

# ANONYMOUS

Witness Name:

Statement No.: **WITN0105/001**

Dated: 16/01/2019

## INFECTED BLOOD INQUIRY

---

WRITTEN STATEMENT OF

---

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 December 2018.

I,  will say as follows: -

### Section 1. Introduction

1. My name is  My date of birth and address are known to the Inquiry. I am married and have two children.
2. I intend to speak about my infection with the Hepatitis C virus ("HCV"), which I contracted as a result of being given contaminated blood following an operation.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the devastating impact it has had on my life and the rest of my family.

## ANONYMOUS

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

### Section 2. How Infected

5. I was infected with the HCV in May 1980 at the Broadgreen Hospital in Liverpool where I was having orthognathic surgery.
6. At the time, my operation was groundbreaking. My surgeons had not performed this particular type of surgery previously. To this end my operation was filmed for medical students, and during my recovery I was filmed intermittently with my consultant surgeon to outline my recovery to the students.
7. My operation included breaking my lower jaw, breaking my upper jaw, inserting bone from my hip into my upper jaw, having a 'cage' bolted into my skull for 6 weeks, together with metal braces over my teeth for a number of months. In total, I was off work for three months.
8. I spent a number of days in intensive care, followed by a week on a surgical ward. During this time I received blood as well as fluids via intravenous drips. I distinctly remember one of the nurses laughingly asking me whether I had relatives in America who had donated blood, as the pack of blood she was changing was from the USA. I later learnt I had contracted HCV as a result of being given this blood.
9. In 1995, whilst on holiday, my husband and I decided to give blood at a mobile blood transfusion service vehicle. By the time we returned home, I had received a letter from the National Blood Authority asking me to urgently get in touch with my GP, as it appeared I had been infected with HCV.

## ANONYMOUS

10. I have been asked if I was given adequate information to understand and manage the infection, and the answer is I do not believe I was. My GP very dismissive of my infection and I was required to go around him and contact other medical professionals in order to receive treatment. I was not given information on cross contamination by unprotected sex or by blood or told how to protect my family and the people close to me from infection.

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

11. I do not believe that as a result of being given infected blood products I have contracted any infection other than HCV. I don't know if I have been tested for HIV.

12. After I received the letter telling me I had tested positive for HCV, my husband was tested and found to be clear of HCV. Given the ages of my children, my doctors were fairly certain my children were also clear.

### **Section 4. Consent**

13. I have been asked if I believe that I have ever been treated or tested without my knowledge or consent and the answer is I do not know if I have been tested for anything without my knowledge.

### **Section 5. Impact**

14. When I received a letter from the National Blood Authority informing me I had been infected with HCV, I went to visit my GP. My GP sent me away, telling me 'they' were more concerned with Hepatitis A & B, and I shouldn't worry.

## ANONYMOUS

15. After an initial feeling of relief, I realised the National Blood Authority would not have written to me in the way they did if it was nothing to worry about. I subsequently rang the service and explained what had happened with my doctor. They told me to change my doctor or speak to someone in the practice who could help.
16. I rang the practice nurse, who realised the importance of me being seen by a specialist, and managed to draw up a referral letter and surreptitiously asked my doctor to sign it.
17. In late 1995 to early 1996, at Whiston Hospital in Prescot, I was treated with Interferon. As this was in the very early days of HCV, they explained that currently there was not a 'cure' for all those infected. They really did not have any answers to my questions of prognosis as they were still learning themselves. Despite this, I have to say my care at Whiston was faultless.
18. My doctors at Whiston Hospital told me that the record keeping at Broadgreen left a lot to be desired, as they couldn't trace my records. It was only years later I realised the implication of this statement.
19. I 'managed' my infection through the use of the drugs they gave me. The side effects of Interferon were devastating; rapid hair loss, depression, skin flaking off from all parts of my body including my face. I also suffered nausea, weight loss, dreadful fatigue, terrible joint pain and feelings of utter hopelessness.
20. During this time I visited my GP to ask for help for the side effects; I was told these were simply the results of a very powerful drug and I needed to learn to cope with them.
21. I had 2 small children during this time; the effects on them are felt to this day.

## ANONYMOUS

22. After a year of Interferon treatment, I was told I still had Hepatitis C. I was told that if there were a change in treatment protocol I would be contacted. I felt abandoned, very alone and frightened beyond belief.
23. In around 2002/2003, doctors at Whiston hospital contacted me to try out a new HCV treatment called Pegylated Interferon. I think this lasted roughly the same time, with the same side effects as before. I was told the side effects would not be as severe, but whether I imagined it, or they were a build up from my earlier treatment, I do not know, but I felt the effects just as badly.
24. Despite the elapsed time from my initial treatment, I was not offered any help to cope with how I was feeling; again it was a case of just putting up with how this powerful drug was affecting me.
25. In 2004 or 2005 my consultant informed me I had cleared the HCV from my body.
26. During my treatment I lost my business and livelihood. My children were taken from their school, as we could no longer afford the fees. I could not access dental treatment. I could not access life assurance.
27. I lost the standard of living I had become used to, and became dependent upon my husband. I was forced to take very low paid jobs. I had to become adept at explaining why I had not worked for years, as disclosing my illness would have certainly meant I would lose any job application.
28. My wider family do not know the circumstances of my illness. I was initially advised to tell people I had a 'type of leukaemia', which explained why I had to give up my successful business.
29. The mental trauma is with my family and me to this day. I can still taste the Interferon at the back of my throat. My daughter is especially sensitive to what we went through as she was older at the time and remembers so

## ANONYMOUS

much; me not able to get out of bed, me unable to go to parents evening as I couldn't stand for long periods. She remembers brushing my hair at one point and clumps of hair falling out.

30. I feel extremely guilty for putting my children through this trauma. I also feel guilty about not giving them the education they so deserved.
31. The physical effects include; regular coughs and colds, fatigue, joint pain, the need to take naps through the day, being unable to stand for long periods, being unable to garden, being unable to cook for myself, being unable to carry shopping. I also had to give up driving almost 20 years ago as my vision was impaired, and I certainly feel I have no night vision.
32. I felt I got colds and flus more regularly. I certainly tired much more easily than friends of a similar age. I retired from work early as a result of the physical effects I suffered. They made work simply untenable for me.
33. At the time I was infected I had been married for quite some time, I had two small children. I have only ever had one sexual partner and I've never taken drugs. I do honestly feel that had I been younger or unmarried, I would have had assumptions made about my life, which is grossly unfair.

### Section 6. Treatment/Care/Support

34. I have been asked whether I faced any difficulties or obstacles in accessing treatment. The only obstacles I came across were accessing Interferon initially and accessing help dealing with the effects of my treatment. The medical profession seemed immune to pleas from me asking for help. My doctors from this time have since either died or retired, maybe they were old fashioned in their thinking, but complaining about the side effects of a drug which was hopefully going to cure me, seemed churlish and rather pathetic on my part.

## ANONYMOUS

35. As these were the very early days of HCV, and the medical profession were trying to catch up, I don't believe the information given to me was either helpful or relevant. My doctors at the hospital were as open as they could be about the infection, but were at a loss still to predict who would or wouldn't be cured through treatment.
36. It was terrifying and so awful to think that even the experts did not have all the answers.
37. I received no counselling, nor was information on accessing psychological services offered. Looking back it certainly would have helped me to cope and understand what my body was going through.

### **Section 7. Financial Assistance**

38. I found out about the Skipton Fund from a friendly solicitor in 2010. Up until this time I had no idea there was assistance out there, and indeed had never been told there might be help.
39. I applied to the Skipton Fund and was initially rejected because my medical records were 'missing'. The Skipton Board felt that my operation would not have required blood products despite my assurances, and assurances from my family and friends who visited me in hospital where they witnessed my blood 'drips'.
40. I then embarked on extensive research to find out more about the history of my operation. In the 20 years since my operation, surgical procedure had moved on, and indeed the Board was right that in the new millennium blood products are generally not required for this operation.
41. However with the help of my children, I tracked down many research papers, which confirmed my statements regarding blood products. Indeed, I

## ANONYMOUS

also found research, which suggested blood products would not be required in straightforward Orthognathic surgeries. These would have been written around the late 1980's.

42. I submitted my appeal to the Skipton Fund, and this was accepted. I received a Stage 1 payment in 2011.
43. Since then I have received help from the Caxton Fund. I think it was the Skipton fund that informed me about the Caxton Fund. I had to complete a financial questionnaire and I think I received in the region of £200 per month.
44. In 2018 I was awarded SCM payments from EIBSS scheme.
45. I have to say that all the financial organisations that deal with government assistance have been nothing but polite and efficient. I understand many of my fellow sufferers have been dealt with in an unsympathetic, and indeed very rude manner, but I have not experienced this.

### **Section 8. Other Issues**

46. For those of us who are still alive, I believe that despite all we've been put through we are the lucky ones. I still have my children, I still have my family, I'm still alive.
47. I would like this opportunity to express how disgusted I am with the way we have been treated over the decades. I, like many others, had my professional and personal life turned upside down. No one, until David Cameron's twenty-second grudging apology, had acknowledged our suffering, our losses, or how after decades of lying to us, the government refused to help us.
48. It has only been through the tireless research of action groups like Tainted Blood that we were informed of what successive governments already



# ANONYMOUS

knew; blood from high risk groups was known to cause illness in recipients yet they continued to use it. To compound matters they destroyed our medical records in order to deny culpability.

49. For the first time in many years I feel confident that this Inquiry will give us some answers. What it can't do is give me back the life I had, the life I still grieve for.

## Statement of Truth

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

Signed                     GRO-B                    

Dated 17/1/2019.