

Witness Name: MARTIN DAVID THEAKER

Statement No: WITN1560001

Exhibits:

Dated: NOVEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARTIN DAVID THEAKER

I, MARTIN DAVID THEAKER will say as follows:-

Section 1. Introduction

1. My name is Martin David Theaker. I was born on [GRO-C] 1964 and I live at [GRO-C] Lancashire [GRO-C] with my wife Denise. We have three sons aged 32, 30 and 25 and five grandchildren. I am by occupation a Sales Manager of a software company.
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

3. I have Haemophilia A, classed as severe. Haemophilia runs in my family. I had an uncle with haemophilia and it was suspected at just 9 months of age that I too was a haemophiliac. At that time, a table fell on my hand breaking a

bone. The resulting swelling from the fracture was so great that it broke the plaster cast. The diagnosis was confirmed one year later.

4. I was treated at the Manchester Royal Infirmary Haemophilia Centre under the care of Dr I W Delamore. I was treated with Cryoprecipitate until around 1973 or 1974. In or around 1974 I began home treatment of Factor VIII (FVIII) on demand/as and when needed to treat my bleeds. The FVIII would be despatched by the Manchester Royal Infirmary and collected by us from the Blackburn Royal Infirmary Pathology Lab overseen by Dr Newsome.
5. I became infected with the Hepatitis C virus (HCV) from contaminated FVIII.
6. No advice was given in relation to the potential risk of FVIII treatment to my parents as far as my mother can recall. You were just told what to do with your treatment. As far as she and I can remember, all the advice/instruction to us at that time revolved around my learning how to mix the FVIII and self-inject intravenously. I was just 10 years old and the focus lay with teaching me what to do to treat myself and nothing was said about risk.
7. Dr Delamore has since retired and his position at the Manchester Royal Infirmary taken by Professor CRM Hay. Professor Hay told me of the HCV diagnosis in or around 1999 or 2000 during what seemed to me nothing more than an 'oh, by the way' type of chat at a routine appointment. He asked me how I was, and I responded with words to the effect that I was a 'bit knackered, feeling low, working lots of hours and doing a lot of driving'. The advice I received was "well you've probably got Hep C" to be quickly followed by "so, how much are you drinking?". I did not consider myself an unusually heavy drinker, only having the odd/occasional beer or glass of wine at home mid-week and a few beers at the weekend with friends at the football. Upon me telling him that, he said "you will need to cut that right back and we'll look at some treatment".
8. He then arranged for me to have a blood test and said I would receive a letter asking me to return for an appointment with Denise to discuss treatment. The

discussion was all very casual. I get on very well with Dr Hay but I do not believe that the manner in which I was informed of my diagnosis was serious enough given the deadly nature of the disease. I subsequently received the letter inviting us to the follow up appointment, but I am unclear as to when I first tested positive for HCV and/or whether Dr Hay knew for sure that I had HCV when he said to me that I 'probably' did.

9. In subsequent conversations Dr Hay intimated that I had had HCV for some time.
10. A nurse caring for me after an ankle fusion operation in 2016 told me that I was apparently 'assumed' to be HCV positive from the mid 1980s. I believe that I became infected between 1983 and 1985. I was during that period using a vast amount of FVIII to treat my bleeds (sometimes twice weekly). I was given the access code to that department so that I could obtain the FVIII I needed at weekends when the department was shut. I would complete and leave on the desk the medical records extract detailing what I had taken. I would on occasion pick up 20 bottles and use them within a week/10 days and then get some more. Dr Newsome called me in at one time and asked me to stop using as much because I was 'blowing the budget'.
11. The decade of the 1980s was a very difficult time for me. HIV/AIDS was high profile in the media with all the connotations that had for haemophiliacs.
12. My uncle was diagnosed with HIV from contaminated blood in 1984 and very sadly died 2 years later in 1986. I was first tested for HIV around the time of his diagnosis. It was also later suggested that I bring Denise in and they would test her and my son. The tests were negative.
13. Aside from the fact that I had been told by Dr Newsome that I was affecting his budget, I knew that every time I sought FVIII I placed myself at risk of HIV. I was fearful of contracting HIV, opting to leave the smaller bleeds untreated. I also felt guilty that my uncle had died having been treated just once or twice per month. My aunt would comment upon just how unlucky my uncle had been and I felt the need to apologise because I was still free of HIV even

though I had received FVIII regularly, sometimes twice weekly. My feelings of fear and guilt and lack of self esteem at that time resulted in me failing to treat myself with the regular and sufficient FVIII I needed. Whilst I was not advised against taking FVIII by my medical team, I was in no doubt in my own mind that some of the large batches of product in Dr Newsome's lab would be infected. It was such a difficult time for me that I missed quite a lot of my haemophilia appointments. In addition to losing my uncle to contaminated blood a very good friend of mine (also a haemophiliac) had become infected with HIV from infected Factor IX after a car accident. He had not up until then had treatment for 18 months. He subsequently died in 1988 or 1989.

14. I have had multiple joint replacements and fusions by operation because I have not had regular/sufficient treatment. Dr Hay has confirmed to me that the damage to my joints was undoubtedly caused by lots of small bleeds left ignored/untreated.

Section 3. Other Infections

15. I do not have any other infections than HCV. I have been immunised against Hepatitis A and B and have kept on top of the immunisations. I received a letter saying that I may be at risk of vCJD. I did not feel able to do anything more than to park that information mentally. I took the view that as and when that ever became an issue I would be told and I would deal with it then. I try not to deal with problems until they materialise. I find it easier to cope that way.

Section 4. Consent

16. I believe it to be highly likely that I was tested for infections without my knowledge and consent.

17. The hospital always took blood and in hindsight I believe I was being tested. I was not told the result. I have often wondered too if I was being given FVIII to

see what might happen? I believe so. I believe we haemophiliacs were used as guinea pigs.

18. I had a long chat with a nurse in hospital in 2016 in the dead of night (at 3 am) whilst I was recovering from ankle surgery (as referred to at paragraph 10 above). She took an interest in my medical history and I asked her to take a look through a rather thick pile of what she told me were my medical notes to see what she could see about the HCV diagnosis (if she found the time to do so).

19. She subsequently informed me that some documents appeared to be incomplete or had been removed. There were conflicting references to the first positive HCV results being 1998 and then 1999. Of greater concern was the letter from Dr Newsome at Blackburn to Dr Hay at Manchester intimating that it was 'assumed' that I had been infected with HCV much earlier and as long ago as the mid-1980s.

20. It is clear to me that I had been tested for HCV without my knowledge and consent and that I was never informed of my positive result or that I was not tested when I should have been, at a much earlier stage.

Section 5. Impact of the Infection

21. I have had multiple joint fusion operations to my ankles and shoulder and a hip replacement because of inadequate treatment for the bleeds. The damage is done once arthritis sets in.

22. In terms of the HCV, my attempt at clearing the virus in or around May or June 2002 was horrendous and unsuccessful. I was told that the treatment could successfully cure the virus, but until you have run the full 12 month course and gone beyond that, I would not know if it is successful or not. I had to wait for the hospital to apply for funding and obtain it before they could go ahead. That took 6 to 12 months to secure before the treatment started. I did not know the enormity of what I was letting myself in for.

23. Before the treatment started I was called in by Dr Hay and the nursing team to run through the side effects and what might happen. I was told to come in with my wife and family. Denise came in with our youngest, Jordan. The other two were at school.
24. It was only when the nurses addressed Jordan directly about what 'daddy might go through' and how he should not 'be upset by it' did the enormity of it all begin to dawn on me. Denise looked at me and we shared the same thought 'what the hell is this?'
25. I would take my Ribavirin tablet in the morning and my Interferon injection in the evening on a weekly basis. Within seconds of having my very first injection I had convulsions, sweating, hot then cold, shivering and a headache like you would not believe. Denise did not know what to do and whether such an extreme reaction was normal. This continued for about 24 hours and she was worried out of her mind to the point that she rang the hospital for assurances.
26. It was a big shock and a wake-up call as to what to expect for 12 months. It got worse, over the next months but I stuck it out. There were some serious episodes in which I would flip. I did not know what I was doing and had no recall of them after. I had extreme mood swings, completely out of character for me. I was a loose cannon. I would throw things around and down the stairs. I trashed the DVD and on one occasion I took off in my car from the house driving like a lunatic. Denise called my dad for help and he found me in a layby 2 to 3 miles from home as calm as anything with no recollection of anything that had just happened. Months later Denise told me some of the things I had done and I was amazed.
27. I took the treatment on a Thursday so that I could work Monday to Thursday. I would stay out of the way of the family in my bedroom mainly between Friday and Sunday so that my mood and behaviour had the minimal impact on them. I did not want my wife and kids to see me like that.

28. At the end of the treatment to be told it had failed was like a hammer blow to me.
29. I lost my job half way through the treatment. I had been upfront about my haemophilia, the HCV and the treatment and side effects and my employer, a Manchester based company, was initially sympathetic.
30. They ended up finding a way to make me redundant because my quality of work had been affected and I was having so much time off. They said that they as a company were changing direction and I did not fit into their new plans. The reality was that I was unable to concentrate at work and my mind was all over the place. They had underestimated the enormity of it as much as I had so found a reason to get rid of me. I had been earning approximately £35,000 a year plus, bonuses, a pension and a company car. The redundancy had a huge financial impact on the family. I racked up £8,000 to £10,000 worth of credit card debt whilst out of work to pay my mortgage, food for the family and other outgoings.
31. It was hard to get another job. I was upfront in relation to my health status but was unsuccessful upon application or interview even when I thought I had got the job. I was more qualified and had more experience than most for the jobs I went for. The law of averages should have applied at least.
32. When I eventually found employment, I had to take a huge cut in salary. Within the last 10 to 15 years my focus has been on just making sure I am working. In the early 2000s I realised I needed to get some of my joints replaced and needed consistent/stable employment. I could barely walk 3 to 4 steps and could hardly drive because of pain. I found local, office-based work and took painkillers daily to see me through.
33. I had further employment related issues in 2007 when I went into hospital for an operation. A friend actually called me on the day of the operation to tell me that he had just interviewed for *my* job (as my company apparently could not afford the resulting drop in sales during my absence). He told me he would not take it even though I knew he wanted it.

34. They invited me in for a disciplinary meeting during my recovery period for not reaching my sales target that month. I had to pay for legal advice about employment disability discrimination. I was exonerated but it was a difficult time and an unnecessary worry.
35. I had a second attempt at clearing HCV this year over 4 months – February 2018 to May 2018. The treatment was nowhere near as intense as the first treatment. If it had, I would have been reluctant to embark upon it and I would have taken myself away somewhere for that 4 months. Again, I experienced flu-like symptoms and this hit my mood because I was run down and tired (insomnia). I had a lot of itching too.
36. In terms of stigma, I felt stigmatised because of the association between haemophiliacs and AIDs. GRO-C is a small close-knit community. Everyone knows everyone's business. My close friend that died in 1988/89 was a fellow haemophiliac. Everyone found out that he had contracted AIDs and he was shunned. People knew that he was a friend of mine and I had haemophilia. I started to notice people whispering when I walked into a pub for example. Because we had a young family we did not go out. I wanted to protect Denise and the children from exposure to whispers and sniping. The first duty of a husband and father is to protect his family. We missed Christenings and Weddings we were invited to. I did not tell Denise why I was unwilling to go. I made excuses that I had a bleed or that I just didn't fancy it. Our social life suffered. I only wanted to attend family events.
37. The psychological impact has been huge, the mood changes, irritability and isolation you feel during treatment, waiting for results to see if they are clear, the blow from learning HCV is still there and the resulting depression, the worry now that the HCV will return after clearing.
38. I cope by bottling things up and isolating myself. Denise understands me and makes excuses for me when I need to be on my own for example to the grandchildren "Grandad is upstairs working".

39. Denise and I flew out to Ayia Napa for my son's wedding on the last day of my clearing treatment in May this year. During that time, the emotional floodgates opened from the stress of what I have gone through over the years and the results hanging over me to face upon my return. I was tired and worn down with it all. I had been under far more stress than I was even aware of let alone given myself credit for. I have not had any alcohol since January and feel it unlikely that I will opt to do so again. I tried to remove myself from friends and family socialising at the pool, making the excuse that my elbow hurt. I broke down and cried in my room. Denise insisted I confide in the boys although I would have preferred to just get through the wedding. She said I had to because the mental demon in my head was destroying me. It is so difficult to tell anyone except the person you are closest to how you feel. I sat with my eldest two the day before the wedding and told them. We all had a bit of a cry and talked about it.

40. I still get angry and frustrated. I feel like I cannot deal with insignificant things that other people worry about at home or work and try to involve me with. My head is full. All I can focus on is staying clear of HCV. When I get my next round of blood tests and they are below the level then I will be happy. But I know it can always come back.

6. Treatment/care/support

41. I was not aware of any new treatment option after my first attempt at clearing HCV failed. For 14 years (from 2003 until 2017) I thought that nothing could be done for me. In November 2017 I knew something was wrong. I felt unwell and Denise persuaded me to go to my GP. After I was bizarrely disturbed by Blackburn Hospital at 2.00 am (because I tested positive for haemophilia and it was not on the hospital notes), I ended up seeing a Hepatologist at Blackburn, Dr Gkikas, and had a fibroscan. I was only then asked if I had ever been offered the new treatment (with a success rate of 80-90%).

42. I should have been offered the treatment sooner. The fibroscan result had by then revealed that my liver is on the cusp of being cirrhotic. I did not get the opportunity to consider the treatment sooner because no one had ever mentioned it to me. Dr Hay asked me if I wanted to be involved in clinical trials and gene therapy but no further HCV treatment had been suggested by him.

43. No counselling was ever offered and it may have helped. I asked my GP for counselling in or around 2010 but he said it was not available and prescribed antidepressants which I subsequently disposed of without taking.

44. I found my own support by chance at a meeting in Manchester run by a drug company running a drug trial and seeking patient feedback. I met other haemophiliacs there with very similar experiences to me and it has helped to talk to someone that understands what you have been through. I also met someone through twitter and discovered he had HCV and Haemophilia. Speaking to people that have gone through the same thing does help but I had no guidance or offer of support. I have had to self-generate this support. I found all of these people myself.

Section 7. Financial Assistance

45. I received the Stage 1 £20,000 ex gratia payment from the Skipton Fund in 2003/4. Dr Hay confirmed I had HCV. I used that to pay off some of my credit card debt but it did not go very far. It helped too towards a bit of work on the house at the time.

46. I did not apply for individual grants. I was not aware that I could get anything else.

47. I receive regular monthly payments, now through EIBSS.

Section 8. Other Issues

48. I attended the opening of the Inquiry in London and could not help but be moved by the stories of others. I consider myself lucky to still be living and able to keep working.

Anonymity, disclosure and redaction

49. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I have no objection to giving oral evidence to the Inquiry if asked to do so.

Statement of Truth

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

Signed

GRO-C

Dated

29th November 2018

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness statement has been prepared without the benefit of access to my full medical records. .