

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN2590001

Exhibits: WITN2590002

Dated: 7 August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. I, GRO-B will say as follows: -
2. My date of birth is GRO-B 1964. My address is known to the Inquiry.
3. I live in Worcestershire with my husband. We have two children, one of whom is my daughter GRO-B: D who is now 24 years old.
4. I make this statement to set out how I believe my daughter, D was infected with contaminated blood, and how I became infected as well as a result.

Section 2. How Infected

5. My daughter, D sustained a head injury on 15 GRO-B 1995 when she was nine months old whilst in the care of her childminder. D was taken to the Royal

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Berkshire Hospital. When we arrived in A&E [D] was strapped to a gurney and had a Glasgow Coma Scale of 4 with one vital sign. We were told [D] was going to die, and if she didn't die then she would be severely brain damaged. She had a bleed inside her skull and four major and eight minor fractures. [D] was intubated in A&E and also on intensive care. When she was in intensive care I remember her being given a clear blood plasma. In ITU the doctors handed her to me and I thought they were giving her to me to die. She looked up at me and said, 'mumma'. I remember thinking we just had to get through each minute and each hour. Somehow she improved and the following week she was discharged. One of the nurses later told us her recovery had been a miracle.

6. When [D] was four she was playing at a friend's house and jumping on the sofa. She fell and a pen that had been on the sofa went through the skin on her head and caused a lot of bleeding. Her friend's mother called me and said she was taking [D] to Frimley Park Hospital, where I met them. When I saw [D] she was covered in blood and still bleeding. I kissed her and hugged her. [D] had stitches to her head and made a good recovery.
7. In July 1998, six weeks and one day after [D] accident I was attending a work event. I ate something and was immediately sick and then felt better again. Later the same day I ate something else and was again sick straightaway, and then felt fine. I went to visit family in Stockton that weekend and felt very odd. By Sunday I had turned bright orange. My nana, who worked in a GP surgery, thought something was seriously wrong with me and got me to call the GP who advised me to come in the next day where they took blood. They too advised that something was seriously wrong with me and sent me home. I had to go back for further blood tests the next day and then the GP asked for my family to come in and be tested. [D] result tested positive for Hepatitis B (HBV), and so did mine. We were advised that I had caught it from [D]. We both had genotype D, which comes from Pakistan and is a particularly difficult strain to clear.

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8. Our doctor had never met anyone with HBV before and could only give me very limited information. I had to find out information online about what it was. The GP did the right thing by ordering the blood tests and acting very quickly once he had the results, making the right referrals. He arranged a health visitor to investigate how [D] had come to be infected, and although this would have been the right thing to do, it felt as if the medical and social care professionals cared more about containing our infection than helping us. We were given some information about the risks to others and the rest of our family were all inoculated very quickly.
9. **Exhibit WITN2590002** is a page from my GP records which notes my GP was liaising with a Dr Simon Tanner and a Dr John Simpson, Consultant in Communicable Diseases at Basingstoke for guidance on the infection. The notes show Dr Simpson advising that my husband and the children need testing and immunising. Further down the page is a note to 'screen and immunise all those concerned' and that there was a 'chat re dangers and implications' including 'general contraceptive advice'. I do not recall being given specific contraceptive advice in relation to HBV.
10. I was not given enough information or advice to help me understand and manage the infection. When I was subsequently referred to Kings College Hospital, London, we were given more information, but it was still relatively limited as very little was known. [D] was one of the first people to start clinical trials at Kings and as little was known about treatment they could not tell us whether it would work. I don't know whether more information should have been provided to us, at the time it felt as if there was no other information available. There was certainly a lot of misinformation, as there continues to be today.
11. The local authority said they needed to investigate the virus further and tested everyone around us, including all the children at [D] nursery, their family members and childminders. I received a letter from the local authority at the conclusion of the investigation which unfortunately I no longer have, but I

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distinctly recall the letter saying that, as a result of no infection being found throughout the investigation, they could only conclude that [D] infection was as a result of her treatment at the Royal Berkshire Hospital when she was nine months old as that is the only medical intervention she has had. The letter said they would understand if we wanted to take things further but at that time we were dealing with so much as a family with both our infections that we did not pursue anything. I must have then somehow been infected through blood to blood contact with her when she had stitches to her head at four years old. Her accident at age four was the only time she had a blood spill, as when she was nine months old the injuries were all internal.

12. When [D] received blood plasma at nine months old at the Royal Berkshire Hospital we were given no information or advice about the risk of being exposed to infection through infected blood products.
13. As a result of being given blood plasma [D] was infected with HBV. As a result of blood to blood contact with [D] was also infected with HBV.

Section 3. Other Infections

14. I do not believe that I have received any infection other than HBV as a result of [D] being given infected blood.

Section 4. Consent

15. I do not know whether I have been treated or tested without my knowledge or consent or for the purposes of research but they certainly took a lot of blood from me when I was first diagnosed and there was a lot of confusion about how it might have happened.

Section 5. Impact

16. The physical effects of the HBV infection were severe. I was advised that my HBV could not be treated and to hope that my antibodies kicked in to fight the virus. I was given two drugs, one to stop the nausea and the other was a type of chemotherapy. I learnt that your ALT score should be around 40 and you started to die when it reached around 500. Mine got to 1060. After 18 months my body managed to clear the virus.
17. I could hardly get out of bed for the first year. The virus makes you very tired, but seems to pick and choose the days it does it. At the time I was employed and I managed to continue working by working from home and only working three days a week, sleeping the rest of the time. I would feel ok one day and the next I would be unable to get out of bed, unable to wash myself and unable to look after the children. I think I have blocked out much of that time from my memory and my husband tells me now that I was so unwell he thought I was dying. I was bright yellow.
18. Mentally, I don't think I have ever really dealt with the virus from an emotional perspective because ever since I was diagnosed the real focus has been trying to cope for [D]. As long as [D] is ok then I can manage. I feel great relief that I was diagnosed when I was, otherwise we might never have found out and [D] may well be dead by now. That thought is too painful to address. I try to remain positive: [D] did not die, she is still with us. If I dwell on it too much it will screw me up. I will always live with the guilt I carry.
19. I am not aware of any further medical complications or conditions which have resulted from my infection. As far as I am aware my liver is fine and it was checked at the time of my infection, but I have had no follow-up. I understand that now I am clear I can never contract the virus again.

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20. [D] remains on treatment with anti-retroviral drugs, Entecavir and Tenofovir. Her viral load was 17 million parts to 1, it was extremely high and that is why she was so infectious. She is now at 233 parts to 1. The drugs she is on are very harsh: Entecavir reduces your viral load and Tenofovir boosts your HBV immunity so when you stop taking Entecavir your antibodies will fight it and clear it. However, the medical professionals don't think that [D] will clear it.
21. I don't know what this means for [D] future and whether or not she can have children. When pregnant you can continue taking Tenofovir and so far there is a really good success rate and babies have not contract the virus. Babies are then immunised at birth. I don't know what decision [D] will make about this.
22. We were told that [D] liver would likely fail when she reached 25 because chronic HBV causes liver failure. She has HBV genotype D and there is little understanding of how it works. The anti-retroviral drugs she takes try to find the infection and fight it. If she stops taking the drugs the virus comes out again. She will probably never clear it. Her viral load is 233 and it would need to be zero for ten years before she should be taken off the tablets. We have been told they may try to take her off the tablets in ten years time anyway to see what happens. She has had two liver biopsies and recently there was a lesion of 3.6cm found which was thought to be a tumour. All of our fears about her liver failing at 25 years old returned, but it turned out to be a collection of blood cells that presented like a tumour. She has had an MRI to investigate and is being monitored. [D] will continue to have follow-up every six months which involves attending Kings College Hospital for an ultrasound, an appointment with the consultant and the nurse, a repeat prescription and then the results by post two weeks later.
23. I was not given treatment for my HBV and was advised instead that with adults they wait for the virus to clear itself. As described above, I was given two drugs, one an anti-sickness drug and the other a form of chemotherapy. I do not think I faced any difficulties or obstacles in accessing such treatment. I am unaware if there are any treatment I ought to have been given but was not.

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One of the long standing effects of the virus is that I am not able to give blood ever again.

24. The impact of the infection on our private, family and social life has been almost overwhelming.
25. In terms of my private life, my husband and I have never really got over it. When I found out I had HBV I told him on the Sunday night and said he and the kids would have to get tested the next day. He was very confused. Everyone thinks it is an STD. He asked me who I had been sleeping with. It all now feels understandable with hindsight but at the time we were both angry, fearful and in shock. We split up for eight years and divorced: he never got over his concerns and I never got over his anger. Years later we have eventually reunited. We now get on well and are very different people to the people we were back then. My husband still suffers from both our diagnoses: he thought I was going to die and we are both still living with [D] ongoing chronic infection. He cannot deal with [D] diagnosis and struggles to attend hospital with her, which has upset her over the years.
26. Many years ago I developed a drinking problem as a coping mechanism. Before any of this happened I didn't drink at all. I know that I used drinking as a way to help me cope with what had happened to [D] and I, and the impact the infection had on her physically and emotionally, and on our relationship with each other. The drinking was also one of the reasons for the breakdown in my relationship with my husband. Three years ago I completely stopped and have not drunk since then.
27. The impact on our family life has been long lasting. My relationship with [D] has been extremely difficult over the years. [D] and I have had screaming rows which have been horrendous. She blamed us for a long time and asked many questions about how she contracted the virus. She didn't believe we were telling her the truth. She has suffered very badly: she has binged on alcohol, self-harmed and tried to kill herself. She has suffered so much with

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her physical health with the infection and all the treatment regimes, and has had difficulties with her liver. My take on it all was to just let her shout at me: the damage to her has been phenomenal, I will always love her. When I have to mention to others that she infected me I know she feels an incredible amount of guilt even though it was not her fault. The problem for us is that we have never been able to make any sense of it all.

28. We still have rows sometimes, particularly over what to do about it all now, including whether to make these statements for the Inquiry. It has been difficult to know what to do and how to find out more over the years. It was always just been a question of trying to get through that argument, that day, that week, trying to stop [D] hurting herself. There was a time when she missed out on around two or three years of her life when she just couldn't cope. She has turned a corner and is now studying again, which is amazing. We are now very close and can recover from our arguments together. I want to make this statement for the Inquiry so [D] can get some answers, and I need answers too.
29. We moved our family out of the small town the children had grown up in because of the stigma [D] suffered. We wanted to give her a fresh start and should have done it much earlier than we did.
30. The virus has impacted on [D] older brother too. He is older than [D] and can remember seeing me very poorly for about a year and being in bed most of the time. [D] and her brother's relationship has suffered and they have argued a lot over the years.
31. Socially, we have struggled. I lost my best friend over the virus because of the way she reacted after finding out [D] had kissed a boy. I felt I could no longer be friends with her.
32. We no longer tell anyone about the virus. I do not talk about my infection because it might lead to a discussion about how I got it and people might then

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find out about [D] There is therefore this huge part of my life which none of my friends know about.

33. The stigma of the virus has impacted on our family in many ways. The effect of the health authority investigating the virus when I was first diagnosed meant any confidentiality was breached and it was broadcast to everybody. The investigation was meant to be carried out confidentially but in fact everyone was informed of [D] name and this was the start of a huge amount of bullying and name calling which has lasted throughout her life, as set out in her statement. People used to approach me and ask what was going on with [D] why did she have an STD at nine years old?
34. When we first met the consultant at Kings they told us not to tell anyone at [D] school. When it all eventually came out at school [D] was called 'HIV girl' and 'AIDS girl'. [D] once recorded a phone call she got, telling her to 'get out of our town, you disgusting Hep girl.' Even a friend of her boyfriend has said, 'oh, she's that dirty AIDS girl'.
35. We have chosen not to tell anyone about the virus unless absolutely necessary. However, when we do have to tell others they assume that I have infected [D] rather than the other way round. There is still a lot of ignorance about the infection and people just don't understand. We now choose not to tell people how we came to be infected because there is no need and it causes us both so much upset and guilt.
36. The infection has impacted on [D] education, as described in her statement. It has also impacted on my career. When I was first diagnosed I was still employed. I was able to invent a story about how I had contracted Hepatitis A from food during a trip, rather than HBV, because it is possible to contract Hepatitis A from food. I needed to be able to explain to my employer why I had to start taking drugs when I was first diagnosed. The timings didn't work but no one questioned me further about it and I managed to keep my job during treatment. After some years I made the decision to become self-employed so I

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could work from home and spend more time with [D]. Over the years we have had to go to London quite a lot for hospital appointments, sometimes every week, and I wanted to be able to do this with her. The move to being self-employed has impacted greatly on my career and certainly significantly reduced my earning potential and prospects.

37. Financially, the virus has impacted on our lives, particularly [D] infection because that has been so long standing. We have had to travel to London very frequently for hospital appointment, and borne the costs of all of [D] prescriptions. [D] has been involved in four clinical trials and we have had to pay for all the drugs on prescription.

Section 6. Treatment/Care/Support

38. [D] received a half hour session of counselling when she was 14. Although I told the hospital in advance that I thought [D] needed to talk about puberty and her development and would not want to talk to a male counsellor, the counsellor offered was male. [D] felt this was yet another example of no one hearing her or even trying to understand. She then had a further few sessions with a female therapist who brought the therapy to an end after two or three sessions saying 'she is absolutely fine', whereas the [D] we had at home was deeply troubled.
39. I had therapy when first diagnosed as I felt as if I had gone into coping mode and wasn't feeling anything, except the guilt I felt at not being with [D] when she was injured. Although I had asked the GP for a referral the waiting time was too long so I paid privately.
40. Neither of us has been offered any further counselling and I think both of us would still benefit from counselling or psychological support.

Section 7. Financial Assistance

- 41. Neither [D] nor myself have ever received any financial assistance as a result of being infected with HBV. I have looked into the EIBSS scheme but it only appears to cover those with hepatitis C or HIV.
- 42. Some years ago I looked at accessing benefits for [D] because she was attending college but not coping and she needed money to get by. Some days she couldn't even get out of bed because she was suffering with the side effects of the treatment she was on. I was told that she didn't qualify for any disability benefits.
- 43. I would like [D] to receive some kind of financial assistance. At the moment she is studying and trying to get a job, but I would like her to be resting instead so that she can focus on her studies and not feel too exhausted from the HBV.

Section 8. Other Issues

- 44. I am so proud of [D] for standing up for herself through all the years of horrific abuse she has suffered because of this disease. It has somehow formed the amazing person she is now.
- 45. I would like the Inquiry to get answers as to why all this was allowed to happen. I would like these answers for [D] so that she can have some understanding of what happened to her.

Statement of Truth

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

Signed

[GRO-B]

Dated

.....7 August 2019.....