Witness Name GRO-B
Statement No.: WITN0671009
Exhibits: WITN0671010 – WITN0671020
Dated: 28 October 2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. I, GRO-B will say as follows:-

2. This is a supplemental statement made in accordance with the Rule 9 Request from the Inquiry dated 11 September 2019.

3. I have provided my medical records to the Inquiry. This supplemental statement is made to exhibit records of relevance which were not included with my first written statement.

Route of infection

4. Further medical records have thrown more light on the potential source of my infection and the investigations around this, so I have set this out in detail below, with exhibits where appropriate.

5. **WITN0671010** is the Intensive Care Unit Discharge Letter dated 15 June 1995. There is no mention of the use of blood or blood products, however, the letter mentions cannulation and hydration. I do not know whether this would have been a possible route of infection. **WITN0671011** is the Nursing Transfer Summary dated 19 June 1995. **WITN0671012** is a letter dated 20 July 1995 from a consultant paediatrician confirming the injury, treatment and recovery progress. My mother remembers metal shunts and a cannula in my hand and me being hooked up to drips for plasma but she can't remember if I was given any other blood or transfusions.

6. **WITN0671013** is a Certificate of Notification of Infectious Disease completed by my GP and dated 27 August 1998. The form asks whether the disease was or was not contracted in hospital and the doctor has completed the form indicating, 'in my opinion the disease was not contracted in hospital'. However, this form was completed when I was first diagnosed with HBV, and not following the extensive further investigations later carried out by the local health authority (see below, and at paragraphs 8 and 9 of my first written statement).

7. **WITN0671014** is a letter some months later from Dr Booth following her investigations dated 4 November 1998, noting:

'I have recently received the final hepatitis B salivary test results from individuals connected with GRO-B which GRO-B attended. Some of the children had moved away, so there was delay in locating and arranging tests for them.

In addition to children and staff currently at the nursery who overlapped with GRO- 25 other children who had been in contact with GRO-B but who had moved on were also tested. Five staff who had since left the nursery were tested, one had not complied.

No positive results were found which confirms the low risk of horizontal transmission amongst young children.

The source of GRO-B hepatitis B remains a mystery. It is obviously impossible to test all playmates and contacts. I also made enquiries to Frimley Park Hospital concerning GRO-B birth which confirmed that staff occupational health records were in order for those staff involved in the delivery and who were still employed at FPH.

The testing exercise took place without GRO-B identity being disclosed. I am aware of a family friend with young children who has been a regular carer of GRO-B in the past. However, on the basis of an extremely low public health risk and the GRO-B 's desire for confidentiality, I believe we have taken the public health aspects as far as we can at the present time.

I would be interested to hear if GRO-B clears the virus in the future, perhaps following treatment. Assuming she is still carrying the virus when starting school, there may need to be consideration of whether and how to inform the school.

Thank you very much for the co-operation of the surgery with the testing.'

8. There is no other information in my GP records about how the surgery cooperated with Dr Booth on this investigation. I do not know whether this is because there has been incomplete disclosure of my records to me, or because perhaps any such records relate to other patients on the surgery's list and therefore they would not form part of my records. I am surprised there is nothing else in my records at all about this investigation. I believe the records surrounding this investigation have been deliberately withheld or removed. This was an extensive investigation and concluded with a letter being sent to us explaining that none of those tested presented with HBV and therefore they could only conclude that the infection was as a result of my treatment at the Royal Berkshire Hospital. The letter stated that they would understand if we wished to take this further. I believe a copy of this letter would have been sent to my GP at the time, but again, this is not in my GP records.

9. Furthermore, although Dr Booth notes that 'the testing exercise took place without GRO-B dentity being disclosed' I understand that this was not the case.

My identity was not kept secret as I know that my family was approached by others in our village after the investigation to ask my mum if I was ok.

10. It does appear from this letter that there was very extensive testing of almost the entire nursery staff and children, including any children who had left but had been in contact with me. The letter also confirms that transmission child to child is 'low risk'. I did not know that investigations were made into the staff present during my birth but again, this found no evidence of HBV, which suggests to me that the most likely source of infection must have been when I was an inpatient in 1995 following my skull fractures.

11. On 29 March 1999 there is a record of how my mother was probably infected in a letter following a clinic appointment at Kings College Hospital, GRO- was found to have chronic HBV infection last July, when her mother developed severe acute hepatitis B. It is not known how she became infected, but she probably infected her mother in January 98, when she cut her head and bled profusely.' **WITN0671015**.

12. I remember asking my nurse at Kings College Hospital to help me understand how I had become infected with HBV. **WITN0671016** is a letter from my nurse to Dr Boon, consultant paediatrician dated 13 January 2012, asking GRO-B has many questions regarding how she became infected, which as yet, are unanswered GRO-B has asked with the knowledge and support of her mother whether I can help her to look into the original circumstances around how she may have contracted Hepatitis B. GRO-B mother reports there was an investigation and extensive contact testing performed locally back in 1999 and we wondered whether there was a record made of this tha GRO-B could access?' Despite finding this letter in my GP records, I can find no response to this letter in either my GP or hospital records. We never received a response to this letter. Whenever we have asked for help like this from hospitals we have always met a block.

13. In February 2014 I was seen for review at Kings and the letter from this appointment notes, regarding the potential source of infection, GRO-B was treated at age 9 months for brain injury and multiple facial fractures and might receive[d] HBV infected blood products. She has no other risk factors of HBV transmission. Her mother was tested negative for HBV during pregnancy with GRO-B **WITN0671017**. This is confirms I had no other risk factors for HBV and clarifies that my mother had been tested during her pregnancy with me.

14. There is a further issue I would like to include about my treating team at Kings College. I spoke to my nurse about an idea to develop a website and app that would have helped myself and others like me to be able to connect with others like me and share our feelings and create our own community. My mother could have helped with the implementation of the project as this is her business. This would also have been opened up to HCV and HIV infected patients to help reduce the loneliness associated with these diseases. My nurse said she thought it was a great idea but promptly took it and ran with it herself within King's College. Next time we enquired 'how it was going talking with the right people to make this happen', she informed me they were already doing something like that. In fact we later discovered she was running the project, and had taken our idea for her own. The whole idea was that it shouldn't have been owned by a hospital or health authority but to be designed and run by an infected person and their family.

Treatment

15. My medical records contain an information sheet on treatment of HBV with Interferon and Lamivudine which I received in 1999. The information sheet confirms that, 'when hepatitis B is acquired at birth or during the first year of life, the child is likely to continue to carry the virus lifelong, possibly because in very young children the body defence mechanism (the immune system) is still immature and unable to fight the infection.' **WITN067018**. As I grew older and understood more about this virus I recall this was indeed the advice that I was given about my infection, confirming how difficult it would be to clear it.

16. I started treatment for HBV from the age of five and underwent four rounds of treatment. Having now seen my medical records from this time I can confirm the exact details were as follows (records available on request):

    a. Treated with Lamivudine and Interferon between November 1999 and November 2000 (aged five to six years old), 52 weeks, non-responder
    b. Randomised to be treated with Pegylated Interferon between November 2006 and October 2007 (aged 11 to 12 years old) as part of a clinical trial, significant dose reduction due to neutropenia
    c. Lead-in Entecavir and add-on Pegylated Interferon in 2009 (aged 14), pegylated Interferon stopped after 6 doses due to severe neutropenia and continued with Entecavir monotherapy until June 2011 (aged 16)
    d. Tenofovir and Entecavir from 2011 (ongoing 'management' rather than 'cure' treatment).

17. I remain on treatment with Entecavir and Tenofovir. **WITN0671019** is a letter from 2017 from Kings describing my current treatment regime with the plan being, 'to achieve HBV DNA negativity and then continue treatment in combination for at least six months after HDV RNA would be not detected, then there will be potentially possibility to stop Entecavir and continue monotherapy with Tenofovir but as her HBV DNA still remains detected this is currently not the plan so she still needs to continue on combination of both drugs.' I understand from previous conversations with my doctors that in the adult population roughly 20% of those treated long-term with Entecavir had gone on to clear the virus. I do not know whether these figures necessarily apply to me as I have Sub Type D which behaves differently from other types of HBV.

Obstacles to treatment

18. At paragraph 28 of my first witness statement I noted that I was not aware of any obstacles to me accessing treatment. Having now seen my GP records I can see that in fact my GP initially refused to prescribe Interferon to me in 1999 following a request from Kings College Hospital to do so because he had no experience of treating HBV. Kings' responded to explain that they would do any monitoring required, not the GP, and explained that given the GP's refusal to prescribe Interferon I would not receive the treatment (correspondence available on request). I think this must have persuaded my GP he I did go on to receive treatment with Interferon aged five. This is the first I have heard of this and I find it shocking that the GP would deny treatment to me, a five year old girl at that time.

Follow-up

19. I have frequent liver ultrasounds and an ultrasound in 2017 showed a lesion of 26mm, however, this was further investigated and confirmed to be a haemangioma which I am told means it is benign. It is still there now but is harmless and is being monitored.

Any medical complications or conditions which have resulted from HBV infection

20. At paragraph 27 of my first written statement I described how I am often quite anaemic and have low blood sugar. I also described how my consultant at Kings explained there may be a link between my HBV treatment and the development of my PCOS. I can now see from my medical records from 2010 that, in correspondence from Kings to my GP, 'we do note a downwards trend in GRO-B haemoglobin level. We wonder whether this decrease in haemoglobin could be linked to GRO-B history of prolonged menstrual bleeding and we would ask whether it would be possible for you to refer GRO-B for a gynaecological

opinion.' **WITN0671020**. It appears to me that there must be some sort of link between my HBV, its treatment and the difficulties I have subsequently suffered with in terms of menstruation and PCOS. I had an MRI last week and should have the results soon. The hospital isn't sure if my continued treatment has contributed towards my horrific PCOS or even potentially a recent diagnosis of possible endometriosis. We should have the results soon.

Statement of Truth

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

Signed GRO-B

Dated 28 October 2019