Witness Name: Norman Grundy Statement No.: WITN1890001

Exhibits: WITN1890002-WITN1890008

Dated: 19 December 2019

	INFE	CTED	BLOOI	O IN	QUIRY	
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FIRST	WRITTEN	STATE	MENT	OF	NORMAN	GRUNDY

Section 1. Introduction

- 1. I, Norman Spencer Grundy, will say as follows:-
- 2. My date of birth is **GRO-C** 1960. My address is known to the Inquiry.
- 3. I currently work part time as a courier, and have my own leather craft small business which I run from home. My wife and I live with my step son at my mother's home.

Section 2. How Infected

4. In June 1979, whilst on my way to work, I was involved in a motor cycle accident aged 18. I was taken to Leigh Infirmary, eventually diagnosed with a ruptured spleen, and taken to the operating theatre at around 01:30 the following day. A splenectomy was performed and a considerable amount of blood was given by transfusion. At **WITN1890002** is discharge letter. This is a poor copy and some of the letter is cut off at either side.

- 5. I was not given any information or advice before the blood transfusion about the risk of being exposed to infection.
- 6. As a result of being given a blood transfusion I was infected with Hepatitis C (HCV).

7.	I found out about the infection by accident 16 years later. In 1994, my wife and						
	gRO-C	As part of the initial screening we					
	had to supply a blood sample.	I was absolutely stunned when the results					
	came back and the nurse explain	ed that I had tested positive for HCV. GRO-C					
	GRO-C	This news rocked both of us, and					
	over the coming months caused a substantial strain on our relationship.						

- 8. I was handed a leaflet about HCV that gave some information about symptoms, most of which I was already experiencing, and advised to use condoms for sex, but that was about all.
- 9. The information I was given was not really adequate to help me understand and manage the infection. Although I was given the above information, it was not really explained in full, considering the shock we were in. My memory from this time is almost a blank, which I think is due to the shock I suffered when we received this news because we were expecting the results from a routine blood test GRO-C. As a result, I cannot recall how the results of the tests were communicated to me and whether this was done in a sensitive way or not.
- 10. In terms of whether I was given any information about the risks to others being infected as a result of my infection, I was simply given the leaflet which mainly explained it was a blood borne infection and advised to wear condoms. I remember also being told it was unlikely the infection would be transferred by mouth.
- 11. WITN1890003 is a letter from my consultant gastroenterologist in October

1997 confirming I was found to be HCV positive following routine crock testing. The letter notes 'he had two tattoos performed in 1980. There has been no high risk sexual behaviour. However he did have several blood transfusions in 1978 following a road traffic accident which culminated in a splenectomy. There has never been any history of jaundice and he is currently asymptomatic.' The letter notes that a full blood court, hepatitis A, B and C screening with PCR, ultrasound of liver and liver biopsy would follow. Interferon therapy was mentioned.

12. **WITN1890004** is a letter from January 1998 following the liver biopsy noting it 'does suggest the presence of inflammation rather than cirrhosis'. Interferon therapy was arranged.

Section 3. Other Infections

13. As far as I am aware, I do not believe that I have received any infection other than HCV as a result of being given infected blood.

Section 4. Consent

14. I do not believe that I have been treated or tested without my knowledge or consent, or for the purposes of research. As far as I am aware, any treatment I have had has been with my prior consent.

Section 5. Impact

15. When I was diagnosed with HCV this impacted greatly on my mental health. For the first year or so, in my personal relationship, I felt dirty and a health risk to my wife. This resulted in virtually no sexual contact. I later found out a couple of years after the diagnosis that during this first year my wife also felt at risk, as we had had no definitive advice on contamination risks. I have suffered with depression for many years and was first formally diagnosed

about ten years ago.

- 16. Physically, I had felt tired and lethargic for most of my life. I was infected with HCV at the age of 18 and because I felt so lethargic throughout my adult life I thought that I was simply idle. It is only now, so many decades later, that I am realising the full impact of this virus on my life.
- 17. As far as I am aware I have not suffered any further medical complications or conditions as a result of the infection. In 2017 I experienced quite severe left-sided abdominal pain and had a colonoscopy and ultrasound to investigate. It was suggested the pain was related to scars from past operations so I do not know whether this pain was linked to HCV or its treatment.
- 18. I was told the only treatment available was Interferon and that the results were not guaranteed because in some cases it had been successful, but not in others. I given a course of treatment of Interferon in 1998 which I selfadministered through injections.
- 19. WITN1890005 is a letter from May 1998 from my consultant gastroenterologist to my GP noting my 'PCR is now negative and his LFTs are normal. His liver biopsy showed normal hepatic architecture with no fibrosis. There was some inflammation of the portal tracts particularly with lymphocytes. There was no peicemeal necrosis. These results are very encouraging and follow his three month course of Interferon. I plan to review him in a years time with repeat liver function tests and PCR.'
- 20. WITN1890006 is a further letter from the same consultant to my GP from October 1998 noting that both my wife and I were 'very concerned and alarmed because they feel that they are getting conflicting and confusing advice from different health care workers. Mrs Grundy also suggested that a registrar in my clinic told Mr Grundy that he would be dead within a year although I can find no annotation in the notes to show that the patient was seen by one of the junior doctors. However, in view of their worries I have

arranged to repeat his hepatitis C serology, PCR and LFTs. He will be reviewed with the results.'

- 21. WITN1890007 is the review letter from November 1998 from the same consultant, noting, 'I today reviewed Mr Norman Grundy. His LFTS on the 8th August were normal. Hepatitis B surgace antigen was not detected but he was hepatitis antibody positive. I am quite sure that this represents an immune state. However the laboratory declined to perform his PCR on the grounds of costs. I spoke to my Clinical Director Dr James Tymms who indicated that he is currently in negotiation with the Trust Board in order to have these tests paid for. Under the circumanstances, and because of the anxiety to Mr and Mrs Grundy it has been agreed that Mr Grundy's test will be performed on this occasion before the negotiations are complete. I will see him for final review with the results.' I remember this discussion about the costs of the PCR and recall it made me feel useless and like a nuisance. My wife challenged it on my behalf. I remembering asking how much the test cost and offering to find the money myself.
- There is no record in the notes of a further review with these results but after treatment ended I remember I had a series of tests which showed that I was non reactive but would have HCV antibodies in my blood for the rest of my life. I asked both the hospital doctors and my GP whether this meant the HCV was completely clear, or whether it could return at a later date. I was given conflicting information with some doctors telling me it could return, and others telling me I was clear. Those who told me it could return also gave me differing advice, with some saying the only way I could become actively infected with HCV in the future would be if I came into contact with the virus again, whilst others said my infection could flare up again of its own accord. This conflicting information was and still is very concerning for both myself and my wife as to this day I do not have a confirmed answer to this question.
- 23. I have never had any follow-up since I was told I had cleared the virus at all, save for an annual blood test with my GP, which includes liver function tests.

- 24. I did not face any difficulties or obstacles in accessing treatment, save the delay in PCR testing referred to above which was initially refused on the grounds of cost.
- 25. I do not know whether there were any treatments which I ought to have been offered but was not. At the time I was told that Interferon was all there was.
- 26. The treatment impacted on my mental and physical health. I was off sick during treatment because I was very poorly, showing physical signs of jaundice where my eyes went yellow. At the time I did I not know whether it was the effect of the virus itself, as I had just been diagnosed, or whether it was the treatment that made me so unwell.
- 27. In 2002 I felt unwell, tired and had pain and stiffness in my wrists, shoulders and elbows, so went to the doctor. WITN1890008 is a letter in my medical records regarding this consultation noting, 'I would like some help interpreting the blood test results for the 41 year old man who initially came to see me [...] complaining of feeling generally unwell, tired all the time and he had asymmetrical polyarthritis affecting both wrists, both shoulders and both elbows.' The letter notes that my symptoms did not respond to treatment with anti-inflammatories and pain relief but did respond to steroids. The letter goes on to say 'the reason for my letter is that on his 2nd visit he told me about his history of hepatitis C for which he received treatment in 1998. I repeated his LFT and these are normal. His Hepatitis C antibody is positive. My question is really about the relevance of positive Hepatitis C antibody and could ongoing Hepatitis C infection be responsible for some of the symptoms I described in the light of a normal liver function test.' I cannot find a reply to this letter in my medical records. I am including this information in my statement because it demonstrates the limited understanding around HCV, its treatment and the potential ongoing effects for those infected. I don't know if there is a link between the stiffness I experienced in my wrists, elbows and shoulders with HCV but I am including in case it is useful. I had rotator cuff surgery to both

- shoulders in 2012 which has made things much better. I also changed jobs and this has certainly helped, but I still experience stiffness in my elbows.
- 28. I am not aware that my infected status has impacted upon my treatment for any other conditions, whether medical or dental.
- 29. The impact of being infected with HCV was very difficult for me. Initially, I was unwilling to talk about it to anyone, whether it was my family or friends, because I felt dirty. Diagnosis of the infection did not affect my social life because I did not have one as I was permanently tired and depressed anyway. I believe the virus has stopped me having a social life: before I was infected, when I was 17, I was hardly ever ill and was an outgoing sort of person. From the time of my infection onwards I became gradually more tired and depressed. I have never really known what a normal adult social life should be like. I thought that whaever I was feeling was just me: I have nothing to compare it with. Even now, for no apparent reason, my mood can just drop through the floor and be like that for two or three days.
- 30. The stigma of the infection affected me because I felt dirty and a risk to my wife. As I later discovered, my wife also felt very much at risk but had not wanted to say anything to me as she did not wish to depress me any further.). Even now I don't talk about it to anyone unless it is on a form I have to fill in. For me, this is due to the stigma around the virus from the 70s, 80s and 90s. Although things are more open and understanding now, it has not changed how the stigma feels for me.
- 31. My work suffered as a result of the infection as I had to have time off and had to rely on my colleagues to 'carry' me some days because I didn't have the energy to carry out my tasks though they did not know why.. After I had the splenectomy I needed time to recover even after I was back at work, so I was able to talk to colleagues about that. After diagnosis I felt unable to explain why I lacked energy, but I think colleagues could see that I was not so well and that is why they helped me. I worked as a site manager and a lot of the work

involved driving to and from sites. Whilst the driver drove I would sleep in the passenger seat. When we arrived on site my job was to monitor drainage surveys from cameras in the van, so I could remain in the van. When we left, even from that little amount of work I would be exhausted, and would again fall asleep in the passenger seat. Financially, there was also an effect, because I lost a few weeks of employment when I was too unwell to work.

Section 6. Treatment/Care/Support

32. I have never been offered counselling or psychological support in consequence of being infected with HCV.

Section 7. Financial Assistance

- 33. I have never been offered or received any financial assistance. Although I have tried to find out about help and financial assistance over the years I have never been successful. At one point I was told that because my transfusion was in the 1970s it was before screening was introduced so I would not be able to get any assistance.
- 34. My solicitor has made me aware of the EIBSS and I am making an application.

Section 8. Other Issues

35. I am appalled that I only discovered about my infection with HCV through a routine blood test GRO-C. I believe that the hospitals involved, and with the knowledge gained over the years in relation to contaminated blood, should have contacted people who underwent surgery and received blood transfusions in the 1970s and 1980s and offered blood tests to all those potentially at risk to determine who had been contaminated. I consider myself lucky to have only contracted HCV, rather than HIV or antyhing else, and to

still be here to make this statement for the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated19 December 2019...