Witness Na GRO-B
Statement No.: WITN4542001
Exhibits: **0**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 May 2021.

I GRO-B will say as follows: -

Section 1. Introduction

1. My name i GRO-B My date of birth GRO-B 964 and I reside in Mid Glamorgan. I was born in Cardiff but I have lived in GRO-B since I was 16 years old. I am single and I have a daughter and a granddaughter who live nearby and I am very close to them.

2. I work as a caretaker and as a school escort for disabled children. I really enjoy my work as a school escort and I find it very fulfilling, as I have been able to build good relationships with some of the children that have behavioural difficulties and struggle to connect with others.

3. I intend to speak about my infection with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life.

Section 2. How Infected

4. I gave birth to my daughter on GRO-B 1989 at the GRO-B Hospital in GRO-B this hospital no longer exists. I was in hospital for a few days following her birth but there were no complications.

5. I was told by the nurse looking after me that I needed an Anti-D injection as I have RhD negative blood and my daughter has RhD positive blood. I was not warned of any potential risks or complications associated with this injection and I just thought of it as something I had to have. I went home with my daughter and thought nothing more about it.

6. Over the years, I gradually felt more and more tired and suffered from aches and pains, but I generally put it down working 7 days a week and taking care of my daughter as a single parent. It was only in around early 2011 that I really started suffering from joint pain and swelling in my stomach and I thought I should discuss it with my GP, Dr GRO-B at GRO-B

7. When I described my symptoms to Dr GRO-B he thought I might have rheumatoid arthritis and referred me to have various blood tests. He did not explain what he was testing me for specifically and I thought it was just a test for rheumatoid arthritis.

8. Following this blood test, I received a call from my Dr GRO-B telling me that I had tested positive for HCV. I was absolutely shocked by this as I just could not think how I could have become infected.

9. I was asked to come in for a face to face appointment with Dr GRO-B and he went through the risk factors for HCV with me. However, I had never been an intravenous drug user, I had never been a prostitute and I rarely even drank alcohol. Although I have tattoos, all of my tattoos were done after my daughter was born and were done at proper tattoo studios so this could not be how I contracted HCV. I just could not think how I came to become infected, and it was very upsetting.

10. It was only towards the end of my HCV treatment that my specialist HCV nurse Karrina Mitchell noticed when going through my notes that I had received an Anti-D injection in 1989. She explained that this was the likely source of my HCV infection, given that I had no other risk factors for HCV. She seemed quite confident about this and I was finally able to understand how I had become infected.

11. Looking back, I am able to attribute the tiredness I felt as well as the joint aches and severe bloating to the HCV. I also believe I had suffered brain fog for quite some time before my diagnosis, and this has continued to this day. It is only after my diagnosis that I could really understand why I felt the way I had.

Section 3. Other Infections

12. I was not infected with any other infections apart from HCV. I believe I have been tested for most infections now.

Section 4. Consent

13. I was asked to sign a consent form prior to receiving the Anti-D injection, but the associated risks of infection were not explained to me. I just signed the forms because the nurse asked me to. In those days, you didn't really question the doctors and nurses treating you, and you

trusted that they were acting in your best interest. Looking back, I should have had the risks explained to me before being asked to consent.

14. I was not asked to consent to the HCV test that diagnosed me with the infection. I only find out I had been tested for this when my GP called me with the positive result.

15. I consented to the treatment I later received for HCV and the associated risks and side effects of the treatment were explained to me clearly.

Section 5. Impact

16. Finding out that I had HCV was a real shock and I felt very upset and embarrassed about it. I had thought I might have rheumatoid arthritis, but to find out that the joint pain and bloating I was suffering with was as a result of HCV was shockingly unexpected, and I just had no idea how I could have become infected.

17. When I shared the news with my daughter, she was very upset and cried because she thought I was going to die. She was also very worried about her friends finding out because of the stigma associated with HCV. She did not want to be treated differently as a result. She kept my diagnosis to herself and only really had my mum, her grandmother, to speak to about it. My mum was also very upset, but she was supportive and did more to support my daughter during this time as I was physically unable to.

18. Although my partner at the time stayed with me until after I had completed the course of HCV treatment, he was not very nice or understanding about my situation and it eventually led to the breakdown of our relationship. We had not had issues prior to my HCV diagnosis, and this is what drove him away.

19. After my appointment with my GP, I was referred quite quickly to the Gwent Hospital in Newport for HCV treatment. My GP also advised that my daughter and my partner at the time should get tested for HCV, and this was done at a hospital in Cardiff. Thankfully they both tested negative for HCV.

20. My GP had also advised me about the steps I should take to avoid infecting anyone else with HCV, including preventing others from cleaning up my blood spills and keeping my razors and toothbrushes separately.

21. I received an appointment with the liver unit at Gwent Hospital for HCV treatment in around April 2011. My doctor was Dr Marek Czajkowski but I mainly saw Karina Mitchell who was a specialist HCV nurse. They discussed potential risk factors for my HCV and had difficulty in understanding how I came to be infected in the first place,

22. Dr Czajkowski explained to me that there was a course of HCV treatment available for me to start straight away. He told me that the treatment usually took a year to complete, but it could also be condensed into a 6-month treatment which was more intensive.

23. I was told that the treatment impacted people differently, but the side effects of the treatment could be really unpleasant and I could become quite ill. As I was concerned about the side effects, I opted for the yearlong treatment as I worried about how intense the side effects of the 6-month treatment would be. I was told I could start treatment very soon, although I do remember being told it was very expensive.

24. I started my course of HCV treatment in April 2011, not long after my initial appointment at Gwent Hospital. I just had to have a few further blood tests and some monitoring of my liver before I could start the course of treatment.

25. The HCV treatment consisted of a weekly injection and daily tablets; I cannot recall what they were called. I was shown how to inject myself in my stomach on a few occasions before I started doing them on my own.

26. I have to say that the team at Gwent Hospital that looked after me were absolutely fantastic, and they were extremely supportive throughout my treatment. Karina my HCV nurse was always on call, day or night, to advise me if I was worried about the side effects of the treatment or if I had any questions.

27. Around the time I started the treatment, I was so bloated that I looked about 9 months pregnant. I remember visiting a supermarket on a warm day and being so flustered and hot that a woman in the shop was worried about me being out in the heat, as she thought I was heavily pregnant.

28. I remember being so embarrassed and telling the woman that I wasn't pregnant, and rushing out of the shop. After that, I did not leave the house during my treatment unless I was attending hospital appointments.

29. Not long after I had my first injection, I started to suffer really severe side effects. I felt so sick and I developed such bad mouth ulcers that eating and drinking became almost impossible. I would call Karina to ask if what was happening to me was normal, but she said it was just a side effect of the treatment. I also started having intense shooting pains in my liver. Occasionally I still get these pains which can be triggered by certain foods and carbonated drinks.

30. Before the treatment I was quite a big lady and wore clothes between size 18 and 22, but by the end of the treatment I was wearing age 9 to 10 sized clothes; the weight loss was dramatic. I think I went down to weighing about 60kg, which was very low for me.

31. I had gradually put on weight over the years and been slim when I was younger, but this weight loss was very fast. Despite the weight loss, I still suffered with bloating and my stomach would be distended if I drank any carbonated drinks or ate certain food. I still struggle with bloating to this to this day.

32. While on the treatment, my hair fell out and I lost all of my teeth. I had a lovely set of teeth before starting the treatment and this was so upsetting. I absolutely felt like I couldn't get any lower. I was so tired that I was always either in bed or on the sofa, and I was like this for the entire year I was on the treatment. I was too weak to move and I couldn't even do basic things like cook or clean the house.

33. I also struggled with producing tears and saliva, as the ducts had dried up due to the treatment. I had to take tablets to help with this. It felt like I was taking so many tablets as part of the HCV treatment already, and then on top of that I had to take a lot of additional tablets to deal with all the side effects, including anti-sickness medication.

34. I was too ill to work while on the treatment, and I told my boss that I was seriously ill and would not be able to work for a year. I did not tell them I had HCV due to the associated stigma. He was understanding and I was able to have the time off and return to work once I had completed the treatment.

35. I also suffered a great deal mentally as a result of the treatment. I became very depressed and anxious and had to go on anti-depressants. I still take the anti-depressants, mirtazapine and sertraline now. I felt so down that I became quite suicidal. I kept thinking, why me? I just did not want to be here anymore. I was offered counselling and psychological support by the team at Gwent, and they were supportive of my mental health issues.

36. As I was too unwell to do anything myself, I became very reliant on my mother for support. I was unable to go out and do anything with her or my daughter for the whole year I was on the treatment and as I mentioned above, I would only leave home for doctor's appointments.

37. I started to lose friends because I did not want to tell them what was going on in relation to my HCV diagnosis. I also did not want to meet friends as they would realise how unwell I was and ask questions about what was going on that I could not answer. I have never been able to rekindle a lot of the friendships I lost during this time. I am very much on my own aside from my daughter and granddaughter, as even my mother has now passed away.

38. If my daughter brought friends home I would hide in my bedroom to avoid them, and if they visited unexpectedly, I would turn away and avoid talking to them. If they asked my daughter what was wrong, she would tell them I had the flu, as she didn't want anyone to know about the HCV either.

39. As I mentioned above, towards the end of my treatment Karina saw in my notes that I had received an anti-D injection and was confident that this was the source of my HCV infection. It was nice to finally understand how I had become infected, as I had been so confused about it since my diagnosis. I still have the slip of paper from the hospital confirming I had been given an anti-D injection after my daughter's birth.

40. After completing a year of HCV treatment, I was told it had been successful and I had cleared the HCV. I had to go back regularly for check-ups and still have to be monitored for any liver damage I may have suffered, although less regularly now since I have been clear of HCV for many years.

41. I have been told I have a fatty liver and at my most recent appointment, Karina told me that I have moderate cirrhosis of the liver.

I know that the cirrhosis could develop into liver cancer at any point, and this is something that worries me. I have to be very careful with what I eat and drink to avoid liver pain, and I do not drink alcohol at all anymore.

42. It took a couple of years to recover from the side effects of the treatment. I still suffer from the severe shooting liver pain occasionally, which can be debilitating. I continue to have cramps, swelling as well as forgetfulness and brain fog. I'm not the same person I used to be and don't think I ever will be.

43. The stigma associated with HCV has had a major impact on my life. I have always been so worried about people finding out about my infection and taken steps to prevent this from happening. To this day I am very reluctant to tell anyone about the HCV.

44. When I was having my HCV treatment and needed regular blood tests, it clearly stated that I had HCV on my blood test form so I would always turn it over in order that no one could see it. I would even sit in a different part of the waiting room before I was called into see the HCV doctor or nurse, as I didn't want people to realise what I was waiting for. I was so worried that someone I knew would see me.

45. It is hard to even explain how having HCV mentally affects you. It caused me constant fear, 24hours a day and 7 days a week. I hoped and prayed I wouldn't pass it onto my daughter, and even though I am now clear of HCV, I am still so worried about infecting my daughter or granddaughter.

46. If I cut myself or something my daughter automatically wants to help, but I always tell her to get away from me and not to be near my blood. From when I was first diagnosed, I have always kept my items separately in the bathroom and told my daughter not to touch them.

47. Since the breakdown of my relationship following my HCV diagnosis and treatment, I have not had another relationship and I won't have one in the future. As much as I would have loved to get married and even had more children, I just cannot put myself through explaining the HCV to someone who might not be understanding. The emotional side of things is too difficult to contend.

48. I also have an ongoing fear that I could still infect someone with HCV, despite being clear of it for many years. Knowing I won't have a loving relationship again is difficult, but I have accepted it. I am lucky that I have my daughter for emotional support and she is my best friend. I also love spending time with my granddaughter.

49. I continue to struggle with the brain fog I had even prior to my diagnosis. I have no sense of direction and I struggle to understand and retain basic information, something I did not struggle with when I was young. As a result, I have always taken quite basic jobs which are less skilled and that I know I can cope with, and I feel I have been held back from advancing my career.

50. Although I left school with no education, I would have loved to be able to study further and do some courses but I just could not do that with the brain fog I have suffered. My dream was to become a nurse. If I had been able to get better jobs I would have been able to earn more and have fewer financial struggles. My mum always helped me with buying things for my daughter and treating us to holidays, as this was not something I could afford to do.

Section 6. Treatment/Care/Support

51. I did not face any difficulties in accessing HCV treatment, despite my HCV nurse Karina mentioning it was very expensive. I was treated very quickly and I cannot fault the HCV team who looked after me.

52. However I have faced significant difficulties accessing the dental care I need. The HCV treatment caused significant decay and damage to my teeth, and I needed to have them all removed. When I was trying to find a dentist, I would fill in the relevant forms to sign up as a patient, and I would just not hear from them again. This occurred repeatedly

53. When I would call the dental clinics to find out why I had not heard anything, they would always say that they were not taking on new patients, despite previously having said they were. I strongly believe I was treated this way because I disclosed the HCV on the forms I was completing. Although I do have a dentist now, I had to go to the GRO-B in Cardiff to be treated by the dental students while I was on the HCV treatment.

54. I was offered psychological support and counselling during the time I started HCV medication. The HCV team at Gwent Hospital were helpful and supportive with regards to my mental health concerns.

Section 7. Financial Assistance

55. Once Karina learned about the Anti-D injection being the cause of my HCV infection, she mentioned that I could apply to the Skipton Fund for financial assistance. She told me that she did not know if I would be successful in my claim, but it would be worth a try. She provided me with the Skipton application forms and helped me complete them.

56. After my initial application, the Skipton Fund rejected me on the basis that having an Anti-D injection would not have been the cause of my HCV. However, I also know another woman who had become infected with HCV through an anti-D injection around the same time I became infected, at the same hospital. She got chatting to me and told me she was unwell, and mentioned she had HCV, so I told her about mine,

something I never usually share. She again has no other risk factors for HCV, and it cannot just be a coincidence.

57. I decided to appeal the Skipton Fund application but once again my application was rejected. This was disappointing as the financial assistance would have been really helpful, especially as I was unable to work for a year while on the HCV treatment.

58. I am aware that the Welsh Infected Blood Support Scheme has taken over the role of the Skipton Fund, and I am considering sending in an application for financial assistance to them. I believe it should be acknowledged that women in Wales became infected with HCV through anti-D injections, and should be provided with financial support and compensation.

Section 8. Other Issues

59. Even if I do not receive any financial support or compensation in the future, I hope that providing my statement to the Inquiry helps others who have become infected with HCV through anti-D injections, and that we are acknowledged as a group who were directly impacted by infected blood products.

Statement of Truth

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

Signed GRO-B

Dated 4-9-2021