

Witness Name: Wayne Windley

Statement No.: WITN4361001

Exhibits: NIL

Dated:

## INFECTED BLOOD INQUIRY

---

### WRITTEN STATEMENT OF WAYNE WINDLEY

---

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 September 2020.

I, Wayne Windley, will say as follows: -

#### **Section 1. Introduction**

1. My name is Wayne Windley. My date of birth is GRO-C 1974 and my address is GRO-C I live with my partner and I am a father to four children, aged 10, 17, 18 and 22. I have worked for ASDA for the last 19 years. I intend to speak about my infection with Hepatitis C (HCV) and Hepatitis A or B. In particular, the nature of my illness, how the illness affected me and the impact it had on my life.

#### **Section 2. How Infected**

2. When I was four months old, I was diagnosed with haemophilia. I was the youngest of nine children but I was the only one who had it. I was

told this can happen spontaneously and there does not always need to be a genetic link.

3. As a child, I remember I was treated with Factor VIII at the hospital quite regularly. I would have a bleed as frequently as once a week and have to go into hospital to have the Factor VIII intravenously. I remember one occasion where I got home from hospital in the morning after being treated for a bleed and then went back into hospital the same evening due to another bleed. I sometimes tried to avoid going to hospital, even if I had a bleed. Avoiding treatment could mean I wouldn't be able to walk properly for a few weeks and my doctor told me I had to get treated if I had a bleed.
4. When I was young, during the late 70s and 80s, my haemophilia doctor was Dr Philpot at the Royal Infirmary in Hull. My care was later moved to the Haemophilia Centre at Kingston General (which no longer exists) where I was under Dr Raper. I now receive treatment at the Castle Hill Hospital, Cottingham.
5. Being a haemophiliac meant I did have to go to a special school in Hull. This school had a mix of children with physical disabilities and behavioural issues. Being in hospital so much did have an impact on my childhood but I just got on with things as much as I could. When I was eight years old, my mother died and when I was twelve years old, my father died. I came from a big family so they all mucked in to help me and my step-mother looked after me as well. They took me to my hospital appointments and for treatment when I had a bleed.
6. Although I was being given Factor products on such a regular basis, I do not remember being warned of any risks of infection until HIV became well known. I don't think I was ever told anything about cross contamination of blood or any risks associated with my blood. I was very young when I started receiving Factor products but I cannot recall my

parents, family or step mother ever being warned of anything or at least telling me they had been warned of anything.

7. I remember when HIV became well known in the mid 1980s as it was all over the news and Live Aid was held. I vaguely remember being told at the hospital that there was a risk of HIV through the Factor products but I cannot recall clearly what was said.
8. I do remember when I was around ten or eleven I started suffering from bad back ache, around the side of my back. It kept coming and going but it was causing me pain and difficulty. My father was concerned about me and called the doctor to come and see me. The doctor visited me at home but he told me the pain was probably just growing pains. As he didn't think it was anything serious I just got on with things and eventually the pain went away.
9. In around 1988 when I was in my mid-teens, I went through a period of exhaustion where I didn't really get out of bed for up to a month during the summer holidays. At the time I thought I was just being lazy but now after having being asked about symptoms of HCV I had, this exhaustion could well have been linked to the infection.
10. After I had left school, in around 1991, I was told I was positive for HCV. I don't really remember how this information was passed onto me but I just remember walking down Beverly Road near the hospital thinking 'I have hepatitis C'. I felt confused and I didn't really understand what this meant but I thought, 'whatever happens will happen'. I do vaguely remember being asked how many partners I had been with and I had been with my partner for two years by then. I was told she would need a blood test to check for HCV infection. I'm not sure when she had this but she was negative for HCV.
11. I do not remember really being told about what having HCV meant. They may have mentioned risks of passing it onto others but I was never really that concerned about passing it onto someone else. I also don't

remember ever being told what genotype of HCV I had or being told how serious HCV was.

12.A. few years after being told I had HCV, I was told that I also had antibodies in my blood to Hepatitis A or B, I can't remember which one. I have now cleared this infection.

13.I have never been a drug user or had any tattoos or piercings. Since I have received such a large quantity of factor products in my lifetime, it is clear that my infection with HCV and Hepatitis A or Hepatitis B is as a result of the blood products I have been taking since childhood. I cannot pin point when I would have contracted these infections as I have had so many doses of Factor VIII over the years.

### **Section 3. Other Infections**

14.In around 2011 I received a letter saying that I may be at risk for vCJD. This is because a blood donor that had donated plasma, which was used in a batch of the blood products I received, tested positive for vCJD.

15. As mentioned above, I also had antibodies for either Hepatitis A or B infection which I am now clear from.

### **Section 4. Consent**

16.I do not believe I was ever tested without my knowledge or consent. However, I was given a new type of Factor VIII as a trial maybe around 5 years ago. I was asked to keep a log in relation to this and how I reacted. I remember the word 'Greenacre' associated to this Factor VIII trial but can't remember much more about this.

## **Section 5. Impact**

17. Having HCV did not really have a major impact on my life and at the time I really did not know how serious it was and only discovered this recently. Everyone knew how bad HIV was at the time but HCV was not really known about.

18. When I found out about the HCV infection, my Partner GRO-C  
GRO-C  
and my infection was never something we really spoke about. GRO-C  
GRO-C It didn't  
have an impact on our relationship and we are still together.

19. Although I never really thought I had side effects of HCV, I have suffered from bone aches and pains on and off since I was young. I never thought this was due to the HCV and always put it down to the haemophilia. The tiredness I suffered in my mid-teens may also be due to the HCV but I never really thought about it. I still suffer from achy knees, arthritis and osteoporosis in both ankles and missing cartilage in my ankles but I believe this is because of the bleeds in my ankles, due to the haemophilia.

20. I have also had some issues with my memory, in particular, remembering dates. I did not realise this was a symptom of HCV until the investigator mentioned the term 'brain fog' to me to describe these symptoms. This had not been mentioned to me by my doctor as a possible side effect on being infected with HCV.

21. I think I may have been offered some form of treatment for the HCV infection, shortly after I was diagnosed. However, I'm pretty sure I said no, probably due to the side effects of the medication. I don't remember much more about this but I just thought 'what will be will be'. I didn't really understand how dangerous HCV was at this point either.

22. In around 1999, I had a blood test which showed that I had cleared the infection naturally. I think I was happy with this news but to be honest, I thought this was normal. I wasn't aware that this was quite an unusual thing to happen. I hadn't done anything special to work on clearing the infection and had just carried on living life as usual. Now I realise I was lucky to clear HCV naturally.
23. I probably would have told my family about the HCV but I don't really remember much about telling them. I never faced any stigma from my family once they knew I was infected. Back then, the stigma was mainly in relation to HIV; HCV was much less known about. I am quite a self-sufficient person and just got on with it on my own without involving other people. I never felt I needed to reach out to my family for support even though they probably would have helped me if I had asked.
24. I never told friends about the haemophilia or HCV as it never really came up in conversation; I was not actively avoiding telling them. My haemophilia has always been well managed so there was nothing really to say about it.
25. I did tell my dentist about my HCV infection as my doctor told me to. Although he double gloved and took some extra precautions, it didn't affect me getting treated and I did not experience any stigma from him.

## **Section 6. Treatment/Care/Support**

26. I have not had any issues receiving treatment or care due to being diagnosed with HCV.
27. I have never been offered counselling and support in relation to my HCV diagnosis.

## **Section 7. Financial Assistance**

28. I was told about the Skipton Fund about 13 years ago by Dr Alsop, the Haemophilia Centre Director in Hull. He encouraged me to apply and helped with the application process. After some time, I heard back from the Skipton Fund and was told that they had rejected my application. I believe reason was either because I had cleared the HCV infection naturally or because I hadn't had HCV for long enough.

29. Dr Allsup was confused by the rejection from the Skipton Fund and encouraged me to reapply. Unfortunately, I was rejected once again for the same reason as the first time.

30. I have never received any financial support since being infected with HCV through Factor VIII blood products. Receiving financial support from Skipton would have helped my family. I am aware that I can now reapply to the EIBSS for financial support as the Skipton Fund no longer exists.

## **Statement of Truth**

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

Signed

GRO-C

Dated

10/12/2020

