I would get disciplined if I took too many sick days off, as if I was pulling a sicky rather than being genuinely ill. They would keep hinting that I was going to be let go. It felt like they were using my illness to get rid of me. The thought of getting sacked was stressing me out as I knew I would struggle to get another job after that so, in the end, I just decided to leave myself.

30. I then got a job as a security guard, working for G4S. The doctor warned me that I needed to really avoid causing any damage to my liver area in this line of work. I was there for a few years and then got another job at Northampton University, where I still work today. I took a financial hit when I left Sainsburys as it was better paid. I would have stayed there if I hadn't had the problems I did with them.

31. I already had a house and a mortgage before my diagnosis, so there were no problems there. Travel insurance is high for me as I have to disclose that I have cirrhosis and this has a knock-on effect on where we as a family can go. I don't have life insurance.

32. There has also been a big impact on my social life caused by my HCV – I basically don't have one now. All of my friends go down the pub together and, as I'm not able to drink, that's just no fun for me. I feel silly sat there with a coke and I can't face the questions about why I won't have a pint. Particularly when I was going through my treatment, I just couldn't explain it to my friends. I lost a lot of my friends around this time and that was about the time, as mentioned that my depression came about.

33. There was big impact on my family too. My wife, like myself lacked an understanding of the illness and found how I was presenting difficult to deal with. At the time, GRO-C and the pressure meant we more or less separated for a while. When she had some time to research it and find out how it was transmitted, she came around and was supportive. That was devastating period for me. Would she come back? What about my children and how would this affect them?

34. GRO-C

35. I was reliant on my wife's income for a while when I was off work, which was another strain on the relationship. She was working lots of over time to support us, so she had much less time to spend with the kids as well. I was on personal independent payments for a while during the treatment, but this was withdrawn as soon as they found out I was clear of the virus. You may be clear of it but what about the recovery time.? It is not instantaneous and there is no support to help you climb back to your feet

36. My kids, who were 14, 24 and 26 at the time of my diagnosis. They didn't really know a lot about what was going on. I just told them I was going to hospital for my bad back. They do know now about my HCV though, since my treatment. I lost a lot of time with my kids due to my illness, time that I'll never get back.

37. I didn't really speak to the wider family about it at all. I genuinely felt like I had to stay away from them for a long time. I have two younger brothers that I was very close to, but we have drifted apart as a result of my infection. There was just a long period where we didn't speak because I didn't want to tell them what was going on in my life at the time. I was ashamed although I know I had no need to be.

## Section 7. Financial Assistance

38. Dr Shmueli told me about the Skipton Fund. I got an application form, got the doctor to fill out his section and then sent it off. I found the form quite difficult – I think I was in the middle of my treatment at the time and was struggling to concentrate which made it much harder. I am aware now that I applied in November 2011.

39. I wrote a letter to the Skipton Fund as part of my application, giving all the details of the surgery. I exhibit this letter here, at **WITN4942003**. The letter says that I was running for a bus when my injury was sustained, but this was just because I didn't want to go into all the details with them – it didn't feel necessary.

40. I got a rejection letter in February 2012 after my initial application, saying that there was no proof that I had been treated with blood or blood products. I appealed against the decision but this was rejected May 2012 for the same reason, along with the fact they didn't think a blood transfusion would have been necessary for the surgery I underwent.

41. I wasn't able to get proof in my records as most of them had been destroyed according to the reply when I applied to Northampton General hospital for them. I had lost out on so much money being on sick pay rather than getting my actual wages, so it was a real slap in the face.

42. With the rejection of my appeal and as I still couldn't prove I had received a transfusion, I gave up after this; I had nowhere else to go, no clue how to take it any further. It was such a long, drawn-out process. It really was draining and I knew that I had no way of making them believe me.

## Section 8. Other Issues

43. I have never been a blood donor. It's not actually the initial infection that has dented my faith in the NHS, but the treatment after. It has cleared

the infection, but I don't see the point of a lot of it and it seemed for a long time that nobody really wanted to help me get rid of my HCV. It was all such a long drawn out process and I still go for these tests every year and they say, 'you're still fine Tony'. But am I? I know that it is unlikely that my liver will recover and I will be monitored for the rest of my life. Possibly I could have been treated sooner and that may have meant less damage and given my liver a better chance to recover.

**Statement of Truth**

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

Signed GRO-C

Dated

4 Jun 2021