Witness Name: GRO-B
Statement No: WITN5269001
Exhibits: 0
Dated: December 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

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

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B and I live at GRO-B GRO-B I have been married fo GRO ears and I have two children, GRO-B ears old an GRO-B years old. I am a Shift Manager fo GRO-B at the GRO-B.

2. I was infected with the Hepatitis C Virus (HCV) through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to any of my medical records.

Section 2. How infected

4. I have Haemophilia B (Christmas Disease) with 2% clotting factor. I was born with this.

5. I have always received a 'factor' product. The majority of the product was given to me during my childhood and early teens, and twice in my adulthood. Given that I have Haemophilia B, I understand the 'factor' product would have been Factor IX (FIX) concentrate. I was always treated at hospital and never had home treatment.

6. I was treated at Oxford Haemophilia Centre, Dr Matthews and Dr Rizza were the doctors who treated me over the years.

7. According to my parents, the first time it was discovered I bled a lot, I was holidaying at my grandparents in GRO-B and was 4 years old. I fell over, knocked my front teeth, and the bleeding wouldn't stop. My mum had to take me to Portsmouth General Hospital. My mum insisted at the time that I was tested for Haemophilia as she knew that her father had it. I am unsure if it was determined or confirmed at that point, however some treatment must have been given as the bleeding had to be stopped.

8. At around 7-8 years old, I had teeth removed at the GRO-B Hospital with FIX concentrate administered ahead of the surgery. At 9 years old, my right calf was injured, and I had an internal bleed. I was hospitalised for two weeks at the Nuffield Hospital as a result. At around 10-11 years old, my thumb was crushed in a car door. I was treated at the Haemophilia Centre in Oxford. I was admitted to hospital on several occasions in Oxford from 9 through to 14 years old due to right and left knee injuries and having to have hydrotherapy to enable me to start walking again after being in plaster for two weeks. At 20 years old, I had a heavy fall at work and was treated at the Haemophilia Centre in Oxford.

9. No information or advice was provided to me or to my parents at the times when I needed blood clotting agents.

10. I was provided with the information relating to being infected with HCV by Dr GRO-D during an annual appointment at the Oxford Centre in 1993 or 1994. The information was given to me verbally.

11. From memory, having been told that I was infected with HCV, I was told 'You never know, through medical science/research, in 15-20 years, there could be a cure/ treatment'. I was told there was no need to change my current lifestyle and I do not recall being provided with any literature on the subject. I was not asked how I felt or the impact that being told this information had affected me.

12. I believe that as soon as it was discovered that I was infected with HCV, I should have been made aware immediately. I believe more in-depth information should have been provided.

13. It was a complete shock to me. I was blindsided. I was completely unaware that this was a possibility from the treatment I had been given over the years and I feel that I should have had the opportunity to have a family member or a support person with me.

14. From memory I wasn't provided with any information relating to the risk of others being infected. I was (am) married and was sexually active, but at no point was I advised that I could potentially infect my wife.

Section 3. Other Infections

15. I do not remember when, but I later received a letter regarding a possible infection of variant Creutzfeldt-Jakob Disease (vCJD) through blood products. I remember thinking 'What else will they throw at me?'

Section 4. Consent

16. I believe I have been tested without my knowledge and consent, without adequate and full information and for the purposes of research. When I was approximately 13-14 years old a nurse from the Oxford Haemophilia Centre would come to my parents' house every week for about 6 weeks to take blood. I don't know how this was arranged. I would assume my parents received a letter to advise this was going to happen. It got so much for me and I was so fed up that I asked the nurse if she could also take blood from my sister (as my older sisters used to take the mickey out of me) and she said that she could for one of the weeks she visited. We were never told why this was happening and I do not believe that I ever gave consent although I did allow the blood to be taken as I was a child and didn't know any better. I was never informed why this was taken at this time or at any time since. I was never provided with any test results or advised what had happened to the samples taken.

Section 5. Impact of the Infection

17. Over the years I have had several 'wobbles' concerning what I have. I have only every told very, very close friends that I have HCV as I was always concerned about the stigma (particularly in the 1990s) and having to go into full detail to explain how and why I have it. I have always kept to myself. I do try to lead as normal a life as possible, but I am always aware that I have HCV and take care where needed. I have been sure to alert/remind medical professionals (my GP and Dentist) of it to so that they take the necessary steps to protect themselves.

18. The physical effects are that I have lost over 4 stone in weight. My muscles are starting to lose mass (muscle atrophy), I have become incredibly tired and I have had some short-term memory loss. Mentally I have tried to push through how I am feeling, to be strong for my family; I have pushed a lot of how I am feeling away as much as I can. Because of that and up until recently, me being infected with HCV has had a minimal impact on my family. We have tried to live our lives and enjoy them as much as possible without the shadow of the diagnosis looming in the background.

19. When I was first told I was infected with HCV, I can remember thinking that I would be lucky to make it past 50 years old. It has always been at the back of my mind, that I am on a countdown clock. When I was diagnosed with a decompensated liver through liver cirrhosis this summer, I said to my wife that I have lived 2 years longer than I expected. Over all the years, I have pushed a lot of how I have been feeling to the back of my mind.

20. This summer (2020) after suffering all the symptoms of a failing liver, to include ascites and swelling of my legs and ankles, I had several blood tests, scans and was referred to Dr Guphter at Milton Keynes Hospital. Dr Guphter then referred me to the Transplant Team at Addenbrookes Hospital in Cambridge. The diagnosis is that HCV contracted through contaminated blood products has decompensated my liver to such an extent that I need a liver transplant and I am on the waiting list. My liver has been struggling to work and is now failing.

21. I am left devastated with this news. It was totally unexpected. It has impacted my life to the extent that I am currently having to work from home as I can't do my job fully at my place of work. I am extremely tired. I am unable to do a great deal other than take care of myself.

22. My wife and children have been affected. We are a very happy family and this has come as a huge blow to all of us, my wife is ensuring that I am well looked after and taking care of me, my children are also supporting, but all of us are scared and worried that this won't have a positive outcome for me.

23. I have always been able to work, but I now have to work from home and as I continue on the waiting list and possibly deteriorate while waiting, there could be further impact if I am unable to work at all. Having cirrhosis and working from home has already affected my salary (to the extent of £5,000-£6,0000 per year) as I am unable to work shifts as before. If I am not working, my annual bonus paid three times a year of £5,000 to £7,000 (dependant on individual and company performance) is also lost.

24. I have not had treatment for HCV. I was given to understand (through blood tests) that I had self-cleared the virus (albeit I am aware that it can sometimes lie undetected in the liver glands). I went through a stringent assessment at Addenbrookes Hospital from 16th to 18th November 2020 and there is no trace of it.

25. I now have to take the following medication for my liver cirrhosis: Carvedilol 6.25mg twice daily; Spironolactone 200mg once daily; multivitamins daily and I will be taking autoimmune medication for the rest of my life once I have had the liver transplant.

Section 6. Treatment/care/support

26. I have not faced any difficulties in receiving treatment, care or support, but no counselling or psychological support has ever been offered to me.

Section 7. Financial Assistance

27. I am unsure of when and how I was informed about the Skipton Fund; I believe this came from the Oxford Haemophilia Centre. I received the £20,000 Stage 1 payment from the Skipton Fund in or about 2004.

28. I was advised about the EIBSS Stage 2 payments when I was taken ill this summer and had to visit the Oxford Haemophilia Centre. They provided me with the claim forms. I received a backdated amount of £39,438.35 and monthly payments of £1564.33 for Stage 1. I received backdated payments for Stage 1 because my details should have been passed from the Skipton Fund administrators to EIBSS. However this didn't happen, so when I applied for Stage 2, they advised I was owed money from Stage 1. I then continued with my application for Stage 2 and I have been advised I will be receiving a £50,000 lump sum and a backdated monthly payment to when the Stage 2 claim form was received of £2,426.01 and then monthly payments of £2,373.00 going forward.

29. I received the forms, sent them off, spoke to Chris Boddy at EIBSS on a couple of occasions and received the money due within their timescales. I had to provide disk evidence from my medical records to confirm that I had cirrhosis, which I obtained and sent when requested.

30. On the original Stage 1 application form there was a declaration from the Government to say that they were not liable and that you couldn't bring proceedings against them going forward. Whilst I appreciate the financial assistance being offered, I feel the £28,000 (approx.) amount being paid yearly is a very small price for a life. If I die within 10 years, then it puts a £280,000 value on my life. I can see people in Northern Ireland and in Scotland receiving more. I would ask 'what makes me, living in England, so different from the rest of the Union?' I do believe that I should receive more financial assistance. If I have to give up work entirely the annual figure of £28,000 is less than half of my current salary. I won't be able to claim benefits, as I am a home-owner, so I will have no

further support. I want to be able to clear my mortgage and ensure my family and I am financially stable which is what I have always strived to work for.

Anonymity, disclosure and redaction

31. I am seeking anonymity and would like this Statement redacted before publication.

Statement of Truth GRO-B

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

Signed GRO-B ....

Dated..............24.12.20...............