Witness Name: GRO-B

Statement No.: WITN3539001

Exhibits: WITN3539002 - WITN3539004

Dated: November 2022

#### INFECTED BLOOD INQUIRY

|    | WRITTEN STA | TEMENT OF           | GRO-B |  |
|----|-------------|---------------------|-------|--|
| 1, | GRO-B       | , will say as follo | ows:  |  |

#### **Section 1: Introduction**

1. My name is Dr. GRO-B . My date of birth and address are known to the Inquiry. I have a pHD in Philosophy Theology. I was previously employed as a first aid officer for the NHS and then in the same role at the Cabinet Office. I am now retired.

#### **Section 2: How Infected**

- 2. Although born in GRO-B, Kent with hereditary haemorrhagic telangiectasia (HHT) and Von Willebrand disease, they were only diagnosed in 1975 by Lewisham Haemophilia Centre. As Von Willebrand disease is a deficiency of a Clotting Factor VIII i meant that I received hundreds of blood products such as fresh frozen plasma (FFP) and Cryoprecipitate from 31 January 1975 onwards.
- 3. The first time I received blood products was on 31 January 1975. My right knee had swollen significantly and would not go down. I was taken to

Orpington General Hospital. My twin, GRO-B: B, had already been under Lewisham Hospital Haemophilia Centre after his denist, and later his GP, referred him after hearing about how much I had bled after just one extraction. Dr David Whitmore, at Lewisham Hospital had said to B that I must be seen urgently. took the Von Willebrand disease В papers to show the Sister at Orpington General Hospital, who agreed that I should be seen by Lewisham Hospital, but as it was too late for transport my parents drove me. В went into Lewisham Haemophilia Centre and explained the situation and I was then seen by Dr Whitmore, who was called out by the duty Haemophilia Centre doctor. I was admitted straightaway and set up on an IV drip of FFP which continued overnight and into the next day. On the Saturday Dr Whitmorecame and ordered more FFP.

4. By the Monday, x-rays revealed that my right knee had bone cysts as well as a current bleed (effusion of blood)/hemarthrosis. Both and I had what the consultant said was clinical evidenceof deformities due to extensive childhood "bleeds into knees". An arthrocopy was undertaken on my right knee with both Dr Whitmore and a Consulant Orthopaedic surgeon working together. A torn cartilage was identified as well as "hundreds of telangiectasia's bleeding". A medical conference was held the next day and was attended by haematology/pathology/orthopaedic consultants and registrars. They were shown a picture of the inside of my right knee and it was agreed that it was unknown to have telangiectasia within joints and that it would make further surgery problematic. A full right knee operation was conducted about a fortnight later. I stayed on the Medical Ward throughout as the nursing staff knew me, rather than transfer to the orthopaedic ward. The operation was, in those days, a significant one, which meant I was treated with over 100 units of FFP for over three months, both in hospital as an in-patient and at home. I continued to go back to the hospital after further bleeds. I was treated with FFP every time. This happened every couple of weeks. Every time I would have terrible rigors during treatments/always minimum two bags mostly, if severe four or more, shivering uncontrolably initially, as my

temperature rocketed and nurses packed warm towels round me and helped me drink hot tea in a beaker. As the 'sweating' stage took hold, they gradually took some blankets off and gave me juice drinks.

- 5. Bot ! В and I were never told about any risks of transfusion of FFP. I would get rigors every time I had a transfusion and eventually I was given Piriton intravenously, which meant I would sleep heavily through the procedure, and still feel drained afterwards. I think I was sometimes given Cryoprecipitate with the FFP, but this was usually following dental treatment at Lewisham Hospital. The dental team also made a plastic like denture for me, which was clear in colour, which would be placed in the roof of my mouth with added protection to cover the socket when they extracted my teeth after Haemophilia Centre had given me FFP via IV. I was also given a glucose drip as a new condition had also been found, low blood sugar, but there was no family history of it. They also involved a consultant dermatologist for external bleeding omy wrists and arms of telangiectasis.
- 6. After the transfusions, my skin would be more sensitive to bites or scratches, and used to flare up. I would also have a reaction sometimes that made my tongue swell up. I would feel a prickling and burning pain going up my right arm from my wrist. My local hospi tal had no intravenous anti-histamines and so they tried intravenous steroids instead. I do not think the hospital ever found out what the cause of this reaction was; I certainly did not.
- 7. After completing my education, I was accepted to train as a nurse at St Thomas' Hospital. I was accepted to continue nurse (SRN now RGN) training which started in Bromley Hospital in the 1970's and then moved to Queen Mary's Hospital, Sidcup, Kent as a midwife. However, lifting patients had caused bleeds into my shoulder and upper arms which resulted in me being placed in hospital on bed rest. My parents and

were unable to treat me except for pain relief, and said that I was dying.

B went outside to be sick, my parents then left and they all returned to the car and just drove home in silence. My mother rang her twin sister who said that she and her husband would travel to see me — I knew nothing of this at the time. I was prescribed BlueLabel Vodka due to the side effects of analgesics.

B had asked our GP, Dr GRO-B, about my condition as the family were all stunned at me being 'written off' as dying. He was sympathetic.

- 8. Very soon afterwards, in early February 1977 I was working at a GRO-B GRO-B in Bromley. My twin brother was the manager there. We had been receiving coded warnings about a possible bombing all week. On this day a bomb had been left in the children's department of the store downstairs. The explosion was a big one and I was badly injured I suffered a significant injury to my head, brachial plexus and pelvis as well as other assorted physical injuries. My parents were told had been killed, however firefighters had been able to pull me out of the debris and resuscitate me.
- 9. My GP, Dr. GRO-B, had responded to emergency calls for all doctors to go to A&E Bromley to help. He thought it best if he drove me straight to Lewisham into Haemophilia Centre hands and I was admitted. He left to tell my parents, and, as a military family, they took over the care. I was given FFP and I also received extensive physiotherapy and the occupational therapists made arm splints as the newes were damaged in my neck and spine which caused muscle spasms and shortening limbs. A catheter was subsequently needed to drain my bladder due to retention.
- 10. I slowly recovered with physiotherapy and occupational therapy. Treatment with FFP continued at Lewisham. Unfortunately, the head injury caused my IQ to plummet and I never quite felt well again after that incident. I had GP sick certificates due to over two years treatment for the bombing injuries.

| 11. | In 1978 I moved with my family to <b>GRO-B</b> , Kent and was then          |
|-----|---|
|     | treated at the Margate Haemophilia Centre. Dr Sterndale was the             |
|     | Haemophilia Centre Director at the time. In 1979 I was referred by my GP    |
|     | due to a dental abscess, but they had no dental department. The GP also     |
|     | arranged for Mr Wright, Consultant Ortho to carry out a home visit as I had |
|     | a 'bleed' into my hip. I was immediately admittedto the GRO-B               |
|     | Hospital for traction. My parents and B were told by the Ward Sister        |
|     | that I had blood in my urine but nothing was done about it at the time and  |
|     | I knew nothing about it for many years.                                     |

- 12. The last time I received blood products was in Margate in 1982 by Dr Mark Winter. I was never given a reason as to why the blood products stopped. I was still having bleeds, but was treated with bed rest and analgesics.
- 13. The bed rest recommended to me involved being admitted on the Viking Ward at Margate Hospital. I have never forgotten my experience there, and the horrific treatment of patients in that ward These were patients dying of (what I now know to be) HIV and AIDS, butstaff did not want to go anywhere near them. Due to having a military fa mily background we had been brought up to help those less fortunate than ourselves and to see so many young patients without any visitors was heart breaking. I did meet one dedicated wife, her husband GRO-A was a haemophiliac and one day as we recalled she found their young son playing with Daddy's razor so she had to take it to protect him in case any blood was on it. He'd said "Daddy won't mind". GRO-A died in a side room. I wanted those alone who were to die to have human contact as no vicar visited! I would use my hands to cup theirs with a tiny cross made of woodto comfort them. There were so many and that is why I have made this statement, so that they are not forgotten, as I speculate other hospitals had a similar set up. They refused to feed them and left their food on trays outside the door, irrespective of whether a patient could physically get up to take their food

or not. I was tarred with the same brush of "infected person" because I was given blood products.

- 14. Only on being returned from x-ray did I read the corridor signs of "Authorised Staff Only" and "Danger of Infection" and "No Entry" etc. I was left alone outside, I think they used a bell (like children's wards often did/do, then they were gone!).
- 15. One Saturday morning in Broadstairs I cut my hand and went to see my GP. He kindly (ungloved) bandaged it and said that I must get A&E at Margate Hospital to stitch it as it was bleeding profusely, despite pressure elevating my arm. A nurse at the hospital refused to clean or stitch the wound. She called one of the Doctors to do it and he said "I have taken the Hippocratic Oath but truthfully, I don't want to treat you. Here is the suture set. I will tell you what to do, you will have to do it yourself." I had to stitch up my own wound. Once your notes say you have had blood products, that was it. Nurses on the ward would tak out loud about the fact that I had received blood products and I would see people move away from me.
- 16. Also in the late 1970's I recall attending St Thomas' Hospital London where Professor Ingram took blood from both myself and B and he agreed with Lewisham Haemophilia Centre that I had 100+ FFP and Cryoprecipitate, both as an in and out patient and in 1976 especially. He prescribed FFP and Cryoprecipitate much later, July 1976, and tranexamic acid to curb the bleeding, and the same drug was administered during dental extraction procedures I had there.
- 17. As a family, we moved to GRO-B in Lincolnshire for a short spell from 1984 to 1985, where I was treated by Dr Adelman at the Lincoln Haemophilia Centre. Both B and I had blood taken and physical examinations to see external telangiectasia's. Heconfirmed the diagnosis but also wrote to us both saying HHT also (unheardof) inside our joints

which bleed. I was given no explanation of why or how treatment with blood products had become a problem, and no information or advice about potential risks were given to me.

- 18. Soon afterwards the family moved back to GRO-B Kent, and to the Margate Haemophilia Centre at the end of 1985. I spent some time in the Viking Ward again at this point with leg/knee bleeds. Whilst I was in the Viking Ward I believe I was tested for HIV without my knowledge, by Margate Haemophilia Centre Director, Dr Mark Wither.
- 19. Soon after that time I trained as a first aid officer and worked for some time within the NHS and then for the Cabinet Office. In 1992 I was attending upon a man who had collapsed unexpectedly I put him in the recovery position and was administering treatment when he pricked me with a needle he was hiding up his sleeve. Although I wore disposable latex gloves routinely and washed, the wound was bleeding so I cleaned and dressed it. I wrote up the incident, photocopied it and gave it sealed to B to put somewhere safe as it may never be needed. The man's partner told me he was infected with HIV and Hepatis C.
- 20. The man who had pricked me later died of Hepatitis C and so I decided to have myself tested, about two months after the incident. I was not given any advice to do so by colleagues or any staff members where the incident happened. I took annual leave at the time as I wasvery stressed by what a test could reveal. I asked my GP about how to get tested and she informed me that there was a special clinic held at GRO-B Hospital who would keep the result confidential unless I gave consent. I specifically asked my GP not to record her advice to test in my medical notes as I was worried about what would happen to my job, but promised to warn healthcare staff should the test be positive, but also to prevent being given medication that could compromise my liver.

| 21. | The test for HIV was negative and it took three days for the result. I had   |
|-----|--|
|     | telephoned and as the result was negative they were happy to let me know     |
|     | over the telephone. They informed me that I must atend the hospital to       |
|     | obtain my HCV results which took three weeks. I went to the hospital and     |
|     | had a counsellor sat beside me to go in with me tosee the consultant for     |
|     | the results. I guessed, and was right, that I had tested positive. She said  |
|     | that it was a new condition and they did not know much about it. I went to   |
|     | a special clinic at <b>GRO-B</b> Hospital. As promised, I wrote to my        |
|     | GP to give her results with written consent for it to be used for healthcare |
|     | staff to be made aware of and said I would inform my dentist. I put the      |
|     | letter through her home mailbox so her husband (also my GP) could act        |
|     | on it and refer me to Dr Mark Winter at Margate Hospital for testing.        |

- 22. I was tested again at the hospital and Hepatitis C was formally diagnosed by Dr Mark Winter, Consultant at the Margate Haemophilia Centre. It was presumed that this was due to the needlestick injury. However, no-one discussed the potential that many years of blood transfusions could equally have been a cause. Prior to the needlestickinjury I had never been tested for Hepatitis C. This was in 1993, however I was not referred until June 1994.
- 23. That same month there was an article in the British Medical Journal (BMJ) discussing the significance of contaminated blood.My GP had not heard of this and so wrote enclosing a cheque to the BMJ and obtained the article from the British Medical BMJ directly. He told me the article described the condition as "a silent epidemic" and spoke to me about the number of people that were becoming infected and the symptoms being seen.
- 24. When Hepatitis C was diagnosed I suggested my brother take a test as well as he had been helping me contain my bleeding and changed dressings for me. 

  B was not tested as his GRO-B GP, Dr GRO-B, refused.

25. At no point was I given any information about the condition, the risk of cross-infection or advised about treatment. I do not know if this was because they presumed I had some medical knowledge but I did not know anything about Hepatitis C, neither did my GPs or Margate Hospital.

## Section 3: Impact of the diagnosis and the condition

- 26. When my partner at the time found out that I had been diagnosed with Hepatitis C, he did not stick around. He believed I had been sleeping with other people. I have been celibate since that relationship. I feel the stigma of this diagnosis will follow me forever. Even in 2019 an A&E doctor shouted out for all to hear that a lady who was HIV positive was on the way in having taken an overdose. The doctor was suspended for six weeks after her sister heard him and reported him. This was at Margate Queen Elizabeth The Queen Mother Hospital. Will our NHS ever stop us being pre-judged? Patient confidentiality is ignored when admitted to the ward as well.
- 27. After the diagnosis, and with time, I began to feel more and more exhausted all the time. I constantly had flu-like symptoms and have never really felt well again. I also began to feel down about it all mentally and had worsening joint pain.
- 28. I used to have lots of friends. I told them about my diagnosis and, save for one, their behaviour began to change. They would more their cups of tea away from me if I was sitting with them, I was no longer asked to babysit for friends, and was slowly excluded from their lives. I began to feel like a leper.
- 29. Treatment at hospitals was no better. Sisters on the ward would warn staff that someone with my condition was coming in and I heard them say "don't let them bleed on you". It was a hostile, defensive environment.

| 30. | The one friend that stuck with me was my best friend from school. She   |
|-----|---|
|     | said she would help me in any way she could. My brother and his friends |
|     | were supportive as well. My brother and his partner GRO-B met in 1986,  |
|     | nearly 40 years ago. GRO-B is a chef and B was teaching at the time.    |
|     | They live apart, but GRO-B is B 's carer due to chronic Pancreatitis.   |
|     | They knew very well about the stigma associated with my condition and   |
|     | had seen it affect their own friends. They are my day-to-day support    |
|     | system.   |

- 31. Unfortunately, B was not spared the stigma of my condition either. In 1981/1982 he had to go to hospital for a ganglion operation. He was taken to the ward and, I believe it was a nurse that came out onto the ward to remark that no-one had told them that he had a bleeding problem.

  B was diagnosed with a bleeding disorder in 1975, just before me, and he was told that he must get me urgently transferred to Lewisham Haemophilia Centre. The surgeon was called and had to ask what the fuss was about.
- 32. In 1979 B had to have an appendectomy. He was sent home, driven home by me and went straight to bathroom to change into jog pants instead of a tight suit. He had a swollen abdominal area with severe deep bruising from his nipples to his knees including his penis. He felt like he had been tap danced on as he was so sore. No analgesics were given to him by the hospital, they gave him Paracetamol (family kind of remedies), with the original dressing on his wound it had not been changed since he had been in theatre. He asked me to look at hisoriginal dressing which had come loose so I covered it with a new dressing and rang his GP informing him that theatre had put it on and not replaced it since. His GP asked me to drive him back to Margate Hospital and up to the ward for a new dressing and the GP agreed to ring ahead to inform them. On arrival at the hospital B was told off for returning, however, they changed the dressing and taped around it. He was sent away with more dressings.

B has never received any blood, although he has not been tested for infection at any point, unless during an operation and was never told. It was assumed that because I had a bleeding problem that he was probably infected as well.

- 33. When I went back to work after the diagnosis I declared the condition and explained how I presumed I had become infected. My employers typed a letter and required me to sign it. The gist of the instruction was "don't touch anyone, don't give anyone advice". Under crisis of "conscience" rules I wrote out that if no one else is able to be instructed how to help someone who, without my intervention, would die, I shall do all I can. They reluctantly agreed. I was assisted by the Civil Service Union representative. My pay was restricted. I remember thinking that had I still been working for the NHS I would have kept 100% ofmy salary. I never knew that I could apply to a Criminal Injuries Compensation Authority (CICA) Award after the incident.
- 34. After a few months I took sickness absence and applied for incapacity benefit. This payment continued until 1995 at whichtime I had sold and moved out of my flat to GRO-B. It was quite hilly and there were a lot of smokers in the building. I was really struggling to manage in that location and in 1997 I moved into a bungalow which I paid for from my savings. I had some renovations done to include a wet room which made it easier for me to shower and safer for my carer to shampoo and shower me.
- 35. My incapacity benefit was suspended for a year when I moved house.

  B was my carer and after a domicile appeal, with consultants backing and occupational health medical report, the doctor at my home found our case proven so the DWP had to reinstate it. I had had to exist on my savings. My father had prostate cancer and bone metastases for which I had asked B to be his and mum's carer and GRO-B and friends worked around the paid carers to look after them. I beganto use them too as DLA

was being paid. It meant I could not visit Dad (and mum) as often as I wished due to having a 13% mortgage and negative equity interest only, half what my flat cost.

- 36. Not long after my diagnosis I asked King's Hospital for advice because the Consultant at my local hospital did not seem to have a clue. Professor Williams at King's Hospital wanted me to have Interferon Alpha at the time. The Registrar explained that the treatment was like chemotherapy, with ongoing risks of depression and sickness, hair loss(Alopecia).
- 37. It was decided that I should have a liver biopsy before beginning any treatment however, this did not go ahead when they learnt about my bleeding disorder. I was referred to a haematologisat King's Haemophilia Centre. Whilst he knew that I had received hundreds of FFP/Cryoprecipitate since 1975 he did not inform me of risks which were known at that time. The haematologist took blood and a history from me , and then discharged me. He did not believe I had Von and Willebrand disease. I could not bring myself to trust his diagnosis and so decided not to have the biopsy. Consequently, the Interferon Alpha treatment also did not take place. B had to take me on the train to Kings and as I suffer with travel sickness I had had to take medication and wore acupuncture bands on my wrists to prevent vomiting. It took all day and I was exhausted and it took me over two weeks to recover. continued feeling exhausted and had to change my diet as I would get indigestion and heartburn very easily. I could only manage bland food as I was nauseated too.
- 38. At the time Professor Williams admitted they were still on a "learning curve" with the condition, and so I continued to go to King's Hospital for regular reviews every three months. Whilst there I was offered the opportunity to see a psychiatrist to determine if depression was the cause of my constant tiredness. At the time, I was forcing myself out of bed every day, the exhaustion was overwhelming. My parents, as pensioners, had

a better quality of life, boundless energy, early mornings and late nights. The psychiatrist wanted me to try new anti-depressants but I did not want to be a guinea pig again especially as I knew it was physical causes, as has now been confirmed.

- 39. At King's Hospital, King's Professor and Registrar, Matthew Cramp, told us Cryoglobulinemia had shown up in my tests. Genotype tests were not available at Kings. Cryoglobulinemia was found inmy blood tests results and were the cause of my joint pains.
- 40. I was never warned/told of renal, maxilla facial cancers or teeth rotting all due to HCV that they, as a specialist liver unit, Ithink, should have known about or at least should have written to my GP. Ispent thousands of pounds on dentistry.
- 41. After 2000 I was not offered any other treatment but I did undergo a Fibroscan to assess my liver condition at William Harvey Hospital in Kent. The results of this showed liver fibrosis that was within normal limits but suggested a need for medication.
- 42. In 2016 I was seen by our dentist who made a photograph of my face. I had previously had a perfect full set of natural teeth, yet the following year they became cracked, chipped and I began to have root problems. I was put on a waiting list, but then referred under thetwo week cancer rule due to concerns about tongue cancer. I had surgery to remove my wisdom teeth, but despite the precautions that the Director of the Haemophilia Centre in Margate took, my jaw dislocated and they tried to sew me up quickly to stop the bleeding. They had left the ro ots of my teeth in place, which still need to be removed.

- 43. I know that I was supposed to have a six month review which never happened. The dental surgeon discharged me becausel did not attend an appointment, however, I had not received detailsof the appointment. I was then re-referred by my current dentist, however, the letters were going to a dental practice that had shut down. This went on for two and half years. I have documentation concerning the maxiofacial expert who states "this lady attended clinic for extractions on 31 01 2020, she had fallen out of the system with a concern about her clotting requirements". I had taken evidence with me to prove I had a bleeding problem which was a letter from 2015. He had just ignored it and hasput the wrong detail of it and then has said "This level of bleed could be managed surgically as she needs 4 units" (4 teeth extracted), which has now gone up to 6-8 we will arrange to have that to be done under local araesthetic here at....." and goes on to say "...under my care and I will take responsibility for packing sockets with thrombogenic product to help with bleeding". Had I attended when he expected me to I would have died because he did not even have a clue about the bleeding problem, even though I had pointed it out to him. I have still not received treatment and now not well enough to attend the surgery.
- 44. A couple of years ago I had a HIV test before therapy was recommended. I was offered Harvoni medication and I did not want to accept this because of the potential side effects which I thought would be worse than the current medication I was taking; Cyclizine, fentanyl patches, tramadol, and dermatological medication for skin problems which has been prescribed since 2000.
- 45. Treatment for Hepatitis C was then discussed with me about one year ago but I declined to undergo this. I did not have anytreatment before this. I know that new treatment is available now, but the risks and side-effects of it have not been explained to me. I remain reluctant to try new treatment; I do not want to be used for an experiment.

- 46. Up until recently I was also living in a hotel and have been in and out of very expensive, but poor, rentals, for example a six month tenancy via estate agents. This was due to significant flood damage to my property in 2017. At all three properties I have stayed in the bedding was gross and so I had to buy a new mattress topper/bed sets at each one. I was also charged £100 after reporting the fire alarm sounding constantly on Christmas Eve. I was charged £100 to replace the battery, yet the one he removed was three years out of date so kept going on my electricity charges. The man who came to replace the battery came in without a ladder and so he went back out to his car and dragged dog poo from a grass verge into the property which then meant I had to call a cleaning company in to clean it up which cost me £80 as it was intolerable. Had they told me of the charge to stop the smoke alarm I would have got a friend over to replace the battery.
- 47. Due to the above circumstances I did not want to start new treatment when I was not living in my own home. Whilst at the hotel they also had prebookings from when I moved in in March 2019, whichmeant that on every Friday, Saturday and Mother's Day and all Bank Holidays I had to book alternatives and only another one existed in the GRO-B area and even that had no breakfast facilities, despite being some £20 per night dearer (excluding taxi fares and surcharge for luggage loading/unloading for me). I had to vacate by 10.00 a.m. so precious time was spent worrying about what would happen if every B&B/guest house/hotel/Airbnb were unavailable. Several times I was forced out of thearea which were more costly and so were cab fares.
- 48. I have faced difficulties receiving medical treatment when I have needed it. I have been reluctant to accept invasive treatment.
- 49. I am very anaemic and I do not know why but I suspect it relates to the two-three years I spent on a very poor diet, always being too tired or feeling too unwell to eat much. Any wounds still bleed heavily and I do not

want further tests and examinations done which are poking around and making it worse. I struggle with antibiotics due tomy allergies, which is a more recent change.

50. My illnesses and the medical community's reaction to them has led me to significantly mistrust medical professionals.

# Section 4: Other infections, conditions and medical treatment

- 51. I was vaccinated against Hepatitis B as part of my employment. As far as I am aware I never contracted Hepatitis B.
- 52. I was told by King's Hospital that I had cryoglobulinemia as a result of the Hepatitis C which is affecting my joints. They believe I have rheumatoid arthritis. This is noted in my GP records which meant that I lost out on compensation due to injuries from a road traffic accident, it was said that it was pre-existing but I was never told. I do not agree this is the case as a Consultant Rheumatologist referred me for a Dexa scan which confirmed Osteoporosis at the **GRO-B** Dr GRO-B , had refused after Consultant said to refer, he, the GP, also re fused medication that was ordered by Consultants i.e. 10mg instead of 20mg, despite being given 20mg in hospital. The GP was told again to p rescribe, likewise Consultant Anaesthetist Pain Clinic who ordered Co-Codamol/Tylex and he refused. I was in very severe pain, but just as previous GP had done, he gave me a bottle of liquid Codeine and Paracetamol, which were huge pills and I was unable to take so I asked for liquid of that too or capsules. Eventually I fell over trying to cope indoors and the bottle smashed. I was then admitted for review.
- 53. When King's Hospital diagnosed the cryoglobulinemia they did say this was connected to Hepatitis C. I had heard that Nat King Cole's daughter's death was possibly linked to Hepatitis C and a kidney condition, and so we made both my GP and King's Hospital look into this. I mentioned it to

the hepatologist as well, but he did nothing about it as my care was under a urologist at the time, due to episodes of bleeding in my kidneys. I should still have hepatologist reviews, the last one I had was in December 2017. I kept asking the hepatitis nurse practitioner (and also at Kings beforehand via Professor Williams). The Haemophilia Centre Director (at Margate Hospital) provided cover to ensure bleeding was kept to a minimum. I was given Tranexamic Acid, but was right to be wary abo ut no FFP.

- 54. Originally, in the 1990s, I did have trouble getting a dentist to treat me, although this has improved in recent years. I had the same experience with chiropodists.
- 55. My last dental extraction was at Margate Hospital in 1996. The surgery was supposed to take place in a brand new endoscopy theatre on the ground floor to avoid contamination of the lift or other theatres. I remember I had been placed at the top of the list even though it was known that I had Hepatitis C and a risk of bleeding. When the anaesthetist found out he was horrified that he had not been informed about my condition and I was moved to the end of the list for my procedure. He left after to speak with Dr Mark Winter about both issues.
- 56. Since 1996 I have been reluctant to have non-essential surgery although the bleeding in my gums and teeth continues. I am being referred to a maxillofacial surgeon to determine the reason behind this.
- 57. I am always pushed to the end of the line for GP appointments, and then I receive letters at home telling me I failed to attend when they have not been able to get to me at the end of the day.

#### **Section 5: Financial Impact**

58. I have not applied for any financial assistance from the various Trusts and Funds as a result of the Hepatitis C and no-one offered any to me. I did

not think I would be included until The HaemophiliaSociety put me in touch with EIBSS. I therefore made an application to EIBSS. My current GP who I have had since 2016 is very good and he spent eight hours searching my notes but no blood/bleeding disease is noted whatsoever. So, he said that unless I can obtain proof he could not sign it. Despite King's and St Thomas' promising copies of my blood logs, only Lewisham Hospital kindly did as asked and after waiting about a year for my notes they were sent to my GP [WITN3539002]. I had to pay for a report and lost time as I could not claim until I had the proof. The blood logs were then sent off with my EIBSS application forms.

- 59. EIBSS agreed and Stage 1 payments were awarded. I am now in the process of making a Special Category Mechanism withthe help of The Haemophilia Society as I am suffering with fatigue (as well as vasculitis due to cryoglobulin) and am housebound and have been since March 2020. Why was I never traced, I have always had a GP, should the Haemophilia Centre have done so? Should there have been a transfer of service?
- 60. My brother, B, did receive a carer's allowance as he is my carer. I receive a pittance of a pension from the Cabinet Office. This does upset me. The reason I lost my job was an incident that was not my fault. I was just doing my job.
- 61. I am receiving Disability Living Allowance, although I will soon be 65 years old. I was on the lifelong maximum allowance due tohaving Hepatitis C but this stopped on 9 July 2019. I will now have toapply for a Personal Independence Payment. I am going to have a medical expert's examination and will ask for a copy of his report.
- 62. I have had no social life, or holidays as I have needed care for 20 years due to the Hepatitis C and now have joint and back problems. I suffer constant joint pain from the cryoglobulinemia, nausea, memory problems

worsening. I then had a fall in the shower in November 2000 which kept me in hospital for 14 months and made my joint andback problems worse. It was during this time that my father died, but I was not able to attend his funeral.

- 63. Consultants in Dermatology and Pain were involved and I have asked to remain on the same doses of Fentanyl, but now need eight Tramadol per 24 hours (day and night, carefully noting down times taken and when due). I remain on long-term medication to manage the pain and have had external carers since January 2002 who help me daily.
- 64. The financial impact of my condition has been significant. My condition meant that I could not travel as much as I would have liked, or to see my parents when they were ill. When I was able to go to see them, I missed various medical appointment letters, and my incapacity benefit was suspended for a period because I did not attend an assessment that arrived with three days' notice and no phone numberto call and stated Eye Consultant (even the letter said seven days' notice and was blank where contact if unable to attend should have been) I wrote to my MP for help who said he would intervene, but he did not doso. Eventually I was able to get a domiciliary hearing which went in myfavour and my benefits were re-instated and backdated.
- 65. I feel that I could have done a lot more with my life had I been paid properly following the needlestick injury. Since that incident which either gave me Hepatitis C, or led to the discovery of it contracted through years of having potentially contaminated blood products, I have fell like I am constantly fighting. The incapacity benefit has kept me afloat, but not much more.
- 66. B had kept a diary over the years and found some extracts from it in relation to the treatment I was receiving. I have attached this as Exhibit WITN3539003.

67. I have had to purchase Piriton antihistamine tablets for several years due to my skin reacting in any situation of sun or heat. My understanding is that GPs are no longer allowed to prescribe over the counter medication for any common ailments, despite EIBSS saying we are entitled to free prescriptions. Having always purchased a prepayment certificate for decades right up until I retired, I find it galling to still be paying. Perhaps Sir Brian can take this fact into account as well [Exhibit WITN3539004].

#### **Sections 6: Conclusion**

- 68. If I had been warned about the effects of cryoglobulinemia on the kidneys, then I would have been able to seek treatment earlier. I have also always been badly affected by the behaviour of medical professionals that I saw at the Viking Ward in Margate. These matters and the general lack of information, support and advice that has always surrounded my condition, are matters that I would like the Inquiry to consider.
- 69. Looking back, I now think it was far more likely that the use of blood products is how I became infected with Hepatitis C, rather than the needlestick injury. I was given so much blood product over so many years that it just seems unrealistic that that one scrape with the needle is what caused the condition. I suppose I will never know.

| Margaret 1   | <u>M 70033</u>                  |                                   |        |  |
|--|---------------------------------|-----------------------------------|--------|--|
|  | o this action to the widers and | €674 <b>2</b> 814<br><sub> </sub> | un the |  |
|  | GRO-B                           |                                   |        |  |
| The second secon | 08/11/2022                      | !<br>                             |        |  |
|  |                                 | ÷                                 |        |  |