Witness Name: Lynda
Whitehead

Statement No.: WITN1999001

Exhibits: [WITN1999002 –
WITN1999012

Dated: 15 June 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LYNDA WHITEHEAD

Section 1. Introduction

1. My name is Lynda Whitehead. My date of birth is GRO-C 1948. My address is known to the Inquiry. I worked as a bookkeeper from the age of 15 until I retired recently. I also worked in Woolworths from 1991 until they closed in 2008. I have lived in my home for 52 years. My husband died twenty years ago and since then I have lived on my own. I have one son.

2. I have been married twice. My name was Lynda Board during my first marriage. That is why some of my medical records name me as Mrs Board.

Section 2. How Infected

3. I had two emergency surgeries, in 1978 and 1979. During both of these procedures, I received blood transfusions. I was infected with Hepatitis C (HCV) as a result of one or both of these transfusions.

Caesarean

4. In January 1978 I was 41 weeks pregnant with my son. On Monday GRO-C 1978, my waters broke. I attended Blackpool Victoria Hospital straight away and was admitted. I feel that I was largely ignored between my arrival and Wednesday GRO-C At noon on GRO-C I was suddenly whisked away for an emergency caesarean-section to deliver my baby. I do not recall much of this time as I was not alert for several days. This impacted my ability to bond with my son as I did not have contact with him for three days. I never complained about my treatment at the time, but I do feel that I was neglected at the hospital and that my son should have been delivered sooner.

5. I know that I had a blood transfusion at this time because I saw a bag of blood above my head going into my arm. In those days, I simply trusted doctors to make the correct decisions for my care. I did not ask about the blood transfusion and was never informed of the reasons for the transfusion or any risks of HCV or other diseases associated with transfusions.

6. I now know that I received two units of blood on GRO-C 1978, the day my son was born. This is set out in two documents from 1978 within my medical records **WITN1999002**.

Bowel Resection

7. I first started feeling unwell around Christmas of 1978. My tummy did not feel right, I was losing weight and feeling ill. I had also stopped getting my period. I went for

a scheduled X-ray and was informed that I could not have one because there was a risk I could be pregnant **WITN1999003**. I feel that doctors largely ignored my concerns, and I continued to feel unwell. My symptoms at this time are described within my medical records **WITN1999004**.

8. On 19 August 1979, my arms and legs were feeling funny and I felt dizzy and unwell. I attended Blackpool Victoria Hospital in a haze. I was quickly whisked away by doctors into surgery. I woke up in a side ward alone with tubes everywhere. Again, I saw a bag of blood above my head going into my arm.

9. I later found out I had been diagnosed with Crohn's disease and had undergone an emergency bowel resection (also called a right hemicolectomy) **WITN1999005.** I was not informed by any doctor that I had had a blood transfusion. The only reason I knew I had been given a transfusion was because I had seen the blood going into my arm.

10. I was not told of the possibility of needing a transfusion or informed of any potential risks associated with transfusions before the surgery. I was not informed of the risks of HCV or any other infection from transfusion either before or after the surgery.

11. I am not a troublemaker or a complainer. I did not feel able to ask questions of my doctors and understood both surgeries as emergencies, required to save my life. I had no reason to ask about the necessity of the blood transfusions or about any associated risks.

12. The fact that I had received blood transfusions was confirmed when, in 2009, I went to my GP surgery and requested the relevant pages of my medical records in order to apply to the Skipton Fund.

HCV Diagnosis

13. In late 2008, I got up for work and did not feel well. I decided to make an appointment at the GP and was offered an appointment on the same day. I saw

my usual doctor and decided to bring a urine sample with me as I had recently had a bad bout of cystitis. My GP offered to test the sample. I was taken very seriously and my concerns were listened to.

14. My doctor called me back and asked me to come into the surgery before they opened for the day and asked me to go for a blood test. Some time after the blood test, I was again asked to come into the surgery before opening time. My GP told me that they had done two tests which had both come back positive for HCV. It is HCV genotype 3. I did not know anything about HCV. I had a feeling it was something that mucky people had. I had no idea how I had come to be infected.

15. I was referred to Dr Shorrock at Blackpool Victoria Hospital shortly after my diagnosis, in December 2008 **WITN1999006**. Dr Shorrock suggested that I enjoy my Christmas and think about treatment in the New Year. He explained everything I needed to know about HCV and asked me about any potential risk factors. I told him that I have always been a bit of a goody two-shoes and that I had no history with drugs, tattoos or casual sex. He then mentioned that it was likely I contracted HCV through a blood transfusion during surgery. This is also recorded in a letter from Dr Shorrock to my GP **WITN1999007**.

16. I could not fault the hospital's response to my diagnosis. I was given comprehensive information about HCV, how to avoid passing it on, and how to manage my condition. My treatment was supervised by Dr Shorrock and my main contact has always been Nurse Practitioner Mike Rolland who I saw weekly initially, gradually moving to monthly and now to bi-annual appointments.

17. After diagnosis, I felt that my treatment progressed quickly. I had a liver biopsy on 25 February 2009 which found that I had cirrhosis. I then started treatment to clear the HCV virus on 12 May 2009 **WITN1999009**.

18. I feel that I should have been traced, contacted and tested for HCV sooner. After my diagnosis, I found the Tainted Blood website and watched a clip of a women with an identical story to mine. It was only then that I really understood the impact of the contaminated blood on people like me with HCV. Mike Rolland had

explained to me at one point that every pint of blood given during a transfusion was recorded. I do not understand why, if that is the case, I was not informed that I had been given a contaminated batch. I feel that the blood I was given should have been tracked so that I could have been notified and tested at an earlier stage. This may have also prevented me from developing advanced (F4 level) cirrhosis, which I now live with. Details of my Fibroscan findings can be found in this letter from Mike Rolland dated 6 November 2017 **WITN1999008**.

19. I have generally been impressed by Blackpool's response to HCV and contaminated blood since my diagnosis. I have not been mistreated by hospital or GP staff. I feel lucky in that respect. I was happy to see the testing bus in town. I even encouraged a friend to visit and get tested. However, I know that not many people attended. There may need to be more publicity to encourage people to be tested.

Section 3. Other Infections

20. I do not have any other infections other than HCV, as far as I am aware.

Section 4. Consent

21. I do not believe I was tested for HCV without my consent.

22. I was given blood transfusions without my full consent in both 1978 and 1979. However, I understand that this may have been because these surgeries were both emergencies.

23. I consented to be enrolled in a research project by HCV Research UK in August 2014 (Study Number 2900081) **WITN1999011.** I was happy to do this and my involvement did not impact my treatment.

Section 5. Impact

24. I was treated to clear my HCV infection between May 2009 and April 2010 with Interferon (Pegasys) and Ribavirin **WITN1999009**. The treatment was successful and by 29 April 2010 my viral load was undetectable, as set out in this letter within my medical records **WITN1999012**. I also have liver cirrhosis and undergo bi-annual blood tests and liver scans to monitor the health of my liver.

25. During my treatment, I felt very unwell. One of the worst symptoms was brain fog. I felt there were net curtains in my mind I was trying to see beyond. I would often have to pull over when driving, for example, to let the brain fog pass.

26. I still experience tiredness as a result of my liver problems. I can sleep anywhere. I have to take regular naps and have been found asleep in places like the Boots prescription counter. I never catch the end of a film.

27. Another of my liver-related symptoms is lymphedema (swelling) in my leg. I first mentioned this to doctors at the hospital in 2013 and was sent to the lymphedema centre. I attended the clinic for about a year and was discharged with specialist stockings which I still wear. My leg aches all the time, and I have to do regular exercises and elevate my foot. My biggest concern, however, is that I think my leg is ugly. It really upsets me. I know that the lymphedema is caused by my liver issues and was referred to the clinic by the hepatology department.

28. I am able to manage my physical health through my lifestyle. I have not had an alcoholic drink since my 60th birthday in August 2008. I eat healthily and make sure I have lots of fruits and vegetables. I have a home cooked meal every evening. The mental health impact of my HCV diagnosis and treatment has affected me more significantly.

29. At the time of my diagnosis, I had been getting nosebleeds. I found these incredibly scary before I understood how to properly deal with blood as a person with HCV.

30. During my treatment in 2009-2010, I became very depressed as a result of the medication. This drove me into isolation. I carried on working but only because I worked alone. I would spend every day alone, both at work and at home. I even lost two friends because I told them that I would not be able to see them because at the time, I just felt I could not be bothered to socialise. The treatment was costly to me in this way and I found the loss of these friends very hard.

31. Even now, when I first wake up every morning, I am very depressed. I lie in bed and think "will I survive today?" I feel better once my feet hit the floor, but this is something I experience daily.

32. My mental health is impacted by constant worries in the back of my mind. I know the HCV infection could come back. I do not go anywhere near blood; even the word blood strikes horror in me. The risk of liver cancer is always present in my mind, as is the risk of my liver disease getting worse and requiring a transplant, although I may now not be eligible for one.

33. I also worry that I am too well to have cirrhosis, and I berate myself by comparing my situations to others with HCV. I even fear that the Government may take away my regular EIBSS payments and declare me undeserving. Mike Rolland, my Nurse Practitioner, has had to show me test results proving my cirrhosis to calm my worries. My brother has to remind me that I deserve the help provided by EIBSS. I still worry that the Inquiry may lead the Government to decide to take our payments away. I am not sure what kind of life I would lead without them.

34. I like to think of myself as a positive person but blood, cancer and scans are always on my mind. These worries impact my life every single day. I would have liked a life without having to think about these things. It has taken up too much of my life thinking about my health, my HCV, and my liver.

35. In April 2022, I was diagnosed with an aggressive form of breast cancer. I found several lumps while I was recovering from a broken rib, went to the GP, and shortly thereafter was diagnosed and began treatment. I had a mastectomy in May and started chemotherapy at the beginning of June. It's a 12-week course of chemo which will be followed by radiotherapy. Fortunately, during the mastectomy they found no cancer in my lymph nodes. Due to my cirrhosis, I have to have regular blood tests to check my liver can handle the chemo.

36. I have had excellent care since being diagnosed with breast cancer; everyone has been so kind. I have a nurse I can call whenever I need support. The hospital has given me a false breast and a special bra. They also gave me money to buy a wig. I bought my wig at a lovely shop in Blackpool and I'm very happy with it, my best friend couldn't even tell it wasn't my hair.

37. I remember once being told that I was at an elevated risk of developing cancer due to my HCV and cirrhosis, but I am not sure whether that was a risk of liver cancer or all cancers. I was already part of the HCV club, but now I am also part of the cancer club. They are not clubs I'd wish for anyone to be part of.

38. I do not have many people to talk to about my health and my worries. I have had two wonderful husbands during my life, but both have died. I have lived alone now for twenty years. I do not have much family, just my half-brother and my son. Only my brother, son and one close friend know about my diagnosis. I do have my animals to keep me active: Poppy, my Jack Russell, Luca, my three-legged Bengal cat, and Felix my 23-year-old cat.

39. My son is also impacted by my HCV diagnosis. He does not have siblings or children and his father has died. I worry about what may happen to him if I die, and he worries about me getting sick or dying. I am pleased that my son was tested for HCV around 5 years ago and was negative.

40. I have not experienced stigma as a result of my diagnosis, which I am grateful for. I have simply not told enough people to have experienced stigma socially. No one

has ever felt they could not go to the toilet after me, or anything like that. My loved ones are very supportive.

41. After all these years, I still do not know anyone else with HCV. I have no one to talk to who shares my experience. I knew one person with Hepatitis B, but he stopped coming to the clinic and was unable to access the same support as me. I have always had instant help available from the hospital team, which I appreciate. My doctor also once offered to put me in touch with three young men with HCV, but I did not take up the offer as I felt I could not relate to them.

42. I do not believe I have never experienced poor or different medical treatment on account of having HCV.

Section 6. Treatment/Care/Support

43. I have not faced difficulties in obtaining treatment for HCV or as a result of being infected with HCV.

44. I have been made aware of counselling available to me, both through the Skipton Fund and the NHS. I have chosen not to take this up.

Section 7. Financial Assistance

45. I was told that financial assistance was available shortly after my HCV diagnosis, at the hospital.

46. In April 2009, Mike Rolland assisted me to make an application to the Skipton Fund **WITN1999010**. In order to do this, I had to go to my old GP practice to request proof of my blood transfusions in 1978 and 1979. I was provided with two documents which appeared to be letters addressed to my GP from hospital consultants, stating that I had, on both occasions, received a blood transfusion and giving the reasons why. I sent these off with my Skipton application. When my solicitors applied for my GP records to assist with preparation of this

statement, these letters were missing from the set provided. I do not know why these letters are no longer in my medical records.

47. Five weeks after applying, I received my first Skipton Fund payment. I then received a second payment upon my cirrhosis diagnosis. Then, after a year of no payments, Skipton set up my monthly payments and provided a lump sum covering the missed ones. Initially, I did not understand it all. I thought "why am I receiving this?" Receiving these payments made me think I might very quickly die. However, the money has helped me immensely in the years since.

48. The monthly payments help me to pay for people to assist me with things like vacuuming, which hurts my back. The payments make my life easier. The lump sums in 2009 also helped me to stay afloat as I lost one of my jobs when Woolworths closed down.

49. I am satisfied with monthly payments, but I think I would prefer a final lump sum payment as compensation as it would enable me to have closure. However, I fear that my lump sum might be calculated based on how many years of life it is assumed I have left. I intend to live for a very long time and would not want a lower payment on account of my age.

50. Alternatively, I would like an assurance that monthly payments will continue for the rest of my life. This experience has changed my life completely and I feel that needs to be recognised.

Section 8. Other Issues

51. There are two main issues, other than those I have covered already, that I would like to bring to the Inquiry's attention:

    a. I was never officially told I had been given contaminated blood, although I know this to be true. I would like this to be properly acknowledged.

b. I would like all medical professionals to be educated in the contaminated blood scandal and to know that many people have been infected with HCV, HIV etc. through blood transfusions. I also worry that some medical professionals may have been gagged or ordered not to talk about infected blood and HCV. During two recent medical appointments (just before the pandemic and in September 2021) for asthma and a cat bite, I mentioned my HCV and infected blood. The nurses I dealt with on both occasions stated they had no idea about infected blood. I found this shocking and disappointing. I do not feel it is right that medical professionals do not know about contaminated blood or are not allowed to discuss it, regardless of the area of medicine they work in.

52. In my mind there are two versions of the NHS: the old version and the new version. The old NHS gave me HCV through contaminated blood; the new NHS has cared for me and provided me with excellent care and supported me through my diagnosis and treatment.

53. The only problem I am facing with my current care is that, before my last routine liver check-up in November 2021, I was told that my GP surgery will no longer take my bloods. This meant that I had to attend the walk-in centre at the hospital. I am lucky that I could drive there, as I would have struggled to get there by bus. I also had to wait an hour and a half before my bloods were taken. I think that I should be able to do my bloods locally, at the GP. I am very angry about this, but I do not think that the change in policy or practice is based on my HCV status.

54. I am happy with how the Inquiry is being run and that pleased that answers are being sought as to how this was allowed to happen.

Statement of Truth

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

Signed GRO-C

Dated 18.7.22

Consent to use my statement