Witness Name: GRO-B
Statement No.: WITN2002001
Exhibits: WITN2002002-WITN2002016
Dated: 11 September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

I, GRO-B, will say as follows:-

1. My date of birth is GRO-B My address is known to the Inquiry.

2. I currently live alone in social housing in GRO-B I have been divorced for over 20 years, following a marriage of 24 years. I have two children who both live nearby.

3. I am retired and receive pension credit, and extra money from the Welsh Government through the Welsh Infected Blood Scheme which helps to cover my bills and living costs.

Section 2. How Infected

4. In 1974, when I was 26 years, old I fell off a wall and broke my ankle. I had a steel pin for my ankle and, when I was on crutches recovering, I developed a huge cyst on my back because I had also hurt my back in the fall. I had to have an operation at Llandough Hospital, Cardiff, to cut the cyst out. During this operation I received a blood transfusion. This is the only blood transfusion I have ever had. I was left with a hole in my back for about six months which had to heal from the inside out.

5. I received no information or advice before the operation about the risk of being exposed to infection. As a result of the blood transfusion I was infected with Hepatitis C (HCV).

6. I found out I was infected thirty years later, in 2003 when I was living in Scotland. I had a rash on my midriff which lasted five days. I had never had a band of rash before so I went to the doctor. I was surprised that he advised me to get my blood tested. I had a letter three weeks later from the surgery telling me to come to get my results. He told me to sit down as he had bad news. He told me I had HCV.

7. The GP surgery was unable to give me any information about the infection. They sent me to a specialist in Aberdeen Hospital, a Dr MacKenzie. **[WITN2002002]** is the GP referral letter dated March 2003 which mentions he had given me the NHS Grampian Advice and Information leaflet regarding HCV. I do not recall being given this information leaflet. The letter also mentions that the GP 'returned the Public Health Department consented questionnaire to them'. I do not recall being made aware my GP was sending this information about me to the Public health Department. My GP records also contain a document entitled, 'Viral Hepatitis C – Revised Information Sheet for Health Professionals', dated June 2001, from the Grampian Health Board, **[WITN2002003]** should this be of assistance to the Inquiry,

though page 2 is missing. I do not recall the GP explaining any of the information contained in this information sheet to me.

8. Dr MacKenzie was very helpful. Dr MacKenzie wrote to my GP in March 2003 following the referral. The referral letter says, 'it seems most likely that he contracted hepatitis C in 1966 at age 18 following a blood transfusion when he suffered extensive trauma to his back in New Orleans' [**WITN2002004**]. I think this must be an error: I was in the GRO-B and fell down the stairs and hurt my back. However, I never had an operation nor a blood transfusion for this and was simply on bed rest for six weeks. The correct route of infection is described in exhibits referenced in paragraph 20 below. The letter goes on to note marginally elevated AAT and occasional right upper quadrant discomfort and itch. Follow-up was noted to be by ultrasound.

9. In April 2003 Dr Mackenzie's letter to my GP noted my ultrasound and blood results were 'reassuring. His liver enzymes suggest very mild chronic hepatitis C and there is no need for further investigation at this stage or treatment. The minor elevation in bilirubin in December, accompanied by an itch, and mild jaundice are difficult to explain with confidence. The normal liver enzymes and normal liver appearance would be against cirrhosis and the mild jaundice could have been due to the passage of a gallstone. It is planned to adopt a watching brief.' [**WITN2002005**].

10. In 2005 Dr MacKenzie advised me not to go for the current treatment, Interferon, as it only had a 30-40% chance of clearing the infection, because I was Genotype 1, which is the most common but the hardest to clear. Because I was quite alright in myself I thought I would wait because the doctor said they had new treatments coming out. The letter from Dr MacKenzie to my GP in January 2005 notes, 'I took some time today to go over the fact that although his liver enzymes have

consistently been normal, he still could have significant liver disease. Although he seems to have had the hepatitis for 30-40 years without any apparent clinical problem, therapy may be indicated if he has moderate-to-severe inflammation or fibrosis on biopsy. I have asked him to consider liver biopsy, and he will phone in 4-6 weeks to let me know his views. I also explained the nature of the Interferon/Ribavirin therapy, and that the success rate with his genotype would be about 40%.' **[WITN2002006]**.

11. In 2005 I had a liver biopsy which shoed 'mild-to-moderate portal tract inflammation, with no interface hepatitis and no significant parenchymal inflammation [...] in conclusion, the appearances were those of mild necro-inflammatory disease, consistent with chronic hepatitis C.' This letter goes on to say, 'his liver enzymes are normal and the genotype 1a, probably having been infected 39 years ago in America'. Again, this comment about the route of infection is a mistake as I never received a blood transfusion in America. I was told that this was mild disease and that therapy would not be indicated at this stage. **[WITN2002007]**.

12. I was given no information to help me understand or manage the infection. It would have been helpful to have information at that time, such as help with dietary things, and advice not to drink alcohol.

13. I was given no information about the risks of others being infected as a result of the infection. Years later I told my children to get tested.

Section 3. Other Infections

14. I do not believe I was infected with anything other than HCV as a result of being given infected blood.

Section 4. Consent

15. I do not believe I was treated or tested without my knowledge or consent, or for the purposes of research.

Section 5. Impact

16. The mental effect of being infected with HCV was mainly fatigue. I suffered from fatigue and tiredness during the late 1970s and all of the 1980s. I was depressed because I was so lethargic and tired. I hardly worked from 1975 to 1989, apart from odd jobs, because of the fatigue. I didn't know what was going on, I didn't seek help, I thought I was lazy. My ex-wife accused me of that. I thought I was idle.

17. Following my diagnosis the main effect for me was the worry and the sadness. I felt very sad. I suddenly knew I had been living with this killer disease for so long and had been beating myself up about the way my life had turned out. My quality of life would have been much, much better if I had not been infected with HCV. When I was young I was full of energy and optimism. I was infected when I was only 26 years old.

18. Over the years when I was undiagnosed I suffered with tiredness, itchy skin (mentioned frequently in my GP notes) and occasional right upper quadrant pain (mentioned in my GP notes in 2001). I was referred with polyarthralgia (muscle and joint pain) in 2000. I started having prostate problems when I was 38 years old, and I don't know if it was linked but I suffered with constant supra-pubic pain for over 10 years. I still have prostate problems now. I have also suffered with hiatus hernia, reflux oesophagitis (2012) and gallstones (2012), and again, I don't know if these conditions are linked to HCV. I can see my medical records note I had raised bilirubin levels (noted from as early as 1999) and AAT levels (noted from as early as 2001). I don't know if any of these signs and

symptoms mean my HCV should have been diagnosed earlier but it makes me think perhaps it should have been.

19. As time progressed I continued to discuss treatment options for HCV with my consultants. In 2008 I had an abdominal ultrasound which showed my liver was 'of normal size and echogenicity and there was no evidence of focal abnormality'. In 2013 my GP records contain reference to me being lost to follow-up, 'it came to attention by the Hepatitis C follow-up project, organised through the Public health Directorate Health Protection Team, that GRO-B was lost to follow-up. He was last seen at GRO-B in October 2010. The last recorded serology tests are that he is Hep C antibody test positive with Hep C PCR positive. I have spoken with him today on the telephone and he is very keen to re-engage with the clinic.' [**WITN2002008**]. The letter from the Public Health Directorate is exhibited at **WITN2002009**. I do recall this, as at this time I did not hear from anyone about my HCV for ages and ages.

20. **WITN2002010** is a letter apparently following this dated February 2014 which notes, 'many thanks for referring this gentleman back to us again. He was reviewed by my colleague, Pauline Dundas, in 2010 when it was established that he had contracted hepatitis C through a blood transfusion in 1972 and he obtained compensation from the Skipton Fund. He has no other risk factors for contracting hepatitis C. He had a liver biopsy performed in 2005, which showed mild necro inflammatory disease. [...] He has a partner at present and I have advised that his current partner and previous partners are checked for hepatitis C. He has two children aged 31 and 34 and I have advised that they also be checked for hepatitis C. [...] he does not drink alcohol at all and denies [ever] drinking alcohol to excess. I have advised him of the importance of this as it can dramatically spread up the progression of the hepatitis C. He has never smoked. He does not take any recreational drugs. He does not attend any support services. He has never been treated for

hepatitis C in the past.' The letter goes on to describe that the doctor advised me on risks, such as toothbrushes, how to treat cuts, etc. The letter notes I was not keen for treatment at this stage and would await the more successful treatments being developed and the nurse referred me to the consultant to check whether it would be right to delay antiretroviral therapy. A fibroscan was done which showed 5.2 kPA, indicating a low risk of significant fibrosis. Further blood tests and an ultrasound were planned as follow-up. I am slightly surprised at the detail of this letter and wonder whether it was because I had been lost to follow up for several years and this was suddenly realised. It seems strange that I would be advised of the risks of sharing toothbrushes in 2014, 11 years after being diagnosed with HCV in 2003.

21. In 2015 I had a review in the blood borne virus clinic . [**WITN2002011**]. At this appointment I had a fibroscan which showed F0/1 disease (5.3 kPa). Treatment options were discussed and success rates with Interferon and Ribavirin were explained to be around 40-50%, with a multitude of side effects. The other option was 'watchful waiting' to allow development of newer pegylated interferon free treatments with success rates of over 90% with minimal side effects. I chose this option. The letter says, 'he does appreciate that this will be based on patient need, i.e. the patients with the most severe disease would be eligible first which would mean he would have to wait'.

22. In September 2015 I had an ultrasound of my abdomen which noted 'liver is of normal echotexture, no focal lesions seen. Normal portal vein Doppler. The gallbladder contains at least two calculi but is not thick-walled' [**WITN2002012**].

23. In July 2016 clinical notes show a fibroscan result of 6.7 kPa [**WITN2002013**]. In October 2016 I consented to become part of the HCV Research UK Cohort by donating blood to a biobank in order for the project to study the progression of HCV.

24. In 2016 I underwent 12 weeks of treatment with Viekirax and Exviera. I was told the side effects may include headaches and tiredness but that there was a 95% chance of clearing the virus. After one month I was told the viral count was down, from a baseline viral load in excess of 2.9 million. Six months later, in 2017, I received confirmation I had cleared the virus and there was no trace of HCV. I suffered no side effects of treatment.

25. Once I had achieved SVR I was discharged in May 2017 with no further follow up at all [**WITN2002014**]. A letter three months earlier, from February 2017, said a fibroscan would be done in three months' time, i.e. around the time of this May 2017 appointment, but this never happened [**WITN2002015**]. All I have had by way of follow-up is blood tests. I would like to have more in-depth follow-up so I can find out how my liver is.

26. In early December 2018 I had a routine blood test. The following week I received a phone call from the hospital saying they had found traces in my results which may indicate some HCV. I attended a follow-up appointment and understand the virus has not returned and there is no HCV, but this worried me greatly at the time.

27. I did face difficulties in accessing treatment as I had to wait for the Welsh Government to authorise the treatment. They were giving it to others before I received it. The Welsh Government then decided to give it to everyone in Wales who was infected. It was not given to everyone in England. I think they are still battling in England.

28. I think I should have had the new treatments earlier than I had them. I think the Welsh Government was talking about this a few years before they were made available to me.

29. I did not think my infected status has not impacted upon my treatment for anything else in my life. However, I have subsequently reviewed my medical records and can see that when I underwent a cystoscopy in May 2017 the page is marked, 'Hep C' under 'relevant past medical history' and in handwriting, '*patient last on list* at the top of the page [**WITN2002016**]. At the time I had cleared the virus and knew I was last on the list but thought this was because my surname, GRO-B is towards the end of the alphabet. I had no idea I might have been placed last on the list because of my previous HCV infection.

30. The impact of being infected with HCV has affected my private, family and social life. Not being able to work put a strain on my young family. I could not afford to take my children on holiday or give my daughter horse riding lessons. My marriage suffered. It created a lot of arguments, stress and disappointment. Our relationship couldn't take the strain. We had lasted 24 years, but the last 10 years were sheer hell. I blame it on the tiredness. I had no social life at all. Now it is a little better. I have joined the University of the Third Age, and a walking group. It is the best time of my life.

31. When I got diagnosed and read about HCV everything became a little clearer and I started understanding and maybe even forgiving myself.

32. I did not suffer from any of the stigma associated with a diagnosis of HCV. I told people my story.

33. In terms of the work-related effects of having HCV, I could not work at all from 1974 to 1989. In 1989 I had to go to work, I forced myself because I was so broke and desperate. I began selling rubgy shirts and then books. I feel having HCV stopped me having any real career and the associated social life that usually comes with a career, the opportunity to meet new friends, etc.

34. I was already retired when I received treatment for HCV so it did not stop me working at that point.

35. The impact of my HCV on those closest to me was very great. It contributed to my divorce: we are still not friends. We have two children. I disappeared from my children's lives for 16 years following the divorce because I went to live in Scotland. I have made amends with my children now and we are close.

Section 6. Treatment/Care/Support

36. The only obstacle I faced in obtaining treatment was the delay which disappointed me.

37. I have never been offered any counselling or psychological support in consequence of being infected. I would certainly have taken up any offer of counselling and think this could have helped me. Sadly, I now think it would be too late for such support to have an effect as so many decades have passed.

Section 7. Financial Assistance

38. When I started researching HCV I came across the Skipton Fund. I got in touch with the Trust in London and applied. I received £20,000 from the Skipton Fund in 2005.

39. When I moved into my home I applied to the Caxton Fund for moving-in expenses. I was given £3,500 to furnish my social housing flat.

40. I receive £380 per month from the Welsh Government. It is not for life, they have not said how long it is for and they are always reviewing it. It is a worry.

41. Applying for financial assistance was straightforward, especially with the Caxton Fund. I had to send them receipts for everything in my flat. I didn't know what the maximum was but I thought I would stop at £3,500.

42. The Skipton Fund wanted evidence that I had had a blood transfusion, so I got a copy from the hospital and gave it to them.

43. In terms of the amount of financial assistance received, I would have appreciated more, especially from the Welsh Government. It would be good if it was for life.

Additional questions for witnesses

44. I would like the Inquiry to get to the bottom of why they were importing blood from America, if that is what they were doing, and why they thought that was ok.

45. I hope lessons will be learned through this Inquiry so that nothing like this will ever happen again. I would also like there to be further payments to infected people and their children. I have never been able to give my children anything, unlike most parents.

Statement of Truth

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

Signed GRO-B

Dated 11 September 2019