Witness Name: David Thomas
Statement No: WITN2562001
Dated: 26th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DAVID THOMAS

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 13th November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, David Thomas, will say as follows:-

1. Introduction

1. My name is David Thomas. My date of birth and address are known to the Inquiry.

2. I would confirm that I was diagnosed with haemophilia A as a child. Haemophilia is a genetic disorder so there was always a reasonable chance that it was likely to be the case that I would suffer with haemophilia. My mother and all of the family were alert to that during the pregnancy. GRO-C GRO-C GRO-C

2. How Infected

1. I would confirm that during my childhood years I had some cause to visit hospitals and in particular would have to attend for example when my baby teeth were removed. I have memories as a child of recalling that the loss of teeth was quite a miserable time.

2. Sometimes if it was a very small tooth I might be able to get away without attending hospital however if a molar had to be removed I would have to attend hospital for that to be done and my treatment records for that period make regular reference to cryoprecipitate.

3. I had a haematoma on the brain when I was 9 years old and therefore was always very concerned about any injury to my head. Cryoprecipitate to explain was a treatment where plasma was frozen and thawed and a rich source of factor 8 was left which became known as cryoprecipitate. The cryoprecipitate would be injected with a very large syringe and I recall that it would take the Nurse about three quarters of an hour or so to carry out a full administration.

4. My memory is of nurses having a bag of plasma and having to squeeze and roll that bag of plasma to get the material into the syringe. I recall that factor 8 subsequently became easier to administer when different blood products were used. I wonder whether commercial factors were a driving force in the move to factor 8 concentrates, due to the reduced time it took to administer the product.

5. I never had to receive injections of clotting agents on a prophylactic basis. I would only ever be injected on a reactionary basis. I can recall that I had a hip bleed when I was approximately 13 or 14 years old and also a nose bleed the following year which I will come back to. I would normally only attend hospital perhaps once a year. As indicated my treatment was always reactive rather than prophylactic as I was regarded as being at the lower end of the

haemophilia scale and was given a 10% clotting factor. I would attend the Haemophilia Centre at the University Hospital Wales ('UHW').

6. In addition to the spontaneous hip bleed I had a nose bleed approximately a year later. I can recall at that point that I was exposed to the factor 8 concentrate, this was after a school disco around the year 1983/ 1984 when I found I couldn't walk after getting out of my friend's parents car. I went to hospital and simply let them get on with it. I knew that it was different as at the UHW Haemophilia Centre they would withdraw the material from one bottle to another and would inject saline into a dry concentrate. I can remember that they would have to warm it up and they would actually ask me to roll it between my hands for five minutes or so and they would inject. I can remember that it would have been approximately the summer of 1985 as I remember a song by the Colour Fields called Thinking of You which was in the chart at the time.

7. I recall that I had a bump playing football. As a result, I had a nose bleed that recurred for three weeks involving three visits to the hospital. During the first two visits I received factor 8 having attended the Haemophilia Centre at UHW. On the third visit, the doctor decided the wound needed to be cauterised and no treatment was needed.

8. I also recall other incidents where I had a bleed in my foot after going to a concert and a festival and then a bleed in my knee in approximately 1987. When I was in Cardiff on my 18th birthday I was assaulted, beaten up and subsequently admitted to UHW. Again I must have had factor 8 blood products then as well. When I was a little older I went to Sheffield University. I graduated from Sheffield in 1993.

9. When I came back to Cardiff at the age of 22, my Mum was aware of GRO-C GRO-C. She said that I should go and get tested. That prompted me to go and be formally tested for Hepatitis C. I confirm that at that point I had no symptoms and no issues at all. I can recall going for blood tests and going to get those results.

10. I was formally diagnosed with Hepatitis C in 1994. I cannot recall who informed me about that but I believe it must have been a specialist. I believe it was in that period around 1984 that I was actually infected with Hepatitis C from the blood products. However my hospital records do not document this as they're conveniently missing. This is something that alarms me as my diagnosis has completely changed my life.

11. In terms of what I was told then I would indicate at that point I felt very well and was asymptomatic. My liver function tests were raised and I would confirm that it was certainly never spelt out to me what it meant to have Hepatitis C.

3. Other infections

1. As far as I am aware, the only infection I had contracted around this time was hepatitis C. Although I did receive a letter from UHW informing me that I had previously received Factor 8 from a donor who had gone on to develop and later die from variant CJD.

4. Consent

1. In 1983/84 when I was admitted after being unable to walk from my friend's car. I don't recall any discussion taking place regarding the fact that it was a new treatment or the nature of it or any risks or anything of that nature. I would say that there was at least 50% less fluid injected, by comparison with Cryoprecipitate.

2. As indicated there was no discussion at all about any risks that may be involved or any information about the nature of the change of treatment. I am certain that I would not have given consent nor did I have any knowledge of the nature of the testing that was carried out in Sheffield. I then came back to Cardiff and returned home. I would confirm that the liver problem I had was

still managed within the haemophilia clinics and I almost felt as if there was a bit of cover up to some extent in terms of the effects of it. Haemophiliacs were already dying from liver failure and advanced liver disease was becoming common place for many haemophiliacs.

3. I feel that there was greater knowledge out there at that point which wasn't shared. I continued to be treated with Factor 8 and I recall that there was a match up so I was treated with the same batch. In effect therefore I was effectively continually re-exposed to the Hepatitis C virus.

4. My feeling in hindsight is almost that they were continuing with Factor 8 because there had been so much of the product bought that they had very little option but to continue to use the stocks that they had. Again, patient safety took second place to commercial interests.

5. The Government were reluctant to spend money on new stocks. I felt like I was being re-infected over and over as they kept using the same batch of contaminated product.

5. Impact

1. I can recall being very shocked of my diagnosis of Hepatitis C. This would have been in 1994. I can recall going there on my own, being told that I have Hepatitis C and coming out being very shocked. In fact, I remember as I walked out of the clinic I saw a school friend of mine who was an engineer working on the two storey car park situated there. He actually made a comment that I looked as if I had seen a ghost.

2. My view looking back on that moment was that the seriousness of my diagnosis was very much under played. My feeling now looking back on it is that they should have been far more open about the effects of Hepatitis C and should have talked about lifestyle choices that I could and probably should have made at that point.

3. At that time I was aged 23, I had a good social lifestyle having just come back from University. I would drink on a Friday and Saturday with mates on a social basis but other than that wouldn't regard myself as a very heavy drinker. If it had been explained to me the effects of alcohol on the liver and the effects of Hepatitis C then I could have made different lifestyle choices and abstained.

4. I have now had the chance to examine my medical records and what is disturbing is that the notes within these records allude to the fact that health professionals were aware that I was potentially suffering with undiagnosed Hepatitis C before January 1994. In fact, now having received my medical notes from the Royal Hallamshire Hospital, Sheffield. It is now apparent that my HCV infection was known as early as 1990.

5. The reason for me saying this is that within the records I have seen correspondence which alludes to abnormal liver function tests and Hepatitis C is mentioned. I confirm however that I was absolutely unaware of that. That letter I am referring to I believe was in 1991 and was a letter from Royal Hallam hospital to Professor Bloom.

6. There were certainly no discussions with me at that stage about having Hepatitis C. I remember them saying to me at that time that my liver function test was slightly elevated. I remember them saying that I should consume alcohol moderately. Certainly, in hindsight I very much wish I had been told.

7. During that time, there was also the whole stigma of the Hepatitis C virus. This was in the days post HIV but it was a blood borne virus transmitted by the prostitutes, drug addicts etc, and I think there was always a feeling that there was a stigma attached to it.

8. I can recall telling my Mum that I had Hepatitis C for example. Her view was to tell no-one and to keep it to us as a family. Probably from the time of diagnosis up until 2010 it was very much kept under wraps and there was less publicity probably about it until the HIV situation and I could almost put it to the back of my mind. I also tend to be glass half full person and therefore I obviously felt there may be a way back from it.

9. I would like to state that that GRO-C were also infected with Hepatitis C. As the time moved on GRO-C health deteriorated and whilst mine remained reasonably good I could not help but look at them and the symptoms that they were suffering and it felt almost as if I had been given a death sentence knowing how GRO-C was and how the disease was increasing in severity. I was aware that there were haemophiliacs already dying of liver disease and I really feel that more information should have been provided and I really feel in hindsight that there was a reluctance to do so..

10. The turning point for me came in November of 2009 I had a liver biopsy and had the results in 2010. I put off the liver biopsy a number of times as it was risky because of the haemophilia and I had to sign a disclaimer acknowledging the risk of death as a result of the biopsy. I did eventually have the liver biopsy as I say in November 2009. That biopsy indicated that contrary to all the medical analysis up until that point I was found to be chronically infected and I was diagnosed with stage four of six liver fibrosis. This is the preceding stage to cirrhosis of the liver.

11. This came as a huge surprise in terms of diagnosis but also a massive shock to me and to my wife. At that point I had a two year old daughter and an eleven month old son. I gave up alcohol completely and didn't drink for some seven years. I also at that point looked at everything possible to help with the liver and liver function, for example walnuts, coffee, green tea, blueberries and was basically trying everything that was recommended on the internet.

12. I started attending the gym and underwent personal training to lose weight as this is also beneficial to liver health. I also had very serious discussions with my wife regarding our lifestyle and regarding our future plans. I then began my third round of a treatment known as Interferon. Amazingly, in terms of work I only ever missed five days of work when I was receiving the Interferon treatment. We had two children but we had always planned to have a third. However I felt that it was not right to do that because of the uncertainty of my health and long term position that never happened.

13. Then, whilst undergoing a round of Interferon treatment in 2010, I found out that GRO-C Leigh died and I really struggled with that. I struggled of course with Leigh having died but also the thought that I may eventually have the same outcome and that had a significant effect on my mental health. I became depressed and reclusive. As with the previous two attempts, the combination therapy of Interferon and Ribavirin failed at three months and the course of treatment was discontinued. Whilst on this treatment, I was also being administered a cocktail of other drugs. The drugs included Epo to combat my anaemia, Citalopram to keep my depression in check and Zoplicone to help with my insomnia.

14. In 2015, I began to suffer with insomnia. This was a result of a drug I had been taking made by AbbVie to help with my Hepatitis C. I have looked at various sleep specialists but there is no help available on the NHS at all. I have had hypnotherapy type treatment and for the last two years I have been on Mirtazapine. This is a mild anti-depressant but the side effect of it is it helps with insomnia.

15. I was prescribed Zoplicone to counteract the insomnia. I have read about the drug since and know that it is a drug almost of reducing benefits. In effect the longer you take it the less effect the drug has. For the last two years I have been prescribed 'Mirtazipine' a mild anti-depressant to help with my insomnia that still persists.

16. I was told to take the drug Zoplicone a maximum of four times per week at a dose of 7.5 mg. When I wasn't taking it I was not sleeping on those nights and therefore I halved the tablet but took it for seven days per week. However my body got used to the tablet and I would wake up in the night expecting the drug.

17. I was therefore awake from 1 am most nights and would get barely any sleep. It was so bad in fact that I actually commented to my wife that I would almost rather swap the Hepatitis C for the insomnia, it was absolutely that bad. I am

still taking the Mirtazapine at this stage but I hope to be able to gradually reduce it.

18. All of this has had a huge effect on my wife. My children were probably too young to appreciate at that point. However now they see me quite regularly on TV and I have always been concerned about the ignorance of others around my children. For example I am concerned about parents who may feel there is a risk of cross infection, I never wanted my children to be stigmatised.

19. I have hinted earlier in this statement at the fact that I changed my lifestyle and lost considerable weight. In the immediate aftermath of the diagnosis of cirrhosis in 2010 I comfort ate and became a binge eater and put three stone on. I have lost that weight now and am back down to 12 ½ stone and that undoubtedly helped to arrest the development together with exercise.

6. Treatment/Care Support

1. Physically I was and am quite active and fortunately for a very large period of time the actual Hepatitis C virus did not have a large physical effect and impact upon me. However, I did have three courses of Interferon treatment.

2. My first course was in 1995/1996 called Interferon Alpha/ Ribavirin. I then repeated that in 2003 and had a further course in 2010. The two later courses were both Pegylated Interferon combined with Ribavirin.

3. With the Interferon, the treatment for my Hepatitis C, I would have to inject it into my stomach three times a week and then would take six tablets of Ribavirin. The second time the Pegylated Interferon was reduced to once a week.

4. The treatment is one where you are treated for three months or so. You then have a PCR test and if the treatment appears to be working then you are placed back onto the Interferon. GRO-C initially had some successful

therapy with it but every time that I had did it, at three months the PCR results showed some reductions but not sufficient to allow the treatment to continue.

5. I did suffer considerable problems during that period of treatment. For example, I became anaemic within a week of starting the treatment. I also suffered with nausea. This is something that was common to all of the treatments but in 2010 it became almost unbearable and I had 24 hour nausea, for the twelve weeks of treatment.

6. I can recall going to bed feeling sick, waking up feeling sick and feeling like that all the way through the day. As well as receiving the Interferon then there would also be a cocktail of other drugs which were administered to attempt to counter the anaemia. On the second and third round of treatment, I would have to inject into my stomach with EPO as well to stimulate the red blood cell count.

7. GRO-C also deteriorated in terms of health and was on the waiting list for a liver transplant. My cousin told me what I should do in terms of looking at MRI and a triple phased CT scan. I began to look at that. Before dealing with that then in 2011 a fibro scanner was bought by UHW. Basically, this is a sonic wave gun which administers waves and measures the bounce back of the sonic wave, which then gives a liver score.

8. I can recall after the last Interferon treatment Leigh talking to me about having proper analysis on the liver by way of MRI and a triple phased CT scan. He had also been to Harley Street. I can recall after the last round of Interferon I spoke with my liver Consultant Dr Godkin and also my Consultant Haematologist. I recall that Dr Godkin was a lecturer at Cardiff University and also a Consultant at the Hospital. I indicated to him that I had looked at potential treatment options including a tablet which was at that point available in the USA, the tablet had a 90% success rate. I was told by Dr Godkin in no uncertain terms that there was a less than 1% chance of clearing the Hepatitis C. His view was that there were no other treatments available and the position

was not going to change. I suggested the MRI and the triple phased CT scan and I was told in no uncertain terms that he would not authorise that.

9. At that point I felt frankly pissed off and thoroughly depressed. I felt as if I had been given the condition by the NHS yet they were not prepared to help. I was also still anaemic and I was on anti-depressants following the Interferon treatment and the death of my cousin Leigh. I can recall being very upset after that appointment and I went straight afterwards to the haemophiliac centre.

10. The Haemophilia Centre at UHW was very much a place of peace and reassurance and I can recall talking to the Consultant Dr Raz and he actually approved the CT and MRI scan for me. That gave me some more peace of mind. I felt that really my treatment had been bungled for a year and now they were not doing anything to help, so the fact that I was referred at that point did give a little reassurance and peace of mind. I had much more detailed scans carried out and fortunately it was confirmed that there was no carcinoma on the liver.

11. Over this period I have indicated that I changed my lifestyle. I did not drink, I lost weight and reduced body fat but was also living with the thought about what the future holds, how long would I survive and that was always there with me. I think it is also fair to say that I underestimated the impact that it had on my wife and family at that time.

12. I felt that potentially I wasn't going to be around to see my children grow up. Throughout this period of course GRO-C very much a reference point. In addition to Leigh, GRO-C who died in 2010, GRO-C GRO-C

13. I could see the situation I was in. Even though I was improving I was still comparing myself with GRO-C I kept looking for treatments during this time and I got to the situation where I actually was beginning to raise money to raise £50,000.00 or so for the treatment that was available in America. This included a meeting with work to discuss fundraising options.

14. I can recall a conversation I had with GRO-C about the drug and I was very serious about raising money to get the money to buy it. Amazingly, I was contacted to ask would I be prepared to be part of a clinical trial for the drug produced by AbbVie. I explored via a number of contacts that I had about the treatment. I had contact with a Hepatitis C Consultant in London and his view that the treatment they had offered was in fact very similar to the American treatment and although there were more tablets to take and his view was that I should absolutely bite their hand off.

15. As a result, I did accept and I was luckily admitted to the clinical trial project. I think they had sufficient funding for 50 patients and I was fortunate enough to be one of those chosen. I was accepted by the Blood Borne Virus Group at UHW in December 2014 and the treatment started in January 2015. I had to take a number of tablets per day.

16. It was a three month course and I had a PCR test after four weeks. There was then a two week delay waiting for the test results and amazingly at six weeks I was told that effectively the virus had gone. My first liver function test showed that the levels had fallen to normal levels. I had to go back onto the treatment to finish it but I went back on knowing that the virus had been cleared.

17. I got to three months, had another PCR test, then to twelve months I had another PCR test and was told that I was regarded as a sustained virological response. In effect I was cured of the Hepatitis C. I can recall when the news came through on the initial six week test. I was in work. I had asked the Nurse to text me so I could go somewhere quiet to ring her but I hadn't been looking at my phone as I was busy in work and the Nurse actually rang me on the landline to tell me I was cured. I can remember putting the phone down and work told me to go home. I can remember that I drove 30 minutes home and just cried for the whole journey I was extremely emotional in terms of being very tearful, crying and upset for hours afterwards. It was almost as if all

the relief had come out and I hadn't probably until that point appreciated how the thirty years or so it had affected me.

18. In terms of my current position, I am pretty much back to normal. I had my first pint of lager on my birthday in 2016 and I allow myself to have a few beers on a Friday with friends if there is something going on. I don't drink in the week. I was discharged from Singleton Liver Clinic formally in June of 2017. I am now back under the combined haemophilia/ Hepatitis C clinic and have the occasional ultrasound.

19. Throughout the period the thought of the fact that the liver can regenerate always kept me going and I always clung to that and the possibility of reversing and therefore recovering. Since then I have become involved with the Blood Borne Virus Group to try and elevate the profile of Hepatitis C and I have helped in a peer support group for those with Hepatitis C because I feel incredibly lucky to have survived and wanted to give something back.

7. <u>Financial Assistance</u>

1. I can confirm that I had a payment of £20,000.00 about 2005 approximately from the Skipton fund. It was never really explained what that was for and why it was made however I know that I received it under the Skipton fund stage 1.

2. I was offered some counselling and psychological help probably in the late 1990's but I never took that up as I felt at that point I was quite efficient in dealing with it and packing it away in my brain. I have also done lots of lobbying via haemophilia work and their use of these blood products.

8. <u>Other Issues</u>

1. Whilst I am talking about medical records, I have seen my medical records and I am extremely concerned to note that within those records there is a gap between 1983 and 1988.

2. What is concerning is that the gap is not separate pages of notes missing but instead an entry in 1983 and then an entry on the next line in 1988 which seems extremely strange to me. I believe the missing medical notes could have been an intentional act. I am horrified that these records cannot be found. I find it distressing and very suspicious. It makes me think that a cover up has taken place.

Statement of Truth

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

Signed GRO-C

Dated 26/02/2019