Witness Name: Joanna Gough
Statement No: WITN4964001
Exhibits: Nil.
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOANNA GOUGH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 November 2019.

I, will say as follows: -

Section 1. Introduction

1. My name is Joanna Gough My date of birth is GRO-C 1968 and I currently reside in South Wales.

2. I live with my husband, Rob and we have been married six years. I don't have any children, however, Rob has two children who are both grown-up.

3. We both work in the financial industry and are self-employed. We offer consultancy work and provide our services to my husband's brother, who owns an E cigarette shop, as well as two other businesses.

4. Before COVID, my husband and I regularly travelled to Portugal for six months of the year. We bought some land there and enjoy escaping the cold Welsh winter. I have recently had a COVID vaccine since I am classed as

clinically vulnerable due to my primary immune deficiency condition. I was diagnosed with this immune condition six years ago.

5. I can confirm I am not legally represented and I am happy for the Inquiry Team to assist with my statement.

Section 2. How Infected

6. In September 1983, at the age of 15, I was admitted to Nevill Hall Hospital in Abergavenny, north Monmouthshire, Wales I believe I was under the care of Mr DRB Jones. I was suffering with abdominal pains which turned out to be a symptom of Hemolytic Uremic Syndrome (HUS). I was subsequently transferred to the renal unit at Cardiff Royal Infirmary, and I believe I was under the care of Dr G A Coles. I spent approximately three weeks in hospital.

7. HUS is a condition that affects the blood and blood vessels. It destroys your blood platelets (needed for clotting), gives you a low red blood count (anaemia), and kidney failure. As a result, my treatment included peritoneal dialysis and given blood transfusions. My hospital notes state that I was given daily two units of fresh frozen plasma and received six units in my first week of hospitalisation. The dialysis helped my kidneys and allowed them to get back to normal. I have a vivid memory of being hooked up to quite a few things whilst I was in hospital. At one point in time I was connected to 5 tubes and needles, a blood transfusion being part of that.

8. I do not recall being transfused again. Following my discharge from Cardiff Royal Infirmary, I again started to experience abdominal pains and sickness and was hospitalised for 5 days at Nevill Hall Hospital. I don't know what the diagnosis was for this visit..

9. A month later, in November 1983, I remember going to my GP again with stomach pains and nausea and generally feeling very ill. He took blood for blood tests and upon receiving my results, my Doctor visited me at home. I

was told that the part of blood that fights infections was dangerously low. I was immediately sent to Nevill Hall hospital as an emergency admission. I wasn't entirely sure what the Doctor meant by his diagnosis, however, I remember AIDS was very much in the news at that time and so his statement caused considerable distress.

10. Whilst I was in hospital, for the third time in 1983, I was under the care of Dr Meirion Evans. My symptoms were abdominal pain, nausea and vomiting green liquid. They investigated and my note state "*LFT's showed a hepatitis picture with mild jaundice and markedly raised liver enzymes*". I also had "*large bilirubin*". The diagnosis was *"? Viral Hepatitis"* They requested tests for both hepatitis A and B and these came back negative. I believe they tested for hepatitis because I was jaundiced and my liver function test results were poor. I now know that Hepatitis C was not routinely tested for until at least 1989 and so it is unlikely it would have been tested for at that time (and there is no record of it having been done). However, I believe the symptoms and the diagnosis make it highly likely, particularly after having had a blood transfusion just two months prior. My medical notes at that time included the question "*Has the patient had previous transfusion*?" This was answered – *Yes.* A further question on the Group of Blood given just shows a "?" against it.

11. Whilst in hospital, I was asked about other possible routes of infection – I remember being asked about drug and sexual activity. This was almost funny at the time as I was an extremely shy teenager who had been in and out of hospital for two months! In my opinion, it seems very likely that they suspected something of a hepatitis nature.

12. Following this and during my recovery, I remember taking pain killers and having repeat liver function tests. They monitored me for about a month or two after my second admission. The jaundice disappeared and the pain was not reoccurring.

Section 3. Other Infections

13. After spending the last four months of 1983 either feeling ill; being in and out of hospital; or recovering, , I was not hospitalised again until June 1986 and was diagnosed with glandular fever.

14. I have suffered with periodic infections since 1985, and was diagnosed with Inflammatory Bowel Disease in my 30's and a Primary Immunodeficiency (PID) in my 40's, as well as feeling fatigued and suffering from 'brain fog' much of the time.

15. As far as I'm aware, I have not acquired any other infections that I may have been exposed to in 1983 when I was transfused.

Section 4. Consent

16. At the time of my hospitalisation in 1983, my parents were with me and were aware of the ins and outs of my treatment, but they do not remember being asked to consent to my treatment: the transfusions or the dialysis. I believe that the consensus at the time was to trust all medical professionals, as it was expected they would do the right thing by their patients. My mother has told me that "we put your life in their hands".

Section 5. Impact

17. I found it difficult having to spend three months in the hospital at the age of 15 as I missed out on a lot. My first hospitalisation was unavoidable. However, when I returned home, I was just getting back on my feet and catching up on schooling only to be hospitalised another two times in a short space of time. This delayed everything getting back to normal and this was

particularly difficult as I had mock 'O levels' in the December. This definitely increased pressure for my exams and I missed out on the socialising side of being a teenager whilst I attempted to catch up on my schoolwork. As a result, I lost contact with many of my friends and I feel it was an important three months in my life to have missed.

18. My mother has also told me that she feels guilty for the neglect of my 13-year-old brother due to both parents having to visit me every day during my hospital stays, as well as looking after me before and after those visits. At the time I was in and out of hospital, both my parents were extremely worried about my chances of survival as I was very ill. It obviously caused additional stress for them when I was readmitted two additional times shortly after my September admission. It was really difficult for them and still causes distress when they look back at that time.

19. It's fair to say that I appeared to have cleared all the hepatic symptoms that I suffered with in 1983. However, I am also aware that Hepatitis C is still a relatively new disease and there as many aspects which are not yet fully understood and it can take years for symptoms to show, so it's at the back of my mind whether I may see the impact in the future, which is an ongoing concern. In addition, it is known that it can affect the digestive system, the immune system etc. - both of which I have issues with. I also often feel fatigued and wake up feeling like I haven't slept and I sometimes have problems with 'brain fog' which affects my confidence in social situations - but assumed that this is 'normal' as everyone goes through periods of tiredness and sometimes struggling to remember the right words

20. Since being diagnosed with PID (specifically Common Variable Immune Deficiency (CVID)), I have to live with having a barely functioning immune system. I understand that the cause of CVID is unknown in at least 80% of affected individuals – with a genetic cause being identified in about 20%. I do not know why I have PID. It is also very hard to know what causes what symptoms – Hepatitis C affects the digestive system, but so does PID!

21. As far as I know, there isn't a definitive way to know if any of these illnesses are in any way related to having potentially contracted Hepatitis C from infected blood in 1983 and I am not trying to blame all my health issues on it. The point is, I just don't know. I therefore find it very frustrating and difficult, to deal with, because I don't have closure. It seems logical to me - based on the medical notes - that I had hepatitis C, whether it is linked to my current health or not, but it feels like I am trying to find answers that aren't available to me.

22. As part of my treatment plan for PID, I have to infuse immunoglobulin every 3 weeks for the rest of my life. This obviously has a considerable impact on me.. Psychologically, I have to trust that the process for collecting the immunoglobulins from thousands of people, is more reliable than it was when I received the blood transfusions in 1983! At the beginning, I had to travel to a hospital in Cardiff to receive the treatment, which took up 3-4 hours each time. We were given the choice to continue with these 3-weekly hospital visits or for my husband to be trained up to administer it at home. We chose the latter and my husband and I endured this trip three or four times for him to be trained up to do so. Once my husband was trained to infuse me, it gave us the freedom to deal with this life-long condition at home. They visit us periodically to check we are doing this properly.

23. As a result of my condition, I am more susceptible to infection and specific types of cancer. The infusions only address one deficiency in my immune system, as such it doesn't protect me from everything. Since COVID, I've had to shield in order to keep myself safe.

24. Before my diagnosis in 2014 at the age of 36, I had suffered with periodic infections since the age of 17 and had generally learnt to deal with them. It affected my working life at one point, but you just get on with things as best you can. I recall one occasion when I was suffering with an infection and due to attend a meeting. I was in considerable pain and needed to go home and I remember getting upset and embarrassed telling my boss this. This didn't happen often and most of the time, I could grin and bear it. Despite this, my

employer was fine about it. On the whole, I didn't feel I was held back by infections as I adapted and did my best to get on with it.

25. In December 2014 when I was diagnosed with PID, I was already self-employed, so luckily there was not the added pressure of having an employer to deal with. However, it did impact mine and my husband's life. We were due to get married in April 2015 and we sold our house as we planned to go travelling. Since the initial treatment consisted of infusions at three weekly intervals to be administered at hospital, my immediate thought was that we had to change our whole life plans which was incredibly stressful for me, particularly as it was just a few months before out wedding and moving out date.

26. The three weekly infusions act as a reminder of my illness and the limitations it imposes on my life. We, as a couple, have made an effort to not let it affect our lives too much. Rob is very easy going and just gets on with it. This makes it easier for me.

27. For my 50th birthday, my husband and I planned to travel to 50 countries to raise awareness for PID and fundraise money. We had to check with the embassy in each country about whether we could bring blood products and needles through customs. I need to know that every three weeks, wherever we are and whatever were doing, that we will be able to do my infusions.. There is therefore a significant amount of consideration whenever we want to travel.

28. When my husband administers the immunoglobulin treatment, I sometimes experience discomfort, swelling, and itchiness. It doesn't have many other side effects for me, but these can go on for a couple of hours following the infusion.

29. I also have to take prophylactic antibiotics daily, to prevent infections.

30. I hadn't really considered my present diagnosis could be associated with past illness, but now it does seem a possibility. I have never really received a

definitive answer as to whether my PID is hereditary or if there is another explanation, as my Immunologist very much concentrates on my treatment and current state of health. GRO-C GRO-C GRO-C I have researched PID and the overarching diagnosis is that it is sometimes a hereditary condition, but the rest is unknown, it is a very rare disease.

31. I have recently spoken to the immunologist about whether I can be tested for hepatitis C now, as I thought this may give me closure either way about whether I contracted it in 1983, but unfortunately, I am told I cannot. He explained that the response of my antibodies to a virus and the constant infusions with other people's antibodies would make the result unreliable. I will therefore never know conclusively, if I had hepatitis C or if I have it. This is hard for me as I can never make a statement to that effect and this will obviously affect any claims to the organisations set up to help those contracting it through infected blood.

32. As far as I am aware, the current state of my liver is ok. The immunologist monitors it as part of my 6-monthly blood tests and I have not been made aware of any scarring.

Section 6. Treatment/Care/Support

33. Although I have suffered with periodic infections since I was 17, in my early 40's I suffered a year of almost constant infections and was just continuously prescribed antibiotics. In the end, I decided to seek advice from a private consultant. They asked about my medical history and in particular whether I had had regular blood tests in respect of the kidney failure in 1983. I explained I had not been reviewed regularly since the few follow-up appointments in 1983. The consultant wrote to my GP recommending that I should have blood tests at least annually. It was only then, as a result of repeat blood tests because they picked up something was not right – initially indicated there may be an issue with my liver or kidneys, that my GP

referred me to a Haemotologist and subsequently to the Immunology Consultant. This was in the summer of 2014.

34. I was referred to an immunologist, Dr Stephen Jolles at the University Hospital Wales, Cardiff. He requested various vaccine tests to review my antibodies' reaction to them and in December 2014, he explained the diagnosis of PID. He explained it was a serious rare disease and what treatment I would require.

35. The Nurses that work with my Immunologist are brilliant and are now like friends to me. I feel as if I can get in contact with them regarding any worries or concerns. Stephen Jolles is also brilliant. I cannot fault the specialist Immunology team. One of the Nurses is called Emily Carne, again, she is brilliant. She was very supportive of mine and my husband's travel plans. The whole team emphasises that treatment should be planned around my life. I believe their attitude has helped us get on with things and achieve our goals.

36. Since I was never diagnosed with hepatitis C, I have never had any issues with access to other treatment.

Section 7. Financial Assistance

37. My mother informed me about the Skipton fund after listening to something on the radio and linking this to my hospitalisation after having blood transfusions. I made the initial application in March 2015 and had not seen my GP's input. I was only made aware of what he had written upon rejection in May 2015: *"Admitted to Nevill Hall Hospital Abergavenny 13/10/93 to 18/10/83 with Haemolytic Uraemic Syndrome. She had blood transfusion. 17/11/1983 to 24/11/183 admitted to Nevill Hall Hospital with viral hepatitis: No record of Hepatitis B or C mentioned".*

38. Prior to this, I had no consultation with the Doctor to discuss my case. It seems I was rejected on the basis that "*it appears that you do not have, and it is unclear if you have ever had hepatitis C*".

39. Upon finding out I was unsuccessful in my application, I took no further action. I felt that the decision was unjust GRO-D

GRO-D

GRO-D I didn't feel I could appeal as I felt I would have no support to do so and had no way of proving I had contracted Hepatitis C. GRO-D

GRO-D

With hindsight, I should have appealed, as I could prove with the medical records I had obtained that I was actually tested for both Hepatitis A and B. Hepatitis C was not tested for at that time, otherwise I'm sure they would have tested for that too.

40. I do not think the statement that in my medical records that "LFT's showed a hepatitic picture with mild jaundice and markedly raised liver enzymes" as well as 'large bilirubin" was properly considered in my application. I understand that they could not test for hepatitis C at the time and I cannot be tested now due to the likelihood of an unreliable result. So, how would I ever have proved my infection with hepatitis C? I thought the purpose of the Skipton Fund was to address the issue of the NHS giving patients infected blood products – in particular - those who contracted the virus prior to 1991. However the approach of Skipton feels like a massive contradiction - and certainly doesn't make sense to me - as it doesn't take into account Hepatitis C wasn't routinely tested for until the late 80's/early 90's.

41. I was disappointed in the application process ~~of~~ to the Skipton Fund and subsequently was prompted by my mother to look into it again. I found out that this Scheme had been replaced by the Welsh Infected Blood Support Scheme. I decided against submitting an application in the first instance, but

opted to send an email and explained my situation. They acknowledged the difficulties I raised in obtaining medical records and gaining a medical opinion after such a long period of time. They didn't address the issue that hepatitis C could not be tested for in 1983. They focussed on the need for evidence that I had 'chronic' hepatitis – i.e. an infection lasting more than 6 months. They forwarded my emails to two independent medical professionals for their comments. In response to my medical notes that "LFT's showed a hepatitic picture with mild jaundice and markedly raised liver enzymes" and the diagnosis of "? Viral Hepatitis", they said there was potential that I cleared the infection during the acute phase (first 6 months) without the need for treatment. They stated that the evidence generally accepted by the specialist medical community is that up to one third of patients infected with the virus will clear it spontaneously, without any treatment. I was therefore advised that my application had little chance of being successful. So they did not say I didn't appear to have had Hepatitis C – just that it wasn't 'chronic'.

42. This disappointed me greatly, particularly as the Hepatitis C Trust contradicts these findings, which refers to a lower figure of only around 20% of people clearing the virus spontaneously. The Hepatitis Trust also makes it clear that it is a relatively new disease for which many aspects of it are yet to be fully understood. It also states that "*the course of chronic hepatitis C infection is extremely varied and unpredictable. Some people experience very few symptoms for as long as a decade*". So, how can the WIBSS be so certain none of my subsequent medical issues were related in some way? However, again, I felt I would have no support in continuing with an application, so did not proceed.

43. I found in both instances the onus was on me to prove – what I feel is - the impossible. I am usually rather stubborn, but I think considering the purpose of these two organisations, there should have been more support, or at least more consideration of the likelihood of claims like mine. It felt like I was trying to make a claim against an insurance company; I had to prove everything; and they would avoid payment at any stage.

44. I appears to me that to succeed in any application, I would need the assistance of a clinician. I feel it is extremely unlikely I would be successful in getting any medical professional to comment with any certainty, on what happened 37 years ago and what, if any, impact it has had on my medical issues to date. In any case, it certainly feels like I would hit a brick wall. Given the difficulties with such a task, I believe they could provide more support to applicants in how to approach dealing with this – to achieve, what I understand they were set up to do.

Section 8. Other Issues

45. I wouldn't say I had ever experienced stigma of any kind. Although, as mentioned earlier, I have tried to raise awareness of PID. Because I appear the same as everybody else, nobody thinks there is anything wrong with me and so getting any appreciation or understanding about my issues is very difficult. I have the constant knowledge that I am more susceptible to getting infections and some types of cancer, but during my fund and awareness raising for PID, in response to the seriousness of it a friend actually made the comment to me – "well, it isn't cancer, is it?!" I found this extremely upsetting at the time.

46. Over the years, the infected blood issue from the 80's has become common knowledge. It is extremely upsetting to know that so many families have been affected by this – to a much greater degree than I have. The further knowledge that this appears to have happened against the advice of the WHO and the whole "scandal" that has followed, makes it so much harder to accept. Making those potentially affected by this negligence "jump through hoops" I feel just adds insult to injury.

47. My final comment would be to reiterate that the difficulty for me is the 'not knowing' – in terms of whether I contracted Hepatitis C or not – if so, was it acute or chronic and then whether it is related in any way to my current

health issues and whether I may be affected in the future. What I do know is that I definitely had a blood transfusion in Cardiff in 1983. I also know that I went to hospital two months later as an emergency admission and my medical notes state that "LFT's showed a hepatitic picture with mild jaundice and markedly raised liver enzymes" with "large bilirubin" with a diagnosis of "? Viral Hepatitis" which wasn't A or B. Proving anything beyond this is unfortunately, unlikely. I remain frustrated that two funds set up to support those affected by infected blood did not seem to accept that I may be eligible.

Statement of Truth

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

Signed GRO-C

Dated 21st february 2021