

Witness Name: Jean Paton Short

Statement No.: WITN0445001

Exhibits: **WITN0445002 - 007**

Dated: 8th February 2019

INFECTED BLOOD INQUIRY

25 FEB 2019

WRITTEN STATEMENT OF JEAN PATON SHORT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23rd January 2019.

I, Jean Paton Short, will say as follows: -

Section 1. Introduction

1. My name is name is Jean Paton Short. My date of birth is GRO-C 1951 and my address is known to the Inquiry. I am a retired Healthcare Assistant.
2. I intend to speak about my experience being told that I received blood contaminated with hepatitis C, after a cesarean section at Burnley General Hospital on GRO-C 1983. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

3. In 1983 I had an emergency cesarean section at Burnley General Hospital. Afterwards, I was told by Dr Mahady that I had lost a lot of blood and needed a transfusion. The form concerning investigation of my haemoglobin levels is exhibited as **WITN0445002**. I consented to the transfusion and received two units of blood. The transfusion form is exhibited as **WITN0445003**. I was not advised of the risks of being exposed to infection.

4. It was not until June 2008 that the infection came to light. I was invited for a routine check at my GP's 'Well Women's Clinic' where blood tests were taken as part of a general health check. The tests revealed an abnormal enzyme in my blood. My GP did not know what it was, so he referred me to Dr Green, a Hepatologist at Burnley General Hospital. Further blood tests were taken and I was diagnosed with hepatitis C. I felt shocked and numb at first. It didn't seem to sink in.

5. I recall that Dr Green asked me if I had ever been a drug user; I was shocked and said 'no.' He then asked me if I'd ever had a blood transfusion. I told him that I had received blood some 25 years earlier following the birth of my youngest son. Dr Green said 'well that's it then –it sounds like you've been given contaminated blood'. I was totally shocked. Dr Green gave me some information about the risk of transmission onto others and a few leaflets about hepatitis. **GRO-C**

GRO-C

Apparently there was a 6% chance I could have passed it on to them.

GRO-C

I was not given any further information until a fortnight later when I was assigned to a specialist nurse, Sharon Frayne.

6. Sharon explained to me that Dr Green was looking into my medical history and that he had contacted my GP to retrieve my maternity notes. The notes revealed that I had been given two units of American blood on GRO-C GRO-C 1983. At the time of the transfusion, I didn't give the source of the blood a second thought. I presumed it was British and I was never told anything to the contrary.
7. At that point, I was also under the care of Dr Gkikas, a liver specialist. I would see him when Sharon thought necessary, in order to explain things further. I was provided a good amount of information by Sharon. She explained what hepatitis is, the treatment and side effects and that I should always wear gloves at work. There was a list of things she went through, including my diet and that I couldn't drink alcohol. Sharon always checked if I fully understood the information and whether I had any questions. She also told me to write a list of questions in preparation for my appointments with Dr Gkikas.
8. Sharon took good care of me. I had my blood tested regularly, underwent biopsies and regular scans every six months. My husband, Pat, would accompany me to appointments so that we could both hear the information.

Section 3. Other Infections

9. I did not receive any infection other than hepatitis C.

Section 4. Consent

10. I consented to the transfusion. I thought 'Doctor knows best,' so I didn't query it. I was not informed of the risks associated with transfusions.

11. I consented to all subsequent testing. There was one occasion in October 2018 where I was taken to hospital in a confused state. I was given a consent form to sign, but I didn't understand what it was and I was drawing all over it. I was apparently asked for my address six times and was unable to respond coherently. I remember waking up the next day, confused as to where I was.

Section 5. Impact

12. I was very tired, constantly. I was still working at the time, but I had to keep having time off. I was mainly shocked as to what could happen to me. There weren't many other symptoms until I started treatment.

13. I had regular blood tests, bi-annual liver scans and an endoscopy every three years. Over time, these tests showed a deterioration in the health of my liver and cirrhosis. In 2017, I developed liver cancer. In recent scans, there were lesions around my kidneys; I am waiting to see if the cancer has spread.

14. I also have a blood clot formation on the portal vein around my liver and hepatic encephalopathy. My type two diabetes has been worsened by the hepatitis and I now take a lot more insulin.

15. I was placed on a course of Ribavirin injections once a week and tablets to take at home. This treatment lasted twelve months. I was scanned after the treatment and the hepatitis appeared to have gone. Unfortunately, three months after I finished the course, it came back with a vengeance.

16. In 2015 I was placed on a course of Interferon for nine months. Again, the treatment did not work and the hepatitis returned.

17. In 2017 I was placed on a 24 week trial of drugs which I collected at Burnley General Hospital pharmacy and administered at home. The trial was run by Dr Ustianowski at North Manchester General Hospital and I was admitted onto the trial because I fitted into the categories.

18. I did not experience any difficulty in obtaining treatment for the hepatitis. There were difficulties with the treatment for my liver cancer. Leeds General Infirmary refused to treat me because my platelets were too low and I was referred to Dr Cross at The Royal Liverpool University Hospital. I was placed on a trial using 'Sirtax,' a drug which is unavailable on the NHS. I was prepared to pay £20,000 for this myself, but luckily the Professor on the trial managed to secure alternative funding.

19. The side effects of the hepatitis treatment were dreadful. I lost my hair, had terrible mood swings, nausea and fatigue. I constantly felt down and concerned. I would worry about the rest of the family, not knowing how it would affect them. I felt like 'why me?' I was always thinking of the worst case scenario and sometimes I would break down and cry when it got too much.

20. During September 2018 my legs started to gather water, resulting in swelling and shortness of breath. Mr Gkikas said that this was attributed to the hepatitis. He arranged for the water to be drained and they removed five litres.

21. In October 2018, I was admitted a number of times to the Royal Blackburn Hospital in a confused state. I was kept as an inpatient for weeks at a time, during which, no one was able to explain what was wrong with me. I was very scared. I began to feel very down and concerned. I felt like I was having to 'fight on all fronts' because there was no liaison between the different clinics. Dr Gkikas came to see me in hospital to tell me that the confused state was caused by the build-up of toxins that my liver was unable to clear.
22. Dr Gkikas told me that I was clear of hepatitis in 2017 as part of a general appointment. I was then tested again three months later and it has completely gone. It's left its mark though, with cirrhosis and cancer.
23. I see my dentist every six months. She was perfectly happy to see me and i've been treated as normal with no issues.
24. The effect this is having on my family is that I can no longer be a 'hands on' grandma and have my grandchildren to stay. I feel like I have had that all taken away from me. When the children come, they only stay a little while because I tire so easily and it puts me out for three days afterwards. I feel so cheated in the respect that I am no longer able to be the 'hands on' grandma that I want to be.
25. My husband has to do more or less everything for me now. We don't go out as much. We only go to the local pub if there's something special on and even then, I can't drink. It doesn't really bother me, but now and again I think 'I'd love a drink.' Since this all started it's just been awful.
26. My work was affected because I had to take a lot of time off sick. I didn't tell anyone about the hepatitis apart from my boss. In the end, I decided to retire.

27. I felt the stigma of having hepatitis and for years I wouldn't tell anybody. It's not my fault I have this illness. I didn't tell my sons for a long time. I felt like I couldn't. When I did tell them they were shocked and worried.

Section 6. Treatment/Care/Support

28. I have never experienced any difficulties obtaining treatment for my hepatitis.

29. I have never been made aware of any counselling or psychological support available. I do not know about any support groups.

Section 7. Financial Assistance

30. I found out about the Skipton Fund from Sharon Frayne in 2008. She applied for me and submitted documentary evidence from my maternity notes. I was given £25,000 as a one-off payment in October 2008. I was also given monthly installments, which I still receive now.

31. When I was informed of my diagnosis of cirrhosis and liver cancer, Sharon applied for a second level payment. In December 2010, I was given another £25,000 from the Fund.

32. In March 2011, I received a letter informing me that I could apply for a Stage two 'top-up' payment of £25,000, which I received in April that year. The letter stated I was also entitled to annual payments of £12,800. The letter is exhibited as **WITN0445004**.

33. In June 2015, I contacted the Skipton Fund and requested details of the payments I had received to date. The letter stating the payments which I have received is exhibited as **WITN0445005**.

34. In 2016 I received another letter from the Skipton Fund, stating that the annual payment will be increased to a flat rate of £15,000. The letter also detailed that the Skipton Fund, along with other funds and charities, would be combined and replaced with a single organisation. The letter is exhibited as **WITN0445006**.

35. In November 2016 I received a letter from the Skipton Fund informing me of an increase to the Stage two regular payments to £15,500, including £500 winter fuel payment. The letter is exhibited as **WITN0445007**.

36. There were no pre-conditions on the grants.

37. At the time I thought that the payments were nice. My husband disagreed. He said 'no, it's not right because you weren't right.' Especially in the last two years, I've been very unwell. It's stopped me going abroad and taking my granddaughter on holiday, which I've been promising for years. I've had to buy things to adapt and make my life easier. The payment is not adequate for everything I have been through.

Section 8. Other Issues

38. I have submitted the following exhibits:

Exhibit number	Description	Page number
WITN0445002	Form concerning investigation of haemoglobin levels pre-transfusion.	1 of 1
WITN0445003	Transfusion form showing two units of blood given at Burnley General Hospital.	1 of 1
WITN0445004	Letter from the Skipton Fund stating entitlement to Stage two 'top-up' payments.	1 of 1
WITN0445005	Letter from the Skipton Fund detailing all payments received to date.	1 of 1
WITN0445006	Letter from the Skipton Fund informing of an increase in annual payments and changes to the Fund's structure.	1 of 1
WITN0445007	Letter from the Skipton Fund informing of an increase to Stage two payments.	1 of 1

Statement of Truth

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

Signed GRO-C

Dated 21/2/19.