

ANONYMOUS

Witness Name:

Statement No.: WITN0671001

Exhibits: WITN0671002 –

WITN0671008

Dated: 7 August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

Section 1. Introduction

1. I, will saw as follows:-
2. My date of birth is 1994. My address is known to the Inquiry.
3. I am currently studying psychology at university. I live partly at home with my parents in Worcestershire and partly with my boyfriend in I have an older brother who lives in America.

Section 2. How Infected

4. Some of the information in this statement concerns my early childhood. I am therefore unaware of the details myself and so some of what I have set out below I have learnt from my parents.

ANONYMOUS

5. On 15 **GRO-B** 1995, when I was nine months old I suffered multiple skull fractures when my childminder fell down the stairs with me in her arms. I was treated in intensive care at the Royal Berkshire Hospital. I understand from my mother that I received blood or blood plasma during my admission to hospital.
6. The discharge summary for this admission is attached **[WITN0671002]** but does not mention administration of blood or blood products. However, my medical records also contain a document headed, 'West Berks Pathology Service Blood Transfusion Department'. **[WITN0671008]** It has my first name, surname and hospital number filled in. Under date of birth it says, 'NK', presumably for 'not known'. Under medical officer it says 'unknown', hospital 'Royal Berkshire', ward 'ICU/RBH'. My blood group is recorded as 'A', Rh 'positive', antibody screen 'negative'. There is a laboratory no. recorded of '5.31007'. At the bottom of the form under 'specimen received date' is recorded 15 June 1995. Other than this the form is blank. I do not know why the form is blank but when this was queried with the hospital in August 2019 their explanation was that the record is complete and is a group and save request in case a blood transfusion was needed, which, they say, there is no record of me needing.
7. When I was four years old I cut my head with a biro pen when I jumped on to the sofa whilst playing at a friend's house. I was treated at Frimley Park Hospital. I can remember my head hurting and seeing all the blood. I remember my mum arriving and hugging me and kissing my face. I had stitches to my head.
8. Six weeks later my mother was diagnosed with Hepatitis B (HBV). After she was tested for HBV our family members were tested and my result was positive. We were advised by the local authority who conducted the investigation by letter that there was no other evidence of infection in anyone else tested. They had tested family members, nursery carers and children, childminders and anyone else who had been in direct contact with me. The letter said that they could only conclude that I had received the infection

ANONYMOUS

through medical intervention at hospital when I was nine months old, and they stated that they would understand if we wanted to take things further. Attached to my statement is a letter dated 26 September 1998 [WITN0671003] from my GP to Dr Boon, consultant paediatrician at the Royal Berkshire Hospital, stating:

'Please would you be kind enough to see this little 4 year old girl in your out-patient clinic. She has recently been discovered to be a Hepatitis B carrier. Her mother came to see me back in July with an acute jaundice and testing at that time showed her to have acute Hepatitis B.

In the process of screening her family, we discovered that [GRO-B] was positive for Hepatitis B surface antigen and Hepatitis Be antigen. I enclose a copy of her immunology results which suggest she is a chronic carrier. Full screening almost certainly suggested that [GRO-B] mother had almost certainly contracted Hepatitis B from [GRO-B] and we date this to an episode back in March where [GRO-B] had had a head injury and bled profusely over her mother.

I have been working with Dr Linda Booth, Consultant in Communicable Diseases at Basingstoke and the only conclusion that we can come to is that [GRO-B] has contracted Hepatitis B from her nursery, either from another child or from a carer. As a result, Dr Booth has initiated screening of all children present at the local nursery and of those children that were there when [GRO-B] was there too. In addition, she has also screened all the carers.'

9. The response from Dr Boon, dated 20 November 1998, [WITN0671004], noting, 'it seems likely that her mother contracted the hepatitis B from [GRO-B] but extensive contact tracing has failed to identify the source of [GRO-B] infection.' It therefore my belief, and that of my parents, that it is most likely I contracted HBV during my ICU hospital admission when I was nine months old.
10. I do not think my mother was given any information or advice when I received the blood or blood plasma about the risk of being exposed to infection through infected blood.

ANONYMOUS

11. As a result of being given blood or blood plasma I was infected with HBV.
12. I found out I had been infected with HBV through my parents as soon as they were told about it by the consultant. I then developed a wider understanding of the disease from my parents as I grew older and matured. I recall being told by my parents to be very careful when I bled and not to share things with others. I had it programmed into me to be careful and I became very cautious.

Section 3. Other Infections

13. I do not believe I have received any infections other than HBV as a result of being given infected blood products.

Section 4. Consent

14. I have no way of knowing whether I have been treated or tested without my knowledge or consent or for the purposes of research as I have no memory of the initial treatment when I received blood or blood plasma.

Section 5. Impact

15. As I grew older I gradually learnt more about HBV. When I was around 14 years old there was a sex education class at school. On the board there was something about HBV being a thousand times more infectious than HIV, which I found very distressing. The woman taking the class said something about HBV and I corrected her, and then just started crying. I walked out of the classroom and left the school premises.
16. The other children eventually put two and two together and I also made the mistake of confiding in a close friend. News of my infection with HBV spread around the school. We lived in a small town and soon everyone knew. Other

ANONYMOUS

kids accused me of being raped, using needles and injecting drugs. Once everyone knew about my infection they used to shout at me, 'alright Hep B?'. Whole groups of kids would chant it at me across the school fields. I told my dad about it and said I didn't want to go to school anymore.

17. I felt I had no one I could talk to. I felt extremely exhausted much of the time and my mental state was very low. I was very self-destructive. I began to drink and to self-harm in order to cope. I have had to have stitches to repair the damage done to my body through self-harm. I spent little time at school and ruined all of my GCSEs.
18. The school dealt with my infection very poorly. On one occasion they called my mother into a meeting with the headmistress, the head of my year and someone else, I cannot recall who, and they sat opposite us and said that there was a rumour I had kissed a boy. They said, 'we need to talk about this because obviously she has HBV'. Mum was furious because the only person in the school who should have known about my infection was the school nurse, and clearly that confidence had been breached. Their attitude showed great ignorance about HBV and how it is spread and the way they dealt with the issue was completely inappropriate.
19. Up until the age of 22 I was a different person to how I am now: I wasn't interested in life and hated the world. I battled with depression for years and years and eventually began taking Sertraline, having refused to take any anti-depressants for a long time. When I reached 22 I made a real effort to try to turn my life around when I realised it wouldn't be possible to find closure.
20. I have grown up with this infection and learnt about it gradually over many years. Although I now trust what my parents have told me I have a real need to understand how this happened for myself. My thoughts just run away with me and I want to access my medical records to try to get that understanding. Seeing something in black and white about how I contracted this infection may help me get some closure.

ANONYMOUS

21. The physical impact of the infection I have felt more in relation to the treatments I received which were very, very aggressive with dreadful side effects. I had a liver biopsy at five years old and since then I have received four rounds of treatment to try to eradicate the HBV. I underwent a further liver biopsy at the age of 14 and was absolutely petrified before the operation because I knew what it entailed. I found being put under general anaesthetic really overwhelming and have subsequently developed huge anxiety around this.

22. My GP records note that I was referred from the Royal Berkshire Hospital to Kings College Hospital in February 1999, age 4, for treatment. The first round of treatment involved my father injecting the drug into my leg when I was five. I also recall being given some oral liquid treatment at some point. Later treatments involved injections into my stomach. I remember my dad would inject me and my blood would be tested on Monday. If the neutrophil count was high enough I would have another injection on Tuesday. I was monitored weekly in this way during the initial phase of treatment, and then less and less frequently. I suffered a severe period during this time, with very severe bleeding which was extremely painful. I was told it was a common symptom for a child my age. The treatment went on for 10 months and ultimately failed. I became very anaemic and poorly after treatment and didn't have another period for two years. When I started my fourth round of treatment the doctors told me it was the last shot. We put all our hope into that treatment succeeding and when it didn't work it felt terrible.

23. My medical records contain further information about the details of the four rounds of treatment I received at Kings College. A letter from 5 January 2001 from KCH to my GP, [WITN0671005], describes my response to Interferon treatment at age 6, noting I tolerated 'the few side effects very well', completed the last dose on 6 November 2000, but 'experienced low-grade temperature and headache throughout the treatment period, as well as persisting neutropenia'. The letter explains that due to the neutropenia I could not

ANONYMOUS

receive the full dose. At the end of treatment, however, although viral activity was very reduced during treatment there was not the production of antibody against the virus. 'Nevertheless, we know that the antibodies often appear in the following 12-24 months from stopping treatment, since these drugs trigger the immune response of the patient that is often delayed. If this will not happen it will not be a complete defeat, in fact for one year the virus has been stopped and the liver has not been damaged furthermore.'

24. The notes show that I was kept under review and in 2006 was started on treatment with pegylated Interferon, age 12. A letter dated 2 November 2007 [WITN0671006] following this round of treatment noting that I had completed 48 weeks and did not show any significant change compared to pre treatment levels, noting 'in other words she is a non responder. We will continue to monitor her in clinic.'
25. In December 2009, aged 15, I was offered treatment with pegylated Interferon and Entecavir and the medical records note this was given 'on a compassionate basis', and this began in February 2010 for 48 weeks. My neutrophil count was low at times and this meant I could not receive Interferon on certain weeks of the treatment. A letter from 5 August 2010, [WITN0671007] confirms that the pegylated Interferon was eventually stopped as I was not able to tolerate the full dose due to neutropenia. The letter records that I was upset at the idea of not being able to continue on Interferon as I was keen to fight the virus. The consultant advised I continued with Entecavir alone for 3 years, hoping I would eventually develop antibodies.
26. After failing four rounds of treatment I was diagnosed as having chronic HBV and all further treatment has involved using anti-viral drugs to try to make the infection invisible. I have been taking combined anti-retroviral drugs for around six years now. The side effects include headaches and nausea, and I struggle with eating as a result. My viral load has come down but it has not disappeared and I have been advised I may never clear the virus.

ANONYMOUS

27. I do not know the full extent of any further medical complications or conditions which have resulted from the HBV infection. I am often quite anaemic and have low blood sugar. Very recently I have been diagnosed with polycystic ovary syndrome. When I told my consultant at Kings College Hospital that I have experienced problems with bleeding from the time of my treatment for HBV and ever since, and have subsequently developed PCOS, the consultant explained that there might be a link between the treatment and the development of my PCOS.
28. I am not aware of there having been any obstacles to me receiving treatment in the past. Equally, I do not know whether there are treatments I ought to have been offered but was not.
29. I believe my infected status has impacted on my medical treatment. I frequently have to disclose what medication I am taking and if I say I have HBV then there is usually a slightly shocked reaction from medical professionals. I used to become defensive and explain that it was not my fault, that I was a baby when I was infected. It took me a few years to realise that it is unusual to be a young, white female with HBV. I also now know no one has the right to ask me how I became infected: I don't owe anyone an explanation. When people treat me like this I feel dirty and disgusting.
30. More recently, in relation to my PCOS, a gynaecologist advised that I shouldn't take certain contraceptive pills because of the impact on my liver and suggested I get an implant instead. I made an appointment for an implant and when I saw the nurse she asked about my medication and I explained I took anti-retrovirals for HBV. She said she would need to check with a HIV specialist before proceeding with the implant. I told her I don't have HIV and it is not the same thing. Nevertheless, she refused to give me the implant and gave me a three month depo injection instead so they could seek confirmation from Kings College Hospital that it was ok to give me an implant. Three months later I returned to the clinic for the implant and this time was asked how I had contracted HBV. I told the nurse she had all the information she

ANONYMOUS

needed from my consultant at Kings College on her computer. I find this sort of treatment very humiliating.

31. The infection has impacted on my private, family and social life in many ways. It has impacted on my private life growing up because no one would come anywhere near me because of all the stories that had been spread around about me. As I have grown older and developed intimate relationships I have been very careful never to put others at risk: I am able to explain the precautions I take and the effect of the anti-retrovirals.
32. I now have a boyfriend who is wonderful and who has changed my life dramatically. I feel paranoid that despite the anti-retrovirals he may still catch something from me. I have an overwhelming fear that I might somehow infect someone by mistake. At my request he has had three injections to vaccinate himself against HBV. My boyfriend has to cope with the anxiety and stress I feel about my infection, particularly when I have to deal with things like preparing this statement for the Inquiry. It alters my mood and makes me on edge, and this impacts on him. He is brilliant, but I don't think it is easy for him.
33. When I was younger, my family life was very negatively affected by the infection. I spent a lot of time on my own and isolated myself. I was horrible to my parents and blamed them for what had happened to me as a baby. I told them I suspected they had not taken proper care of me as a baby, perhaps leaving me somewhere where someone could have interfered with me: I didn't believe the hospital infection story. I spent a lot of time attacking them and making their life hell. Thankfully, things have greatly improved and we all get on very well now. I have a very good relationship with my parents but constantly feel very sorry for how dreadfully I have treated them.
34. I am now a very private person. My family know about my infection, as does my boyfriend, but few others. I have not told my boyfriend's family.
35. The infection has impacted on my social life. Following my experiences during my teenage years I keep information about my infection private and have only

ANONYMOUS

confided in one friend at university after she had told her own personal and difficult story to me. Otherwise I only tell people about my infection if it is an absolute necessity.

36. I have experienced the stigma associated with HBV. It affected the entirety of my childhood from around nine years old. It has also affected access to healthcare, as described above.
37. My education suffered as a result of the infection because I was absent from school much of the time. I missed a lot of school not only because of the bullying but also because of all the treatment and how poorly it made me, and found it hard when the teachers criticised me for not doing well when I felt it was beyond my control because of the treatment. The teachers knew about my illness from the school nurse but they were not well-informed about it. When I had lots of time off they would ring my parents and mum would have to explain I was on treatment. I felt as if they had given up on me.
38. I could not get into college with my GCSE results so I studied for a BTEC instead. I attended a college in a different town, away from the small town I had grown up in, where I didn't know anyone and no one knew me. It felt like a fresh start. One evening I went out with friends to a nightclub and from across the car park a guy recognised me and shouted, 'all right Hep B?'. I left the club immediately. I felt the stigma of the disease and the bullying had followed me. I eventually dropped out of college because mentally I just wasn't there.
39. After I dropped out of college I asked mum if I could move away from home. A friend of ours lived in Spain at the time and mum agreed to me going. The friend pointed me in the direction of nice areas to live in where it would be safe for me to live alone. I arranged to go for three months but came back a year and a half later. Although I liked being away from home I hadn't tackled my issues, I just moved them somewhere else with me.
40. When I returned home from Spain I started working in bars, with no intention to continue my education. An opportunity came up to work in the Alps as a

ANONYMOUS

nanny and I took it. Whilst I was there I thought about what I wanted in life. I knew I couldn't just run away again. I wanted to achieve something and get more stability in my life. Whilst there I applied to start university back home in the next academic year. I wanted to study psychology but had to start again from the beginning, retaking my maths GCSE, doing an access course, and then a higher education course at GRO-B College before applying for psychology at university. I have done it and am still studying now. I would like to work with people who have received diagnoses like mine and help them through it.

41. The infection has greatly impacted on my working life. I have never told a place of work about my infection. If an application form asks whether I have HBV I would rather abandon the application, or turn down the job, than tick that box.
42. I feel the infection has impacted on my life financially because of the delay in completing my education. The reason I am still studying now, rather than working, all these years later, is because I failed my GCSEs when I was struggling with the infection at school, both from the mental effects of the stigma, and the physical effects of trying to cope with treatment.
43. My family and I have had to bear the financial costs of all the trips to London to Kings College Hospital for appointments with my consultant. We have had to pay for all my prescriptions. My mother spent a lot of money on my health over the years, particularly when I was around 15 years old and my immune system was very weak. I suffered with a lot of health issues at the time and my parents invested a lot of time and money in trying to rebuild my health.

Section 6. Treatment/Care/Support

44. I was offered counselling through the hospital when I was around 14 years old. I went to see a psychologist at the hospital and the psychologist discharged

ANONYMOUS

me after half an hour, saying I was fine. I know I was not fine but I wanted to be fine and at 14 I was very good at appearing ok.

Section 7. Financial Assistance

45. I have not received any financial assistance from any of the Trusts and Funds set up to distribute payments. There is no financial assistance scheme for someone infected with HBV through infected blood.

Section 8. Other Issues

46. I hope that the outcome of this Inquiry will be to ensure that this sort of thing never happens to anyone else ever again. When I think about what has happened, the scale and the extent of it, I find it terrifying.

Statement of Truth

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

Signed

GRO-B

Dated7 August 2019.....