

16TH APRIL 2019

Witness Name: Paul Anthony Ledger

Statement No.: WITN0151001

Exhibits: Nil

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAUL ANTHONY LEDGER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 07 February 2019.

I, Paul Anthony Ledger, will say as follows: -

Section 1. Introduction

1. My name is name is Paul Ledger. My date of birth is GRO-C 1950 and my address is known to the Inquiry. I am a former forklift builder and have been retired for ten years. I currently live with my wife whom I have a son with.
2. I intend to speak about my infection with the Hepatitis C Virus ("HCV"), which I contracted as a result of being given infected blood products to treat my mild haemophilia A.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it has had on my life and the life of my family.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement.
5. My wife is present during the interview to help recall some of the events that took place and give her feelings on what our family has been through.

Section 2. How Infected

6. I believe that I was infected with HCV in 1981 at the Basingstoke and North Hants Hospital following an operation that required Factor Cover via the blood product Factor VIII.
7. I was first diagnosed with haemophilia when I was around fifteen. Before this, I used to get bad bleeding, especially when I had my teeth extracted. However, I was never diagnosed or tested for haemophilia at the time.
8. In April 1964, I was involved in a serious accident, whilst cycling on my regular route to scouts when an oncoming lorry struck me. The accident resulted in a compound fracture of my femur along with several other bones. The accident also left me with severely damaged organs. I was rushed to the Battle Hospital, Reading to be treated. I was living in Basingstoke at the time.
9. After the accident, I was in hospital for around three to four months and seemed to be recovering in good time.
10. Approximately one year later I banged my leg, which resulted in a haematoma. I visited my local hospital in Basingstoke to remove the haematoma but the doctors could not stop the bleeding. The doctors sent me to Churchill hospital, Oxford. The Doctors at Churchill hospital ran some tests and I was diagnosed with haemophilia A.

11. Now diagnosed with haemophilia, I was moved to Lord Mayor Treloar Haemophilia Centre in Alton. Once the Haemophilia Centre had closed down, it was transferred back to Basingstoke.
12. As mentioned, in 1981 I required surgery at Basingstoke and North Hampshire Hospital, although, at the present time I cannot remember what the surgery was for. I was treated with non-heated Factor VIII.
13. Several weeks after the operation, I became very ill; initially I was diagnosed with yellow jaundice. Dr. Williams, my GP referred me back to the hospital for some tests to find out why I was so severely jaundiced. When the results were returned, I was diagnosed as having been infected with Hepatitis. The diagnosis was first recorded as non-A non-B, as HCV was not classified in those days.
14. I believe that whilst attending a routine appointment in the early to mid eighties, Dr. Aronstan, a consultant at the Basingstoke Haemophilia Centre at Treloar School in Alton, informed me, that I was in fact infected with HCV. It was very matter-of-fact. He gave me no information on how I had become infected or how to manage it. I was simply told that there was no cure for HCV at the time.
15. It was not until I was transferred to Basingstoke Haemostasis and Thrombosis Centre at Basingstoke and North Hampshire Hospital, that I started to learn more about it. They were more honest and open about my infection with HCV.
16. There was no information given on how the infection was likely to progress, or of any measures to employ to prevent further spreading. At the time, I was not told that it was the factor products that infected me with HCV.

17. I am not sure when a different sort of hepatitis was discovered, therefore, I cannot be sure if the results should have been communicated to me earlier.
18. After two attempts to clear my HCV, one in the early to late nineties, which failed and the second in 2010, which was successful, I have been told that I am clear of HCV.

Section 3. Other Infections

19. I do not believe that I have contracted any infection other than HCV as a result of being given infected blood products. However, I do believe that as a result of my infection I have suffered from a series of mental and physical problems. Some of these problems have severely impacted my life directly and impacted the lives of my family.
20. One of these physical problems is cirrhosis of the liver, I have been told that the damage is irreversible and that the scarring won't repair itself. It seems like one thing after another. I start to think what could be next.
21. I have been tested for HIV and for vCJD, thankfully, both of these tests came back negative.

Section 4. Consent

22. I have been asked if I believe that I have been treated or tested without my knowledge or consent. The answer is no, I have always consented to being treated and tested.
23. However, I was never made aware of the potential risks associated with taking blood products either by Dr. Aronstan or Dr. Wassif, another of the doctors who treated me. I know that at the same time as I was being treated with Factor VIII, other individuals were receiving a heat-treated Factor VIII product. I know that I was not. This to me means that they may

have known about the risks associated with the untreated Factor Products and yet I was still given them. I feel as though if there were known risks I should have been told.

24. The implications of being given infected blood products and the devastating effects of being infected with HCV is not something that I had consented to.

Section 5. Impact

25. The mental and physical effects of living with HCV have had and still have a massive impact on my life. The effects really seem to creep up on you. I did not realise how bad you can feel until one day I woke up and the symptoms just became overwhelming. At this point I realised what a state I was in. I am not one to complain unless I really have to, I will always struggle on when needed. I had to accept that the HCV would affect me with the alternative being to simply give up. That is not who I am so I have always just carried on.
26. I suffer from chronic fatigue and exhaustion. Another consequence of the infection was that I suffered from depression. I tried to fight it all on my own at first and I lost my self worth. Eventually, I saw my General Practitioner about my depression and was placed on antidepressants. I came off those after a few years and have since felt generally ok but I am aware it can go in cycles.
27. As previously stated one of the physical effects I have had to deal with is liver cirrhosis. This has made me extremely anxious about what lies in store for the future of my liver. Having cirrhosis, for which there is no cure, makes life very draining. Other physical symptoms I deal with are breathlessness, joint pains and fatigue; this makes it difficult to go for walks or generally travel too far. Even ordinary everyday tasks like I cutting the grass makes me extremely fatigued and tires me out for the rest of the day. My sleep is also affected; I have not been sleeping very

well. Consequently, I get very irritable; I have little motivation to do anything anymore.

28. I was initially put on treatment, thirty years after my diagnosis in the early to late nineties. I was not placed on treatment before this, as I believe there was no treatment available at that stage. Instead I was monitored yearly. The treatment consisted of being given Interferon and Ribavirin and required me to make up injections. I would administer the injections weekly through my stomach or leg and was also put on daily tablets. This combination of drugs almost killed me.
29. The treatment left me in pieces and after three months I had become extremely ill. I had lost three stone, struggled to breath and was clinically depressed. My reaction was so bad that when my consultant at the time, Dr. Ramage saw me the first thing he said was that I had to come off the treatment, due to these side effects. I asked him not to take me off the treatment as it was the only way to clear my infection, but his words in response were: *'Paul, I am supposedly trying to cure you, not kill you'*. It was at that point I realised how ill I really was. I will never forget those words that he spoke to me.
30. I was still working at this stage. It was suggested that I had a rest period from the treatment for six months; in that time they were hoping that there was some new developments on the medication front.
31. After several years, a new treatment became available. My doctor, Dr. Brookes, recommended that I go back on the medication. I was told the treatment had been refined and so I started a course of it again. I believe that the medication was Interferon and Ribavirin again. This treatment lasted a year but was not nearly as aggressive as the previous course and I was able to deal much better with any side effects This time I managed to complete the full course of treatment and as a result was able to clear my HCV.

32. The second treatment did not leave me with depression. I was not sure if this was because I was already prepared, having experienced the treatment previously, which could have made it easier. I seemed to cope much better the second time around.
33. In the past I have had a liver biopsy, at Basingstoke and North Hampshire Hospital. This should not have been done according to Dr. Rammiage, due to my haemophilia. However, the procedure went ahead regardless, as I was only considered a mild form of haemophilia. The biopsy was completed under Factor cover. It was this Biopsy that showed my liver was damaged beyond repair.
34. More recently, I went for a scan at St. Thomas Hospital, London after being referred by Dr. Savita Rangarajan. The result of the scan confirmed the extent of the damage to my liver.
35. I was being monitored annually but since my liver function has worsened I am now seen every six months. I am fearful that this means that my liver function is getting progressively worse.
36. I do not feel as though I was declined any treatment or had any obstacles in obtaining treatment. I have had no trouble with dental treatments as I have had all my teeth out due to my haemophilia. I now have false teeth.
37. Dr. Brookes assigned a specialist nurse, Sister Jean Prosser. I could contact her when I needed; this helped me massively. It helped to know that there was someone on the end of the line to speak to.
38. The impact of being infected with HCV has extended to my family and to a limited degree, my social life. In regards to family, we have not been able to go on many holidays, due to not being able to obtain travel insurance. There is also the worry that if something happens, I am not sure what sort of treatment that I would receive. In terms of my social life, my liver cirrhosis means that I cannot go out and drink alcohol. However, this has

been less of an inconvenience as my wife and I tend to keep ourselves to ourselves.

39. I have been asked if I have experienced any stigma whilst being infected with HCV and the answer is yes. I struggled to get life insurance and struggled to get a mortgage at first; all because I ticked the box that said I had an infection. It also used to bug me that I had to have a yellow sticker with red writing on my medical files, which stated: '*RISK OF HEP C*', I felt as though I was black listed. That message was always on my notes. When I was at Basingstoke and North Hampshire Hospital, I used to be put in a room on my own as I was a risk for transmitting infection. This added to my feelings of isolated and labelled.
40. My infection with HCV has not had any impact on my education, as I left school when I was fourteen.
41. In regards to my employment, my infection with HCV and subsequent treatment did leave me with breathlessness and fatigue. This meant from time to time I did struggle to carry out my work effectively. Thankfully my company were very understanding. A few people at my work knew about my infection and they were very accommodating and supported me in the struggles I sometimes experienced.
42. My infection with HCV has had some financial impact, as previously stated. I struggled to obtain a mortgage and have suffered with problems relating to insurance and excesses. My wife and I just had to make sure that we were careful with our money and save as much money as we could. There was also financial impact when travelling to my hospital appointments in various locations. It is quite a distance from my home to the hospital in Basingstoke but I got to know the staff there and preferred my treatment to continue in an environment I was familiar with.
43. My wife has said that she had often felt isolated; nobody explained to her what my infection meant. She thought it was wrong that nobody told her

what the effects were or how to cope with them or help me to do so. I was informed that it could be transmitted through bodily fluids, but it was hard to know how easily transmissible the infection was. There was no guidance in with regard to sexual relations. My wife further mentioned that it would have been good to have a clinic or information sessions for the wives of those infected. However. we both agree that maybe there was not much information known back then.

44. My wife has also lost a lot of time out of her life accompanying me to appointments, looking after me as well as coping with the day to day running of a family home. I realise that there must have been times, especially when my depression was at its deepest that she struggled to cope but she battled on through it without any outside support.

Section 6. Treatment/Care/Support

45. I can confirm that in the past I have never been offered psychological support or made aware of such support in relation to my infection. I have only been offered a leaflet, which I had to ask about for myself. I believe that I would have accepted psychological assistance to help manage my depression.
46. I can also confirm that I have been informed about the access to the support mechanism that the British Red Cross is providing in conjunction with the Inquiry.

Section 7. Financial Assistance

47. I initially found out about the Skipton Fund via a lady from the haemophilia support centre in Basingstoke. She suggested that I should apply. The process was drawn out and felt arduous. However, I was relieved to find out I was successful. I received Stage 1, which was around £20,000, and Stage 2, which was around £50,000. I believe that there may have been a

condition, in that in order to receive the payments from Skipton I could not seek legal representation.

48. I also receive a monthly allowance of around £1,400 from the England Infected Blood Support Scheme ("EIBSS").
49. I feel as though the money I received has helped a lot. It has secured our home and relieved some of the stress on the financial front. I view it as an added bonus as my wife and I have had various financial struggles, as previously mentioned.

Section 8. Other Issues

50. I would like the inquiry to know that what I find the most upsetting about my situation is that it could have been prevented. For people to know you could have heat-treated Factor VIII and not give it to everyone that needed it is morally wrong. That is what eats away at me. Not that I have HCV or what I have lived through – as that's life, but that it could have been prevented.
51. It seems like heat-treated Factor VIII was a reasonably cheap option and could have been given to everyone. I cannot understand any human being not giving someone in need the best possible treatment. I can only think it must be orders from above, whether that'd be the Department of Health or the hierarchy within individual hospitals.
52. I often think that I might not have had to go through all of this. I feel as though this is why I cannot let go because I feel bitter. This could have been prevented but was not, probably all for the sake of a couple of pounds. Now it is costing them a fortune, all the liver tests and blood tests and all the associated treatments and medication. I wonder if it was all worth it?

Statement of Truth

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

Signed GRO-C

Dated *16TH APRIL 2019*