WITN0053001

Witness Name: Paul GRO-B
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Dated: 2 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAUL GRO-B

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1. I, Paul GRO-B of GRO-B North Yorkshire, GRO-B United Kingdom, make this Statement for the purpose of delivering details of my personal story to the Infected Blood Inquiry.

2. I was born at GRO-B on GRO-B 1957. The forceps used during delivery caused a birthmark on my forehead and another on the side of my head.

3. When I was around 4/5 years, I suffered prolonged and an unusual amount of bleeding following extraction of some teeth. My father was known to have a bleeding disorder and as a consequence I was sent to the Haematology Unit at the Royal Hallamshire Hospital, where coagulation tests were undertaken. The tests indicated that I had both a Factor VII and IX deficiency. I recall being told this was Christmas Disease.

4. I was given a pocket-size, green, hard-covered booklet listing these deficiencies and told to carry it at all times because it would alert medically trained personnel to my condition, so that appropriate action could be taken.

5. Although this booklet has finally perished, I still carry an unofficial card with the same details in case of an accident or emergency. They are:

Blood Group:	A
Rhesus Type:	Positive
Blood Clotting Classification:	Haemophilia B
Blood Clotting Deficiencies,	INR = 1.5, APTT = 33.1 seconds, Fibrinogen = 1.5g/l, Factor VII = 46.5 iu/dl, Factor IX = 49.7 iu/dl

6. My childhood was uneventful in this respect. I managed to enjoy the normal school, sport and play activities. I kept my card hidden and my condition secret. I was always conscious I must seek medical help quickly should I suffer significant bleeding or alert medical practitioners such as doctors and dentists.

7. I became more conscious of the birthmark on my forehead during adolescence. During my mid-twenties, it developed a small but unsightly growth. I consulted my GP and he referred me to GRO-B

8. I have kept a diary on and off since the age of 12 years and have recorded many of the relevant dates when treatment was received. In March 1984, I received notification of referral to GRO-B. I was examined by a doctor who informed me the growth was benign and that the whole birthmark could be removed. The doctor had a poor command of English and did not seem to place much importance upon my green booklet. Nonetheless, I had full confidence in his professionalism and trusted him.

9. Accordingly, on Friday 9th April 1984, my birthmark was removed along with the small growth at GRO-B. Afterwards, I was sent home with my head bandaged.

10. Four days later on 13th April 1984 the stitches were removed at GRO-B

11. Two days later, on 15th April 1984, the wound started to swell and the night it burst, resulting in excessive and rapid blood loss from the wound which, alarmingly, splattered the ceiling and walls of our bedroom. My wife called 999 and an ambulance was dispatched to take me to GRO-B Accident & Emergency department. We showed my green booklet to the ambulance man who seemed very concerned and both my wife and I were frightened for my life. This was the most significant bleeding event I'd suffered since being diagnosed with a bleeding disorder.

12. The attendant medical staff asked to see my green booklet and I recall the wound was stitched *without* a local anaesthetic, which was painful. I assumed this was done to stem bleeding as rapidly as possible. Afterwards, my head was re-bandaged and I was injected with blood factor concentrate and kept in hospital overnight under observation.

13. Removal of the stitches was delayed to ensure the forming scab was sufficiently strong, which resulted in more prominent scarring. The wound took a long time to heal and minor bleeding from the scab occurred when I accidentally caught it on something, especially in bed at night when I rolled onto it. I used to tie down my right arm to the left side of the bed to prevent me doing this. It took several months for the wound to fully heal and I visited my GP and the medical department at work on different occasions. At no stage did anyone mention any risk associated with being given blood clotting factor concentrate and I had no idea of the infection which had been introduced into my body.

14. In August 1985, I was on holiday in Dublin, Republic of Ireland, and I happened to read an article in The Times in relation to contamination of blood products with HIV. I was dumbfounded and very concerned. However, I reasoned that firstly, if the batch

of clotting agent administered to me had been contaminated, someone from the National Health Service would have contacted me by now and I would have been called back for tests. Moreover, I hadn't been ill and felt well, so surely any there was no chance I had AIDS. I was now aware of the awful seriousness and stigma associated with this virus and no doubt forced all doubt and concern to the back of my mind.

15. Between 1986 and 1998 my health gradually began to deteriorate. Initially, I noticed how fatigued I was becoming but put this down to my developing and busy career. I was moving up the management structure of my company and in 1998, achieved Senior Management status. I had role-related objectives to deliver and what felt like significant responsibilities for a large team of people. I felt very proud of the faith the company had invested in me and strove to show it had been well placed. In addition, my wife and I had started a family in 1996 and I assumed my chronic fatigue was a mix of work stress and domestic demands. However, other symptoms began to develop such as unusually bad reactions after going out for a drink and feeling very nauseous on multiple occasions. In 1998, I unexpectedly contracted pneumonia and for the first time had to take time off work. I was very poorly and jaundiced and it took weeks to recover.

16. With hindsight, I now find it amazing how I struggled on, holding my job down during periods of restructuring, coping with staff problems in my team, achieving objectives and trying to be a good husband and father as well , while all the time failing to make any linkage between my deteriorating health, the blood clotting factor I'd been given and the gradual public linkage of HIV to contaminated batches.

17. While working abroad during May 1999, by chance, a local agent of my company told me about a Hepatitis C crisis there. I had never heard about this virus, but when he described the symptoms and frequent outcome, I became very alarmed and finally realised I must find out if I had been infected. I was now all too aware of the huge social taboo around the subject, the possibility of my company getting rid of me

and worse, the possible negative reaction of my wife and children. In particular, the appalling realisation I may have transmitted the virus to them.

18. Feeling a need for continued secrecy for the time being, I discovered I could be tested anonymously at a sexual health clinic without results being placed on medical records. I wept with relief when told the HIV result was negative, but numbed as I learnt I was HCV positive. The following weeks became a psychological hell as I tried to decide what to do. I tried to learn more about HCV and recall a young member of staff in a book shop recoiling with fear in his eyes when I nervously bought a book on the subject.

19. I realised I had to tell my wife and seek medical help, although the prognosis appeared dire. I decided to make it official, so went to my GP, told him of my concerns and symptoms and that I wanted testing for HIV and HCV. I did not tell him about my earlier test and what I already knew. At first he refused, scoffing at the idea but I was persistent and he finally agreed. I returned to his office when the results were ready. I sat down and could see the positive result for HCV upside-down on a form laid between us on his desk. To my astonishment, he said there was nothing wrong with me! When I pointed to the positive result on the form, he became flustered, said he hadn't noticed that and was sorry. I put it down to incompetence, but I have since wondered.

20. Subsequent liver function tests showed pronounced irregularities. My company provided private healthcare for executives and so the GP referred me to a consultant, Dr. A J Turnbull GRO-B After a couple of visits, he referred me onto Dr. Charles Millson at Saint James's Hospital in Leeds.

21. Dr. Millson was excellent, though I was not mentally prepared for the convicts handcuffed to prison officers in his clinic. It greatly increased my sense of being an outcast and that somehow, I was a bad person. Knowing of my scientific

background, Dr. Millson objectively described sampling errors, risks, likely development of the disease but most worryingly of all, the absence of reliably effective treatment. Later, during 2000, he offered to try and get me on a funded drugs trial using Ribavirin and Pegylated Interferon. So far the success rate was 50:50, like flipping a coin.

22. I told my wife. She was tested and her results were negative. Although she took it reasonably well, I feared something had changed between us. I was struggling on all fronts, and fearing the worst, I planned for my own suicide by driving my company car into a tree on a sharp bend near Howden on the A63 and researched necessary preparations. Certain financial entitlements would materialise in the event of my accidental death.

23. I began a 48 week course of treatment in 2002. Injecting myself in my leg was challenging, but nothing in comparison to the psychological effects. I suffered mood swings, bouts of anger and depression which adversely impacted on home life. My appetite collapsed and Dr. Millson warned me that if my bodyweight fell below 71 Kg, I recall, he would have to lower the dose. Maintaining my body weight to receive maximum dosage, religiously taking the drugs, attending clinic and trying to be normal at work to ensure continuity of income became an all-draining obsession. I also suffered shaking, night sweats, hair and energy loss. I looked dreadful and knew people at work were asking questions behind my back as to what was wrong with me.

24. The Liaison Nurse was helpful in helping me obtaining the drugs, injection technique and administration for my treatment. However, there was no psychological support, which should have been provided. I heard rumours that others had killed themselves.

25. During 2002 my position at work was made redundant. Being ill with an unproven treatment, struggling just to go to work, having a large mortgage, two young children, and difficulties maintaining a harmonious home life, the situation now felt apocalyptic. Summoning every ounce of energy left, I set about trying to obtain another position. Suicide, it felt, was now the only alternative if I failed. I presented a plan to the Divisional Board and with amazing luck, was offered a position with the same seniority in an elite commercial function, starting the following year.

26. In 2003, a succession of PCR tests verified the virus was undetectable and I was therefore free of the disease. Naturally, I was jubilant and thankful. I began my new role which was exceedingly challenging, but realised I had changed. I continued to suffer mood swings and bouts of depression. To this day, I often wake up feeling very low. I have attended workshops to address this which have helped but have not eliminated them. I had stopped all alcohol intake after discovery of the virus until after all-clear result, and although I then began drinking moderately, it was and usually is accompanied by worry. Periods of unexpected fatigue always cause me consternation.

27. This whole experience has changed me significantly. I have come to accept my bouts of low and changing mood and that some risk of premature death remains. Although my career remained relatively successful and I enjoyed it, I decided to retire early to ensure I had adequate time to relax and savour a non-working life. This was contrary to the culture of my company where executives retain a strong work ethic in later years. So in 2014, at the age of 57, I took early retirement. Rather than accumulate money for my children's education and training, I decided to focus on my own welfare and spend more time with my family.

28. I was grateful to receive £20,000 compensation, though it seemed a small payoff by today's standards and in relation to the salary I had enjoyed. I also receive £341 per month from NHS-BS and a winter fuel payment.

29. It is incredulous and very wrong, that even now, no proactive monitoring service is provided by the NHS. When I turned 60, I took the initiative and went to my GP to ask for new PCR and Liver Function tests. Thankfully, I remain virus free and my liver appears to function normally.

30. In writing this statement, I find it difficult to convey the impact Hepatitis C and its treatment has had on my life. However, I still consider myself lucky when I learn of the fate of others.

31. I ***attach*** summary of my Hepatitis C infection as Attachment "A" to this statement. [Exhibit WITN0053002].

32. I have some key questions to pose to The Infected Blood Inquiry as follows:

1. In the first instance, as a patient known to have a defined bleeding disorder, why was I allowed to have an non-vital, elective procedure with a possibility that Factor Replacement Therapy may be required, at a time of known viral transmission risk, especially without any cautionary information or comment whatsoever?

2. Why was I prescribed a Factor Replacement Therapy at a time when it was known that such treatment was potentially both HIV and Hepatitis C infectious?

3. Why was I never traced in terms of my Hepatitis C status? I am on the National Haemophilia Database and therefore, it would have been easy to trace me as a recipient of a blood product and recall me for testing Why is it, to this day, that many patients have had to instigate testing themselves? Why has the Health Service not taken responsibility for proactively screening patients at recommended intervals?

4. Why for so many years, was my wife, my family and medical practitioners put at risk in terms of transmission of Hepatitis C from myself?

5. Why was there no mental health support for patients treated with Pegylated Interferon and Ribavirin treatment when there were early indications of serious psychological side effects?

6. Why unlike other countries, has no appropriate compensation been provided to persons infected and affected?

7. Why after all these years and the amount of documented death and suffering, has no one formerly apologised?

I pose these questions on my understanding that I ought not as a person with mild Haemophilia B to have received any blood product or undergone a non-urgent, elective procedure at a time of high risk in terms of transmission of both HIV and HCV.

Statement of Truth:

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

Dated the 2nd day of May 2019

Signed:....... GRO-B ....Paul GRO-B