

Witness Name: GRO-B

Statement No.: WITN0533001

Exhibits: Nil

Dated: 11 February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 December 2018.

I, GRO-B will say as follows: -

Introduction

1. My name is GRO-B My date of birth is GRO-B 1977 and my address is known to the Inquiry. I am an employed computer software engineer.

2. I intend to speak about my infection with the Hepatitis C virus ("HCV"), which I contracted as a result of receiving contaminated Factor VIII, as part of my treatment for haemophilia between 1977 and 1995. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on myself and my family.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. I do not wish to remain anonymous.

How Infected

4. I was born with severe Haemophilia A in The Queens Medical Centre, Nottingham. Since my birth until 1995 I received on-demand treatment for haemophilia mostly in the form of plasma-derived Factor VIII injections, but also Cryoprecipitate. From 1981 to 1988, whilst I was in primary school, these treatments would be administered when they were required at The Queens Medical Centre in Nottingham. Around 1988, my mother began to administer these Factor VIII injections at home.
5. I believe that at least one of the batches of plasma-derived Factor VIII, which I received for treatment between 1977 and 1991, was contaminated and led to me contracting HCV. I was diagnosed with HCV in 1991, however I continued to receive potentially infected blood products until 1995 when my treatment changed from on-demand plasma-derived Factor VIII to on-demand synthetic Factor VIII. At some point thereafter, my treatment changed again from on-demand to daily Factor VIII injections and I currently use ReFactoAF (Recombinant human coagulation factor VIII) daily.
6. When I was diagnosed with HCV in 1991, I received an unexpected letter from Professor Stephen Ryder, Liver Specialist at The Queens Medical Centre, inviting me to come in for an appointment (I no longer have this letter). I attended the appointment and recall being asked if I was sexually active. I was around fourteen years old and found this to be highly embarrassing at an awkward and difficult age.
7. I was then taken inside a room to talk privately with Professor Ryder without my father, mother or any other carer or guardian being present. It

was then that Professor Ryder told me in a hard manner that I had contracted HCV and the effects of that diagnosis could be life threatening. I had no understanding of what HCV or HIV were, or how they might impact my life, yet the Liver Specialist, whom I had never met before, was telling me that I could die. This appointment was when I first knew of and was told about receiving infected blood products and consequently contracting HCV. On reflection I am shocked that as a young teenager I didn't even have a parent in the room to absorb and understand this important news. My mum later phoned the haemophilia unit and she was simply told not to worry.

8. I first became aware of HIV and HCV between 1986 and 1988 whilst on holiday with the Haemophilia Society at the Plas Menai National Outdoor Centre in Wales. I remember a conversation that took place between some of the older haemophiliac boys who were around fourteen to fifteen years old regarding HIV and HCV. One of the boys pointed at me and said: "*You've probably got it*", whilst another told him that I was too young to be told about that. I kept what I heard that day to myself and didn't speak about it to either of my parents. The next time I remember hearing about either HCV or HIV was when I was diagnosed in 1991.
9. I cannot crystallise any memory of ever being told how to manage the risks of HCV. I do not remember receiving any sort of leaflet regarding HCV although it is possible that I was given one. I received no counselling or other psychological help either before or after being told of the infection.
10. Around 2006, I was told that my body had naturally cleared HCV during a brief conversation with Anne Massingham. This was confirmed in December 2017 after a further HCV test at The Queens Medical Centre for the purpose of applying to the Skipton Fund. A letter from Professor Ryder, dated 06 December 2017, stated:

*"I had the opportunity just to explain that we are very confident he has cleared HCV spontaneously after his 2006 tests but just for complete piece of mind I have repeated a HVA RNA today and will let he and you know the result but I am very comfortable that nothing else will be needed... P.S. I am pleased to confirm that **GRO-B** is HCV RNA negative confirming he has cleared his HCV infection and is not at any risk of problems from it in the future."*

Other Infections

11. Between 1996 and 1999, when I was between 19 and 22 years old, I received a letter from The Queens Medical Centre informing me that I had been treated with Factor VIII which included plasma from a person who went on to die of vCJD. The thought of this risk made me feel as though I was losing the will to live and I began to go off the rails. I found the letter so painful I destroyed it. I buried the memory so deep it was as though I didn't even know of the vCJD letter and when I met my wife, I found I was unable to inform her about it. I received no follow-up information on the risk of this infection or any offer of counselling and it has not been mentioned to me by any medical professional again.

Consent

12. I believe that The Queens Medical Centre knew I had received infected Factor VIII and contracted HCV before I was informed of it in 1991 and therefore I consider that I was treated and tested without my knowledge or consent. Firstly, I did not know or consent to HCV tests being carried out prior to the appointment with Professor Ryder when I was told that I had the infection. Secondly, I can recall an incident that occurred between 1983 and 1985 which has since led me to believe that the hospital knew of my HCV infection prior to 1991.
13. As I remember, the incident occurred when I was around six to eight years old; I had fallen asleep with my brother and during the night bled

heavily from my mouth because my tooth had fallen out. When I woke up, my brother had my blood on his mouth and nose. I remember there being cause for concern regarding my brother after the incident.

14. Since being informed of my diagnosis I do not believe that any treatment or tests have been carried out without my consent.
15. I believe that I have been treated and tested without being given adequate or full information because I have not been provided any form of information regarding my HCV diagnosis. Both my parents and myself should have received information and support during and after my diagnosis. I feel immensely disappointed, misled, hurt and confused due to the lack of information I received.
16. I believe that I have been treated and tested for the purposes of research, although not for the purposes of researching HCV. As a result of the mental effects I suffered from being infected with HCV, my weight fluctuated and I went from 17 stone to 9 stone. Due to the weight loss, I wanted a procedure to deal with the excess skin on my stomach, namely an abdominoplasty. During 2004 to 2007, I participated in a research project at the Nottingham City Hospital, which involved taking photographs of my stomach. I agreed to participate in the research because I was told that I would be favoured in having the procedure done through the NHS if I took part. However, I was later told that I was not being offered the procedure because I had not lost enough weight. The experience affected me and contributed towards my excessive dieting.

Impact

17. I suffered both mentally and physically after receiving my HCV diagnosis and I have been experiencing the impact of these issues to varying degrees ever since. My mental health in particular deteriorated as a result of my HCV diagnosis and the fear of a potential HIV infection.

18. After the initial diagnosis I was left feeling confused, angry, upset and unable to cope or reach out to anyone. I felt I couldn't tell anyone because of the stigma associated with HCV and the fear that nobody would understand. I had anxiety, trouble sleeping and night terrors, which have continued to this day. The diagnosis was made at a crucial age for both my personal and professional development, yet there was no support or counselling offered at this very influential stage in my life.
19. After receiving the diagnosis I lost all sense of motivation and enjoyment in life. I was severely depressed, often not wanting to get of bed, and at times I even contemplated committing suicide. I had the constant worry of passing HCV on to others. I found staying on the same plasma-derived treatment that had given me HCV and could possibly give me HIV terrifying. At one point I even threatened a treatment strike because I was fed up of being scared and worried. I believe there was a delay in putting me onto the new synthetic blood products because I had already been diagnosed with HCV and therefore I had been written off.
20. Even now I routinely find myself having negative flashbacks about the moment I was diagnosed and the hospitals where I attended related appointments. I find these thoughts draining on a daily basis. If I don't succeed in managing these negative thoughts then it heavily impacts on my employment, relationship and general mental health, including my ability to medically manage my haemophilia on a day-to-day basis.
21. Whilst being infected with HCV, I also experienced the physical issues relating to having an acute infection, displaying flu-like symptoms, exceptional fatigue and an inability to concentrate.
22. Further medical complications resulted from the HCV infection. The diagnosis caused a serious deterioration in my ability to medically manage my haemophilia, which resulted in many debilitating joint bleeds. I felt there was no point in continuing with my life and therefore would find it increasingly hard to see the point in having my Factor VIII injections. As

a consequence, I have had many knee and elbow bleeds which impacted on my ability to carry out day-to-day activities for myself, such as getting dressed, cleaning my teeth, seeing to toilet needs, driving and importantly giving myself Factor VIII injections. It has been incredibly demoralising throughout my life to have to rely on my parents and others to do these things, on my behalf.

23. The deterioration in my mental health after receiving my HCV diagnosis resulted in me no longer caring about my weight. I felt detached from looking after my health and it made existing problems I had with my weight worse. I frequently fluctuated between 9 stone and 17 stone. This caused several problems for me mentally and physically and in 2008 I underwent a ruptured throat operation due to the effects I had suffered.
24. I found the consequences of the weight loss, particularly the excess skin on my stomach, unbearable and on 15 January 2014 I had an abdominoplasty operation to try and resolve this issue. As I was previously told the NHS were unable to carry out the procedure, I paid to have it done privately at The Park Hospital in Nottingham. The procedure alone cost £10,000. However, I believe that The Park Hospital saw me as a moneymaking exercise and I was emotionally blackmailed into agreeing that if anything went wrong during the procedure I would stay in The Park Hospital's Intensive Unit, costing me £1,700 per day. My haemophilia consultant (NHS) Doctor [GRO-D] oversaw the procedure whilst Doctor [GRO-D] carried it out. I was one of the first people with haemophilia to have this operation, but despite this, Doctor [GRO-D] assured me it would all go well.
25. I had apprehensions prior to having the procedure at The Park Hospital. Doctor [GRO-D] had told me that The Queens Medical Centre had wanted the operation to be performed there and not at The Park Hospital. Although I believed it was a problem to go into The Park Hospital, the doctors there saw it as an opportunity to make more money out of me due

to my haemophilia. Doctor [GRO-D] also informed me that there were no contingency plans in place for the procedure. However, a month before the operation, Doctor [GRO-D] emailed the Haematology team at The Queens Medical Centre and myself, requesting further information and claiming contingency plans were in place. An extract of this email is shown below:

"I will need comprehensive instructions on the management of the Factor VIII and the levels testing etc during Mr [GRO-B]'s stay. It would be normal depending on his final decision for him to be an inpatient for 2 or 3 nights.

If during his inpatient stay he needs blood testing to be performed this will need to be reflected in the admission plan.

This condition and its management are outside my medical expertise and I do not feel able to take responsibility for any aspects other than to perform safe surgery and to monitor the post-operative condition using standard parameters. It is possible that among the nursing staff there are those with experience in this area, but I do not know this for a fact.

I need to know if there additional components to Mr [GRO-B]'s care package which will need to be delivered while he is an inpatient at the Park and that contingency plans exist to admit him to the NHS if there are issues related to his bleeding."

26. I believe that the procedure for the abdominoplasty was carried out completely improperly. Firstly, my procedure should have been done first thing in the morning to ensure that the full support of the hospital could be drawn upon if complications arose due to my haemophilia. However, my procedure was done later on in the day.
27. Secondly, Doctor [GRO-D] had told me that the operation before mine had taken extra time, which resulted in me having less time to have my

procedure done. I am aware that the surgeon's fee for doing the procedure is reduced, if the time runs over and I believe that this may have resulted in my procedure being rushed.

28. Finally, my blood levels must be checked several times before, during and after operations to ensure that my blood is clotting properly. However, during this operation, my blood was being taken at The Park Hospital and then transported over to The Queens Medical Centre to be tested. Doctor GRO-D admitted that this method was risky.
29. The Haematology Team at The Queens Medical Centre were unable to manage and monitor my blood levels and to compensate for this The Park Hospital increased my Factor VIII to abnormally high levels. My immune system tried to fight the high Factor VIII levels and I ended up losing more blood than expected. Despite Doctor GRO-D wanting to transfer me immediately to the Haemophilia Unit at The Queens Medical Centre, The Park Hospital wanted to keep me in. I felt as though I was their patient and therefore their property. I was then given a blood transfusion at The Park Hospital. After the operation, I remember the anaesthetist saying to Doctor GRO-D *"Be careful what you say because GRO-B's coming to"*. Doctor GRO-D then told me that the procedure was a complete success.
30. I discharged myself from The Park Hospital on 18 January 2014 despite knowing that I was not recovering, because I knew that The Park Hospital fees had the potential to bankrupt me. Doctor GRO-D had told me before I left The Park Hospital that, I would require haemophilia services on the following day.
31. The next day, my parents took me to the Nottingham City Hospital. I was initially reviewed in the Haemophilia Unit and I recall a doctor in the Unit telling me: *"We're on your side, not laughing at you"*. I was then taken to the observation ward, where I was ignored by the medical staff. I attributed this to me having the procedure carried out in a different hospital and there being no contingency plans. I became increasingly

frustrated and agitated. I hobbled over to the reception desk, stressed and crying, and asked why no one would help me. I remember saying that I was going to remove the drains in my stomach myself but I overheard a doctor saying they would discharge me if I did. The other patients were looking on and didn't know what to do. I got back to my bed, pulled the curtain closed and sat there crying to myself.

32. After coming home from the Nottingham City Hospital, I started bleeding from my belly button. I phoned 999 and got taken to The Queens Medical Centre Accident & Emergency Department, where the Haematology team suggested removing the drains from my stomach to control the bleeding. Whilst in the hospital bed, I received a call from Doctor [GRO-D] on a private number. Doctor [GRO-D] told me that if I authorised the Queens Medical Centre to take the drains out, he would no longer treat me. Doctor [GRO-D] said that he did not want anyone else to manage my surgical side or make decisions in that area. Doctor [GRO-D] wanted to take the drains out a few days later at The Park Hospital as originally planned.
33. Whilst I was an inpatient at The Queens Medical Centre, I emailed the Haematology team at the Queens Medical Centre to update them on my phone call with Doctor [GRO-D]. Afterwards, I remember speaking to nurse Linda Trower who told me that Doctor [GRO-D] was gagging me. She informed me that Doctor [GRO-D] was trying to get me a referral to another plastic surgeon in the hospital to side-track [GRO-D].
34. I decided to do what Doctor [GRO-D] said and wait to have my drains removed at The Park Hospital. I was too weak to fight on my own, on strong pain medication and hadn't slept since I had come out of The Park Hospital. Doctor [GRO-D] later came to visit me at The Queens Medical Centre and informed me that I may have to go back into surgery to see why I was bleeding from the belly button. I remember pleading with him not to take me back to The Park Hospital as I knew it could bankrupt me. I was living on my own and trying to manage and deal with all of this. I do

not know how Doctor [GRO-D] could have behaved in that way when I was in such a fragile state.

35. I stayed at The Queens Medical Centre and thankfully my situation very slowly started to improve. My body began to fight back; I eventually got more stable, my haemoglobin levels started to increase and I was discharged. After that, I had check ups at The Park Hospital with Doctor [GRO-D]. At that point in time I had no one for support and used to drive myself to the appointments with clothes pegs holding up the drains to the top of my vest. I eventually got the drains taken out at The Park Hospital, which left two holes in my hips that I would hold cotton wool on to stop the bleeding.
36. I realised soon after my recovery that I was not happy with the outcome of the operation. The excess skin was gone but the procedure seemed incomplete and left my stomach looking bizarre. At my final appointment with Doctor [GRO-D], he asked if I had any concerns or complaints regarding the surgery but I was so traumatised by what had happened I said no; I could not face or process having any further surgery. I recall Doctor [GRO-D] telling me that The Park Hospital were hoping I never would never talk about what had gone wrong with the operation because I would be too embarrassed of having the surgery in the first place. I found the whole procedure highly traumatic and I lost trust in all the hospitals and medical staff involved. I felt helpless, threatened and bullied throughout. I believe my HCV spiralled everything out of control and this procedure was one of the results.
37. Prior to my abdominoplasty, my weight caused significant problems for me particularly contributing towards my knee and ankle problems. This resulted in numerous surgeries, including two ankle fusions and a talonavicular fusion, the effects of which still cause problems for me today.

38. In 2016, the screws from one of the ankle fusions became infected due to an ankle bleed being aggressively treated with ice. After four to five months of various appointments and MRIs I almost had to delay my wedding in GRO-B 2016 to go into surgery to take the screws out. I found the pre-operation consultant GRO-D problematic to deal with at the time; he wouldn't speak to me and was notably nervous. I believe this is because he was worried that they had left treating the infection for too long. The surgery took place in August and the screws were removed. However, I still experience a lot of pain and regularly take Tramadol. I had to push to see GRO-D again but his suggestions, such as swimming and using a splint, have not improved the pain.
39. Being infected with HCV impacted upon many parts of my life, including the treatment I received both for medical and dental care. I believe the stigma around me having contracted HCV aged fourteen meant that I was not given safer blood products when they first became available. I had already received an infection and there were people who were free from them.
40. I also feel as though it was more difficult to obtain dental services after the HCV diagnosis. For example, rather than having my wisdom teeth taken out at the dentist, I had to undergo an emergency procedure to remove them at The Queens Medical Centre. I also found registering with the dentist problematic. I could not register until The Queens Medical Centre confirmed that I was telling the truth about my HCV status, despite me signing a statement saying 'HCV resolved'. Again, I felt this was added stigma due to my HCV and I was annoyed at the insinuation that I was not telling the truth about my infection.
41. Being infected with HCV impacted my private, family and social life greatly. I found social occasions and dating tough. I remember holding a baby at an ex-girlfriend's family gathering and everyone in the room looking at my hands for cuts. Some of my friends would understand but others would feel nervous around me or not want to be associated with

me at all. I have found it difficult to make friends throughout life because of my HCV.

42. In March 2018, I had booked to go on holiday through GRO-D and was required to have a 'fit-to-fly' form signed by my doctor to confirm that I was safe to fly. Despite receiving a fit-to-fly letter, the air steward on the plane singled me out and loudly asked if I was fit-to-fly. I felt humiliated by this unnecessary incident and I was concerned that the passengers close by were immediately relating my haemophilia to being infected with HIV or HCV.
43. My HCV diagnosis also severely impacted my educational and professional life. I had months off school at a time due to both my haemophilia and HCV related issues, which resulted in me leaving school without any meaningful or useful qualifications or future prospects. I stopped caring about most things after my HCV diagnosis, I felt as though I had failed already so what was the point in trying. I had no desire to get a job and would ask my doctor (Doctor GRO-B), who had witnessed many of my health issues, to be signed off 6 months at a time.
44. In 2004 I had my first job as a software engineer. Despite enjoying my work and being good at it, I was suffering with left knee bleeds and my ankle joints at the time, due to my weight. The director of the company I worked for was not supportive; he had no compassion or understanding towards a person with a medical condition. I was working full time in software development whilst on crutches and after work I would drive myself to The Queens Medical Centre to get on-demand treatment, with one leg up in my automatic car to control the bleeds. In 2006 I felt forced to resign due to my poor physical health at the time.
45. Throughout the majority of my professional career and prior, I believe that I have been penalised and passed up on opportunities because of HCV and haemophilia. As soon as I had a bleed, employers tried to find an excuse to make me look bad at my job. I have found several employers

unsupportive and inflexible towards my medical condition. One previous employer refused to let me work from home one day a month so that I could receive my home-delivered medication, if I am not there it creates further difficulties for me in receiving and managing my treatment. I have found it difficult to both obtain and keep any form of employment, let alone full time, due to my haemophilia and the associated stigma of the HCV status that goes with it.

46. Both my parents and myself have suffered financial detriments due to my HCV and haemophilia. When I was younger my father had to give up his job as a mechanical engineer to regularly take me to hospital for on-demand treatment. This involved treatment which would be administered at the hospital when I had a bleed, rather than the daily treatments which I received later into my adulthood. When I was older, I was unable to hold down a job because of the bleeds in my ankles and knees. I refused to apply for certain companies because there would be questions on their forms regarding viral infections. As a result, I never thought I would have a professional career or earn any sort of money.
47. I am still affected financially by my haemophilia and HCV, for example having to pay higher insurance premiums. The Motability Scheme has been of invaluable help. However, I am now waiting for a decision from Capita to see if I can still receive a car and blue badge, which I desperately rely on.

Treatment/Care/Support

48. I have not faced difficulties or obstacles in obtaining treatment in consequence with being infected with HCV. I attribute this to the fact that my body naturally cleared the HCV and therefore I did not have to fight to get it. However, no counselling or psychological support was ever made available to me in consequence of being infected. It has taken a lot of effort and work to get to the person I am now and I believe both my

parents and myself would have benefitted greatly from this kind of support.

49. I can confirm that the Inquiry team have made me aware of the psychological support that the British Red Cross can offer my family and myself; I have received their contact details from the Inquiry Team and I will consider getting in touch for their services.

Financial Assistance

50. I was made aware of the Skipton Fund from nurse Anne Massingham, who informed me of the different levels of payment people who became infected with HCV due to blood or blood products could potentially receive. Between 2004 and 2006 I received £20,000 from the Skipton Fund as an ex-gratia payment. Later on I was able to receive monthly payments in the sum of £250 from the Skipton Fund, which was increased to £1500 in January 2018 and funded by the NHS Service Business Authority. I have also received winter fuel payments since 2013 in the sum of £500 per year.
51. The processes of applying for both the initial Skipton Fund payments and the later NHS Service Business Authority increased payments were complicated, technical and difficult to understand. The forms included medical jargon and I was unable to complete either of them without the help of medical professionals.
52. I was disappointed by the ex-gratia payment I received from the Skipton Fund. I was frustrated that the payment was ex-gratia and did not force anybody to take responsibility for what had happened. At the time of receiving the £20,000 payment I was living at my parents and struggling with my condition. The payment allowed me to move out and receive a mortgage but I believe it was not proportionate to the situation I was forced to endure, it merely put me on an even footing to those who did not have to suffer in the way that I did. In addition, the monthly payments do

not secure my future in any way, as the payments I receive are non-committal and could be taken away at any point in time.

Other Issues

53. In terms of my expectations for this Inquiry, I want to know the truth about what happened to me and to those less fortunate than me. I believe that there has been a failing at multiple levels and an epic amount of covering up by numerous departments. The information that has been told to me and the general public I believe has been deliberately fragmented to avoid anybody ever finding out the truth of what has really happened.
54. I also want to be provided with recognition and an apology for what happened to me, as well as a proper settlement figure which is proportionate to the situation I have had to endure, rather than dribs and drabs of non-committal payments each month that could be taken away at any point in time. A lump sum or commitment to a continuous payment would help future proof myself, my wife and any potential children we may have. I am unsure as to how long I will be able to continue to work and I think that the pressure could be alleviated by a payment like this. Both my parents have also suffered mentally and financially and I believe they and others in their position should receive help.

Statement of Truth

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

Signed GRO-B

Dated 11. Feb. 2019