

Witness Name: Peter Brierly

Statement No: WITN1105001

Exhibits: 0

Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PETER BRIERLY

I, Peter Brierly, will say as follows:-

Section 1. Introduction

1. My full name is Peter Henry Brierly. I was born on GRO-C 1965 and I live at GRO-C
GRO-C Suffolk GRO-C.
2. I was infected with the Hepatitis C Virus (HCV) through contaminated blood products, but I was unaware of it for something in the region of 25 to 35 years. I have suffered with a number of complex health complications through HCV and HCV treatment. I now suffer with a very serious condition Immune Thrombocytopenic Purpura (ITP) caused by HCV, the HCV treatment or a combination of the two.
3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I have Haemophilia B (also known as Christmas Disease), diagnosed in 1971 or 1972. My parents were told that I had a clotting factor of 2.7%, classified as (moderate to) severe.
5. I was treated with plasma and cryoprecipitate for the first few years. I then moved on to Factor IX (FIX) concentrate. I remember FIX concentrate being introduced from in or around the mid-1970s. There was a massive push for people to go on to home treatment. I didn't take to learning to self-administer it. I remember falling off a stool whilst trying to find a vein. I was under the care of the Haematology Department at the Norwich and Norfolk University Hospital. I had most of my treatment there between 1975 and 1985. My consultants were John Leslie and Alec Black.
6. My parents were not provided with any information beforehand about the risk of being exposed to infection from blood products. They trusted the doctors to do what was best for me. I do not believe that there were any concerns in relation to the blood products in my younger years. My mother was heavily involved with the local Norwich Haemophilia Society. She held a number of positions with the Society to include Secretary and then Chairman.
7. From in or around the early to mid-1980s (I was going through puberty) my mother (Mum) appeared to have a sudden change in mind-set and wanted me to try anything but FIX concentrate treatment. We didn't have an explicit conversation, but I could tell that something worrying was on her mind. I have three sisters. My eldest sister remembers Mum crying whilst weeding the garden. That was very unusual because she was of a staunch character and she never openly cried. My sister too knew that our Mum's distress was something to do with haemophilia. I believe that she had heard that something might be wrong with the treatment.

8. Taking Mum's cue, I avoided treatment as much as possible. Unbeknown to me, my clotting factor was improving in any event and the bleeds were less of an issue than they had been previously.
9. By in or around 1987 or 1988, I hadn't needed any treatment for a few years. At aged 22 I then went into hospital for a gallbladder operation and, without warning, Dr Black turned up at the foot of my bed with an armful of treatment, syringes and the like. He said: 'Hello Peter, this is your first lot of Factor IX' to which I replied 'No, I don't want it.' On that occasion, the hospital staff actually held me down in the bed to inject me with the FIX concentrate, despite my heavy objections.
10. The medics ran blood tests during my hospital admission, and it was then discovered that I had a clotting factor of 33% (no further treatment needed except for major surgery). They couldn't believe that the reading was right as this was only ever known to have happened once previously for the clotting factor to right itself spontaneously. My case was written up in the Lancet under the name 'Haemophilia B Norwich'. The previous case was known as 'Haemophilia B Leyden' after the name of the City in Holland. I made a conscious decision not to have any contact with the Haemophilia Department after that. I thought my haemophilia issues were behind me.
11. Out of the blue in 2009, I received a letter detailing that I had an appointment with the haematology department. I hadn't seen them in over 20 years, so it seemed very strange to me and I thought they had made a mistake. I called them and asked what it was about to be told that it couldn't be discussed by phone but that it was in my best interest to attend. Before the appointment, I went to my GP surgery and asked the Receptionist about the matter. She looked into it, and she said she thought it might be something to do with HCV. I was convinced that that could not be right as I hadn't had a blood test for years. In retrospect I have no doubt at all that the hospital haematology department were already fully aware of my HCV positive status.

12. I attended the appointment which was set around a month after receiving the letter. Dr Hamish Lyall, the consultant haematologist, took me into a tiny room and said, 'Right, cut to the chase, we believe there is a high chance you were infected with some nasties when we treated you years ago'

13. Dr Lyall went on to say that the department had bought blood products in from abroad and a lot of people had been infected with HIV and hepatitis. He said that whilst he wouldn't want to speculate about it, I may very well have been one of them. It came as a huge shock and I pretty much blew up at him. I asked why I had been kept in the dark for over 20 years and he said that 'I had somehow slipped through the net and that I should have been tested long ago'. All of this was so out the blue that I agreed to the test he suggested. I thought that if I had something like HIV for example, I would have known it. I thought 'not me surely'.

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14. What came as an even bigger shock to me was the manner in which I was subsequently given the HCV positive test result. I wasn't told face to face. I didn't even get a phone call. About four weeks after the test and without any prior warning, I received a letter to the effect, 'following your tests we can confirm that you have tested positive for HCV. You will now be contacted by a liver specialist in due time.'

15. I was not given adequate information to help me understand and manage the infection. In fact, I wasn't given any information or advice about the infection. I searched on Google to see what HCV was all about. Google immediately threw up the various stages of HCV: liver fibrosis, liver cirrhosis, cancer and death. It dawned on me (later confirmed) that I had up until then had HCV for up to 35 years. I convinced myself that that was it for me and I was going to die. From then, I had to wait at least a month or two for a letter inviting me to an appointment to see a liver specialist. That was scheduled for yet another month. Mentally it was like a knife in the back. It was terrifying!

16. I do believe that the diagnoses and information should have been provided to me much earlier. I would have expected the clinicians to inform me as soon as they suspected that blood products given to patients were causing infections. Dr Lyall even said that all the other patients had been contacted, yet I had slipped through the net. I was gobsmacked to hear this. It was far more likely that they hadn't even tried me. I wasn't hard to find. I had always lived within 20 miles of Norwich. I was under the same GP (whom I had seen for hay fever and asthma), I had the same NHS number and had even been admitted to the hospital as an inpatient.

Section 3. Other Infections

17. I do not know what I have been tested for, so I cannot confirm if I have been infected with anything other than HCV.

18. In or around 2006, when I was still married to my first wife, I was having a really rough time which, looking back, adds up. I have had panic attacks since my teenage years and suffer with anxiety and depression, attributable to being infected with HCV (as subsequently confirmed by my liver specialist nurse). I had a very bad bout of depression at that time and was unable to work for almost three months. A letter came through the door which my ex-wife handed to me. I opened the letter and, in essence, it said that I should be aware that there was a chance that I had been infected with vCJD. Mad cow disease had been in the news. I was already in a really bad way, so to receive such a letter was devastating. The subject was never discussed afterwards, and no further information was offered to me. I just put it to the back of my mind as I couldn't deal with it.

Section 4. Consent

19. I am convinced that the hospital already knew I was infected with HCV for decades before I was told. My GP surgery seemed to have been made aware of the issue before me. GRO-D

All the same, it came as a huge shock to me when the diagnosis was confirmed. I am certain that I was previously tested without my knowledge and consent and without being given full or adequate information.

20. When you had haemophilia appointments, the hospital always took blood samples and they go away and do things with it. I can't believe they didn't test me for several infections sooner. I wouldn't be surprised to learn that they treated me for the purpose of research.

21. When I had my gallbladder operation at aged 22, I was actually held down against my will and given the FIX concentrate. The irony of it all was that I didn't need any further treatment after that operation. I was informed that I was likely infected with HCV from FIX concentrate given to me between 1975 and 1985, but I cannot be sure that I wasn't infected in 1987/88 when it was administered to me ahead of my operation. There is no way of knowing for sure how long that treatment had been kept in the hospital fridges. I often wonder what if I had 'dodged a bullet' only to become infected when I had that final treatment. I was also told that even with a 33% clotting factor I would have needed the treatment ahead of a major operation, but how do I know whether that is true. It all makes me very angry.

Section 5. Impact of the Infection

22. Everything in my world changed with the HCV diagnosis starting with a botched liver biopsy leaving me in hospital for a week on morphine.

23. The hepatology nurse I was seen by at the long-awaited appointment (that had initially been pre-arranged with a consultant) warned me that I had genotype 1, which was notoriously difficult to clear and that they needed to perform a liver biopsy before they could offer me any attempt at treatment. I was admitted for what should have been a one-day procedure in the Summer of 2010. It went wrong. The doctor gave me a local anaesthetic and when he

inserted the needle, I felt a terrible pain that struck me right through my shoulder. When the doctor finished, I couldn't breathe. I ended up an inpatient for over a week and later learned that the doctor had pierced through a nerve that went through the diaphragm. When the results of the biopsy returned, I was confirmed to have some fibrosis. However, it hadn't gone any further, therefore treatment was still possible. The hepatology nurse (although kindly) did not prepare me for the treatment at all. She said that the treatment could cause some depression, some mild flu like symptoms and that I could possibly become short tempered, but that was it.

24. Three weeks before commencing the course of Interferon and Ribavirin treatment, the nurse wanted me to take antidepressants. I was also shown how to do administer the Interferon injections myself, but it was a hell of a struggle for me to cope on my own, particularly in the first two weeks. I asked if I could attend the hospital to get the injection, but they refused. In September 2010, I began what should have been a 48-week treatment course.

25. The effects of the treatment were absolutely horrendous. I cannot express in words how bad it was. I think I would have rather had HCV. From the day after I first injected myself, it was absolutely terrible. I had what felt like constant debilitating flu. I had an unbearable and unmanageable itch caused by rashes covering my entire body. I was seen by a dermatologist, but they couldn't help me and in the end it just got worse. On top of my skin issues, I had chronic fatigue. Furthermore, I would spontaneously and uncontrollably start shaking violently. I was both shivering and sweating, feeling extremely hot, yet on the surface it seemed as though I was cold. A couple of months into my treatment (on the occasion of my wife's 40th birthday party that I struggled to attend), a nurse practitioner who worked with my wife took one look at me and told me I should be in hospital as I looked horrendous. I was in a terrible state and it still makes me emotional thinking about it now. My hands and legs shook like I had chronic Parkinsons Disease.

26. A female Registrar I subsequently saw at the hospital said to me 'how long have you been like this?' to which I replied 'ages, weeks'. My medication had been running low and I had erroneously thought I would be allowed to collect fresh supplies of needles and Interferon and go home. The Registrar said 'you are going nowhere' and I was admitted straightaway. As soon as Dr Rushbrook saw me on the ward, he said that they needed to stop my treatment and that I would have to stay in hospital. I ended up there for about ten days during the build up to Christmas. I was under constant observation in hospital and, looking back, I didn't realise just how very poorly I was. I was so upset that they had taken me off the treatment when I felt I had come so far. I came off the treatment for a week and was discharged from hospital two days before Christmas after persuading them to let me try again. I managed to stick it out until February 2011, but by then I was worse than I had been at Christmas. I stopped the treatment at 17 weeks, and nobody believed that it had worked. Ages later, miraculously, I learned that the treatment had worked and that I had cleared the virus. The side effects horrendous as they were, were in fact indicative that the treatment was having an impact on the virus.

27. I will never be as I was. I still suffer with the effects of the treatment. My wife says that the treatment has had a permanent affect on me to this very day. Although I was cleared of HCV, the effects of the treatment have gone on and on. Nothing has been right since. I still suffer today, particularly where my memory is concerned. I now have a short-term memory and a low attention span. Prior to treatment, this was not the case. In fact, it was the complete opposite. Now I feel lousy all the time.

28. I have been hugely impacted financially. Before I was diagnosed with HCV, I ran my own business alongside a business partner. We had an extremely successful limited company in the drinking water industry, and we were generating profits of a quarter to half a million pounds annually. I enjoyed a fantastic lifestyle. I worried about my family and what would become of them if I could no longer provide for them financially. Nevertheless, and as soon as

I was diagnosed, I told my business partner. It all went downhill from there. Apart from dealing with the effects of the horrendous treatment, I needed medical clearance in the form of a water industry blue card. I had always answered 'no' to the question 'have you/have you ever had Hepatitis?' My head was spinning with it all because I had unwittingly placed members of the public at risk. The delay in telling me that I had been infected with HCV for such a long time had potentially put a lot of people at risk. Not only was it physically impossible for me to carry on with the work I had done previously to feign ignorance and carry on with that work would have been morally wrong. In consequence, I had to assume responsibility for the administrative side of the business. Although I tried my best, I struggled to cope due to the side effects of the treatment. I was missing appointments and my ability to concentrate was severely impacted. I was extremely angry and irritable, and I was ripping into high profile business contacts for no reason. In 2013, we had to fold the business.

29. I continued to try to work for quite some considerable time. I did some bits and pieces on my own to include some private contracting work. Because of the brain fog I continued to struggle. I had outstanding tax returns which I couldn't get my head around. The HMRC actually owed me money, but I kept getting penalties for late tax returns. The complex health issues I now live with as a result of being infected with HCV have forced me to retire on medical grounds since Christmas 2021.

30. I was relatively healthy when young. I was one of the brightest students in my primary school and went on to a grammar school. I also engaged in a lot of sports, including football and cricket. Without realising why, I began to lose my energy and my ability to concentrate as the effects of being infected with HCV took hold. I didn't think for a minute that there was something actually wrong, but it progressively got worse. I then had the problem with anxiety and depression. My current health issues have ground me down and caused endless stress. I now have a phobia of hospitals and lighting due to my past experiences. Whenever I go anywhere that has lighting similar to that of a hospital, I get terribly anxious. This includes places like Boots the Chemist. It

has left me a complete mess. My counsellor thinks that I have post-traumatic stress disorder.

31. Within six months of finishing the treatment, most of my teeth crumbled away. I lost my first tooth within weeks of the treatment. I was on the beach with the children and had taken a bite of a soft ice cream, like a Mr Whippy. I never had any issues with my teeth prior to treatment. Having conducted research, I discovered an Australian paper that investigated how antidepressants combined with Interferon and Ribavirin were hypothesised to cause catastrophic dental issues. I had to have all my teeth taken out. I didn't want this!

32. Initially I struggled to find dental care. They wouldn't touch me with a barge pole because I had HCV. I went to my local MP for help. I was furious as I had been given the infection and the resulting treatment (including antidepressants) by the NHS. My MP referred me to an oral surgeon at the James Paget Hospital who told me that I would be fitted with dentures. I couldn't understand why I should have to live with dentures when dental implants were so much better. They insisted that implants were too expensive and not available on the NHS. I got in touch with the Caxton Fund regarding the issues with my teeth, but they didn't want to help. The day after the procedure to remove all my teeth and fit temporary dentures I had to go back to A&E with heavy bleeding. I had more stitches, but the bleeding persisted, and I had to go back again. That was the beginning of the ITP diagnosis.

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GRO-D Dr Suzanne Docherty made the ITP diagnosis. ITP is more prevalent in patients with chronic HCV. It is unusual of someone my age to develop it. I bleed at the drop of a hat. A mosquito bite, the size of a pinprick will leave the sheets on my bed covered in a huge patch of blood.

33. The dentures have been nothing but trouble and they have had to be replaced twice because my gums have shrunk back. My gums have shrunk so far

back, that it is difficult to do anything. The platelets in my blood should be between 120-500mcl but are fewer than 20, so no one will touch me. It's been a constant nightmare. My ill-fitting (and unwanted) dentures create constant chafing even though I regularly have them adjusted. I pre-warned them that that would happen if I had dentures. I have a constant taste of horrible congealed blood in my mouth. I should have been given dental implants. It makes me angry, as the NHS has the capability to fix it for me, especially considering they caused the problem in the first place. Nevertheless, they won't do anything to sort it out.

34. After (part) completing the HCV treatment in 2011, I was left without follow up checks to my liver. In March 2019, I went to Manchester Royal Infirmary (MRI) as I had pains in my back, around the liver area. This pain extended around to my front. My son told me my urine had a bad odour too, so I went to a walk-in centre where they tested my urine and said there were no issues. They also took blood to test, for which the results appeared to confirm my liver wasn't functioning how it was supposed to. They gave me painkillers and told me to return to my hotel. They advised that if it got worse, I should return to the MRI.

35. Soon after, I received a call from the hospital, advising that my full blood results were back, and they needed me to return. They informed me that my platelets were horrendously low and that my liver was functioning very badly. My GP said that he found a letter in my notes advising that I get a check-up every 3 months. They were meant to test my liver every three months and I wasn't tested once. He said I should have received the letter, but I never did. My GP referred me to haematology and a liver specialist. Only as a result of that, did I have a scan performed. Overall, it has been a complete catalogue of errors.

36. In terms of stigma, my infection is something I tried to keep under wraps. I have been open about my situation with my family but have kept it from everyone else. I was treated like a leper several times by medical

professionals. The change in attitude was instantaneous, the split second my HCV diagnosis was confirmed. 'CAUTION. RISK OF INFECTION' was plastered across all my medical records and highlighted in bright yellow. They donned full PPE for me (not for other patients).

Section 6. Treatment/care/support

37. No counselling or psychological support was made available to me as a result of what happened. My wife worried constantly about the risk of transmission. No counselling or psychological support was offered to her.

38. I had a car accident in March 2013, where I was hit by another car. I suffered concussion and lost a whole day of my memory. The other party's insurance company wanted me to see a doctor, who referred me for Cognitive Behavioral Therapy (CBT). I went for CBT sessions and the counsellor came to the conclusion that I had PTSD. They believed it stemmed, not from the car accident, but from my experiences with the hospital.

39. Every issue I've ever had, was worsened by what happened to me. Although some issues came as a result of the accident, my counsellor believed the majority of it came from my past. I went for CBT for about 20 weeks, but the counsellor said I would need many more sessions, as my PTSD was so deep rooted. I couldn't face it all.

Section 7. Financial Assistance

40. In 2010, I received the Stage 1 payment of £20,000 from the Skipton Fund, which all infected persons were entitled to, once diagnosed. I received this payment before the treatment started and it was the easiest payment to get. It came fairly quickly. However, it didn't even cover the time I had to take off work, especially considering the time I took off to receive treatment. I am upset and angered at the lack of help for me with my dental issues.

Section 8. Other Issues

41. I have no doubt that the Government knew what was going on and nothing was done about it. The way I look at it is; if I went to a private hospital for treatment in the same circumstances, a good legal team would have hammered them for compensation and there would be criminal charges.
42. In the same way, with regards to AIDS; if someone puts a needle in you and gave you HIV, that person gets charged. The NHS knew they were risking people's lives by giving them these terrible infections.
43. I want to see someone nailed to the wall for this; I really do. Why should we all suffer? I was trying to provide for my children at the time. I was trying to earn money to ensure that if anything happened to me, I could leave them stable, but I was unable to do so. That right was stripped away from me and instead of helping me as they should, the Government have stripped me of my dignity.
44. I demand compensation to enable me to live the remainder of my life properly and leave my children something for when I am no longer around. Why should I lose all I built because of the Government's incompetence? It drives me mad.
45. When the Inquiry commenced, I followed it quite closely, but I now struggle to do so. It's too difficult. It is great that there's finally press coverage, but on the other hand it is a constant reminder of what happened to me. It brings me back to the times I would most like to forget.

Anonymity

46. I do not wish to remain anonymous and I am willing to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....Peter Brierly.....

Dated.....29/07/2022.....