Witness Name:

Gordon James HADLEY

Statement No.

WITN5907001

Exhibit No.

WITN5907002

Dated:

22 November / 2021

### **INFECTED BLOOD INQUIRY**

# WRITTEN WITNESS STATEMENT OF GORDON JAMES HADLEY

I provide this statement in response to a request under Rule 9 of The Inquiry Rules 2006, dated 20<sup>th</sup> August, 2021.

I, Gordon James Hadley, will say as follows:-

# Secton 1 - Introduction

- 1. My full name is Gordon James Hadley and I was born on GRO-C 1953. I am a married man living with my second wife in the South East of England at an address that is known to the Inquiry and am retired.
- 2. I intend to speak of my having become infected with Hepatitis C (also referred to as Hep' C and / or HcV) and in particular how I came to be infected, the nature of this illness in so much as how it affected me, the treatment I have received and its impact upon my life, my family, my job and friendships.

- 3. As a child, I was found to have Von Gierke Disease. This condition, which is genetic, is also known as Glycogen Storage Disease, or 'GSD' for short. This is a rare inherited liver disease that results in the liver being unable to properly break down stored glycogen. This impairment disrupts the liver's ability to break down stored glycogen that is necessary to maintain adequate blood sugar levels. It also makes it difficult to process any drugs that may have to be prescribed and to fight infection.
- 4. GSD is a lifelong condition which cannot be treated other than in extreme cases by way of a liver transplant. Its nature and impact is such that I have had to learn to live with it as best as I can, and so by careful consideration of what I have to eat or drink. I have, therefore, never drunk any alcohol.

# Section 2 - How Infected

- 5. According to information I gleaned from my mother, I was only about three months old when I was found to have GSD. She had been concerned that I hadn't been gaining weight, post-delivery, as could otherwise have been expected, that I was displaying an enlarged stomach, and that I was experiencing severe nosebleeds and vomiting all of which was unexplained.
- There had been no adverse health background within the family, and I was one of six children of my parents, four brothers and a sister along with me, and none of them had haemophilia or any kindred bleeding disorders.
- 7. At the time, my family and I were living In Essex, so the family General Practitioner (G.P.) referred me, through my mother, to Dr Charles Warren of the St. John's Hospital in Chelmsford. My parents thought that Dr Warren was some sort of miracle worker, apparently, he was brilliant.
- 8. It was Dr Warren who diagnosed the rare condition of GSD, quite a feat as at that time I was apparently the only person in the country to be known to have it. In later life I have met with two other GSD sufferers, both ladies, but it remains extremely rare nationally, and internationally.

- 9. Dr Warren advised us that there was no treatment for the condition, but that he would monitor it at regular intervals and assist and advise as regards lifestyle adjustments which would help as I grew up, including careful choices that would be required regarding my diet.
- 10. As a child, I found that I was prone to chest infections. My condition makes it very difficult to overcome infections, and consequently I had to spend a lot of my time as an inpatient of St John's Hospital under the care of Dr Warren where I became quite familiar with both him and the nursing team.
- 11. My education as a result was a mix of the traditional school-based learning and home learning, but in spite of the difficulties associated with 'missed schooling,' I did well enough to leave school at 18 with qualifications, and started a career in local government.
- 12. By 24 years of age, I had met my first wife, married, and settled down into our own home, still in Essex.
- 13. In spite of the GSD (my PCT had yet to manifest itself), I generally fared well, but in early 1980 I found myself experiencing some breathing difficulties for which I tried various 'off the shelf' remedies, such a nasal-sprays, but they simply didn't work. I visited my G.P. and was referred to a Dr Singh, and Ear, Nose and Throat (ENT) specialist at St. John's.
- 14. Dr Singh advised me that I required a Septoplasty procedure in order for one of my nasal passages to be realigned, which would help clear the airway and relieve the breathing issues I had been contending with.
- 15. My G.P. consulted with Dr Warren about the proposed surgery, for advice and in particular as I had this rare condition of GSD. Dr Warren was no longer my GSD consultant, as he had cared for me as a child, but I was then an adult and my GSD care responsibility had moved on from him, but he nevertheless took a keen interest in my health and was one of the very few medical people in the country with any knowledge of Von Gierke Disease.

- 16. Apparently, Dr Warren agreed that a septoplasty would be beneficial, and contacted Dr Singh to advise him of my condition and to tell him what to look out for. In so doing, he told Dr Singh that I was at a higher risk of bleeding out and experiencing uncontrollable bleeding, as this had been experienced before. I had previously had a cauterisation procedure performed in one of my nasal passages, to control nose-bleeding, but had somewhat ironically, bled extensively as a result.
- 17. In June 1980 I was admitted to the St. John's Hospital for the septoplasty. Having been admitted, the doctors treating me were most reassuring, telling me that it was a risk free simple procedure, commonly performed and that I'd be out of the hospital in about three days.
- 18. Having said that, I was also told that in general terms it wasn't a pleasant operation for a surgeon to have to conduct, because of the nature of the area in which they were working and where they would have to cut away, but there was no cause for me to be concerned. I was also somewhat reassured by the knowledge that Dr Warren, whom I knew and trusted implicitly, had consulted with Dr Singh.
- 19. I duly signed a form of consent for the ENT team to perform the operation, and did so willingly as there'd been no mention of any particular risk. No one told me that there was a possibility of my haemorrhaging, or that I may require a whole blood transfusion or blood products to address any bleeding which may occur. I'd been under the care of St. John's for so long, all of the clinicians there had my trust, a trust developed over many years of what my parents and I considered to have been excellent care.
- 20. The septoplasty was performed under a general anaesthetic, and postoperatively I awoke on a regular hospital ward (not an intensive care or recovery unit as I di not think they existed back then).

- 21. When I came around, I found that both of my nostrils were blocked with some sort of rods which were sort of 'plugged in' to each of my nasal passageways. Dr Singh told me that "there had been a problem," and that as a result, "we have a minor issue, and will have to give you a blood transfusion because you are losing too much blood."
- 22. Dr Singh asked me if there were any religious objections to my being given blood, and I told him that there were not, and that it was 'ok' for him to go ahead. Under the circumstances, I do not believe that anyone in their right mind, finding themselves in a situation such as I did, would have said 'no.' It was evident to me that I would bleed to death unless given a blood transfusion, so I accepted it.
- 23. A senior staff member, not Dr Singh but one of his team, I believe also a doctor, came onto the ward to conduct the transfusion I don't think that any of the nursing staff could do it, or were necessarily trained to do it at that time. I can remember seeing that he transfusion was given via a catheter (needle) through a vein in the area within an elbow from a bag of blood hanging off of a drip stand. The flow was managed by a regulator on the tube from the bag and this showed how long the bag had to go before needing to be replaced. There was no other machinery or equipment involved.
- 24. Within a couple of days, I was given three bags of blood, all of which passed without incident. Different members of staff came and went, checking on the delivery or changing the bags when necessary, but I cannot remember any of them ever having taken any notes of what was seen or being done.
- 25. A fourth bag was put on, and after about an hour and a half of it being administered, I began to feel that something was wrong I hadn't felt that with any of the earlier bags, but with this one I definitely felt something different happening as it was slowly being out into me.

- 26. Some lumps began to form on my head, swellings, and my skin started to erupt in blisters all over my arms and down my chest. I called for a nurse, and the nurse in turn called for Dr Singh. He was very quickly in attendance and said that, "we have to get this down right away," meaning the unit of blood I was connected to. There was still a lot of blood left in the bag, but they disconnected it straightaway.
- 27. Following the cessation of the transfusion, I was moved off of the main ward and into a side room, away from the other patients. The swellings went down after a short while, but my skin remained very itchy and I found myself unable to resists the urge to scratch at it which led to my opening the skin and bleeding all over my body.
- 28. Looking back, I now believe that I was moved from the main ward amongst other patients and into the side ward so that other patients and their visitors couldn't see me as I would have appeared unnerving and they would have been left wondering what on earth was going on?
- 29. The nurses covered me with Calamine Lotion, which I always thought to have been used to treat burns, and that was it there was no other intervention, no medication such as you may expect for an anaphylactic reaction, nothing. I have / had a history of being allergic to certain medications, part and parcel of my having GSD, so this may have been the reason, but I have no intolerance to penicillin, so that could have been given.
- 30. I now believe that having GSD may have actually proven beneficial to me when this occurred, as it most probably led to the identification that I'd been given an infection (via the blood transfusion) and caused my body to react to it, almost immediately, far quicker than others given contaminated blood may have done.
- 31. In more recent times (please see paragraphs 47 & 50) my second wife and I conducted some research and found that in certain cases, patients receiving HcV by virtue of their having been given a transfusion of contaminated blood, had reacted within mere minutes of the transfusion being given just as I had.

- 32. My sister Glynis was a nurse, and at the time of my having reacted in this way, she was engaged as a Senior Nurse at the Broomfield Hospital (also located in Chelmsford). She had worked at most of the hospitals in this part of Essex, including both the London Road Hospital and St. John's. She was familiar with St. John's Hospital and although she had moved on, had friends working there.
- 33. As a result of her connections and being a nurse herself, hearing what had happened, my sister was allowed to call on me outside of the usual visiting hours. Upon arrival she was alarmed to see the rashes all across my body, and asked me why I had been moved into a side room? I explained what had happened, the transfusion and my reaction to it, and she then looked at my notes the ones which the doctors and nurses used to hang on the bottom of your bed in those days.
- 34. Having inspected the notes, she was confused as there was absolutely no mention of the fact that I'd been given a blood transfusion within the notes. Concerned at this omission, she confronted the ward sister on duty at that time, asking why there was no record of the blood transfusion or of my reaction to it.
- 35. Glynis and the ward sister fell out over this, and there was a heated exchange between them which ended with the sister, who in nursing 'rank' terms was senior in position to Glynis, telling her that she had, "no right or business to look through the records." Both concerned and annoyed by what had happened, Glynis told me that she'd look into it further.
- 36. Three days after the blood transfusion and my reaction to it, I was discharged.
  I cannot but think, from her subsequent dealings with me, that the ward sister with whom my sister had clashed, was rather glad to be rid of me.
- 37. My G.P had been looking after my family and I for an appreciable time and was a friend of my father. Following my discharge, Glynis went to see him and asked if he was aware of the fact that I'd haemorrhaged as a result of the Septoplasty and that I'd consequently had to have a blood transfusion.

- 38. Our G.P. told her that not only was he unaware of the transfusion but hadn't been told of my reaction to it as no records of my time in the hospital had been forwarded on to him.
- 39. At the time, the Broomfield Hospital (where my sister worked) and the St. John's Hospital were linked together, sharing management, staff and facilities. My sister was therefore, rightly or wrongly, able to access my records and found notes showing that I had been given a blood transfusion, so she arranged for those notes to be copied and sent on to my G.P.
- 40. Following her intervention, and only because of her intervention, the notes were received by my family doctor, but some four months after the surgery, blood transfusion, reaction and my sister having had to step in on my behalf had she not done so, I doubt very much if anything regarding this incident would have been sent beyond the hospital.
- 41. Glynis found herself in considerable trouble at work for having got involved, and was called in to see the hospital Matron at the Broomfield Hospital who appeared to have been contacted by the ward sister, if not others who had been involved. She was given a stern 'slap-on-the-wrist' for her actions and told by Matron that "it would not be in your professional interests to pursue this any further or do it again!"
- 42. The way in which the various personnel engaged in my care at St. John's Hospital at this time conducted themselves makes me believe that there was a concerted effort to cover up what had taken place and prevent any knowledge of it leaving the ward
- 43. I didn't then know 'why' I had reacted to the blood as I did, and hadn't thought that there may have been anything wrong with the blood I had been given at that time I put my reaction to it down to GSD, a condition which I was aware of and which served to 'mask' what had actually taken place I'd been given blood that was contaminated with Hepatitis C. It was something I didn't find out until many years later.

- 44. In 2012, some thirty two years after I had undergone the septoplasty and been given the blood transfusion, I was diagnosed as having Hepatitis C. This was a lucky chance, as the G.P. treating a skin rash just happened to recognise the rash as being Hepatitis C related. I had originally been referred to the Broomfield Hospital in Chelmsford, then transferred to Addenbrooke's Hospital in Cambridge. The doctors at Addenbrooke's advised me that treatment was available, but that I could not then be treated as the medication as then being used would have had an adverse impact upon my GSD.
- 45. I had already lived with the condition (HcV) for some thirty years, with it slowly impacting upon my liver, and found that I then had to endure a further four years, because of the Von Gierke Disease complication, before a change in available medication meant that I could be treated.
- 46. When first diagnosed, the hospital hadn't given my second wife or I too much information about Hep' C, so we had conducted our own research into the condition what it was, how it could be transmitted, what the symptoms of infection were and its damaging impact upon the body.
- 47. I had always been worried about the condition of my liver and my liver function in general, due to the genetic condition I had been born with, and had taken all steps possible to ensure that I did not expose myself, and in particular my liver, to any adverse effects being particularly careful as regards my diet, for example, and avoiding all alcohol.
- 48. Finding out that I had HcV and then discovering its impact upon the body, especially how it attacks the liver, was dreadful news. I already had a serious liver disease and the information I had of a further condition attacking my already vulnerable liver had a most damaging psychological impact all I could do was worry whether or not I'd develop liver cancer, it really played on my mind.

- 49. The research also confirmed the only possible source of infection the blood transfusion I had received and to which I had almost immediately reacted when the fourth bag had been administered. I had not been exposed to any of the other 'risk factors' associated with Hepatitis C, i.e. self-inflicted tattoos; intravenous drug abuse; promiscuous unprotected sexual activity; or any invasive treatment overseas.
- 50. Having been diagnosed as having HcV, my care was transferred to the Addenbrooke's Hospital in Cambridge in 2012 who finally put me on a course of treatment in 2016 for the condition which was to last for some sixteen weeks.
- 51. However, just a few weeks into the course, the dosage I had started on had to be reduced as I reacted badly to the treatment as my body had difficulty, because of the GSD, in processing the medication I was being given. This is sadly not an unusual situation, as with GSD I often have to take lesser doses of medication, over a longer period, to be able to properly absorb them.
- 52. Although my dosage was reduced, I still found the side effects I experienced to be quite horrible, in particular because I developed severe anaemia. However, I persisted with it, despite feeling dreadful all of the time, as I didn't feel that I had the option to stop.
- 53. My progress was regularly monitored, through blood tests at the hospital to see how the treatment was working on the disease. I completed the course, but still had my blood checked, and then after several months (now in 2017), I was pleased to receive a letter telling me that the treatment had been successful and HcV was no longer detected in the blood test. I still have regular monitoring blood tests. What I didn't know was how much damage having had HcV for so long may have actually done, so the worries, especially about my liver, remained.

- 54. Several years passed, under the care of Addenbrooke's, and all remained well, but then in January 2021 I was absolutely devastated to be diagnosed with a shadow on the liver. A subsequent liver biopsy confirmed it as Hepatocellular Carcinoma.
- 55.I have since been treated I underwent an ablation procedure at Addenbrooke's Hospital, but have yet to see the outcome, whether or not it has proven successful, and if so to what extent. I now have to have three monthly ultrasound scans and the signs are encouraging with the first (conducted in June 2021) having shown no signs of cancer, but I remain very worried as it is still too soon to know just how successful they may have been. At the time of making this statement, I await the result of a scan conducted in September.
- 56. My diagnosis of liver cancer came about as a result of regular bi-annual checkups I have to attend regarding the Von Gierke's Disease, not any 'follow-up' post Hep' C treatment. A scan showed a shadow, further tests were conducted and the cancer identified. Had it not been for my regular GSD appointments, it may have passed undiagnosed with potentially fatal consequences.

#### Section 3 - Other Infections

57. I do not believe that I have contracted any other infection(s) other than Hepatitis C as a result of having been given contaminated blood by the National Health Service (NHS).

#### Section 4 - Consent

- 58. As previously stated, my having given consent to receive the blood transfusion came about as I did not believe that I had any other option at the time, and because I held complete faith in the medical authorities, and as I had no reason to be concerned that any form of risk was associated with the procedure.
- 59. I had already provided my consent for the septoplasty, as I believed it would tackle the breathing issues I was experiencing at that time. Again, as it was explained to me, I had no reason to be concerned that any form of risk was associated with the procedure and I trusted the clinicians.

- 60. I seem to remember that in so far as the septoplasty was concerned, I signed a form of consent, but only had to give verbal consent as regards the blood transfusion I don't think that there was actually any time for anything else, I may have bled to death if I hadn't consented, there and then.
- 61. The above two incidents aside, I am someone who has been treated by nurses and doctors since birth, in particular as a result of my having been born with Von Gierke's. As such, interactions with doctors, nurses and others very quickly became a matter of course event, and neither my parents or I were particularly questioning of their actions or had any cause to question what was going on at any given time.
- 62. This was a position which continued, and whereas I am now, as a result of what happened with the blood transfusion and what I have learned since, far more likely to ask questions of those treating me, leading into the septoplasty I wasn't, I trusted the clinicians and consent, as such, wasn't really an issue for me.

# Section 5 - Impact

- 63. As a person born with GSD, I had always been a sickly child, prone to infection with whatever may have been 'doing the rounds,' coughs, colds, 'flu, and the like and in particular always seemed to catch chest infections, including croup. My growth was stunted, and caused my parents such concern that at one point in time my mother even had me tested for dwarfism.
- 64. GSD meant that I could only eat a high fat diet and I consumed three or four times more food than other children of my age. It also meant that I was often hospitalised, and sent a lot of time growing up, in hospital, which is where I became familiar with Dr Warren and many of his nursing staff people would joke that the ward sister knew me better than my parents, which wouldn't have been far from the truth at times, the hospital staff effectively became my family.

- 65. Throughout, my parents held great confidence in Dr Warren who had amazed them with his ability to diagnose such a rare condition as Von Gierke's Disease as having been the problem I faced. They were always quite comfortable with leaving me in his care, in spite of how difficult this may have been for them, leaving me in hospital over such protracted lengths of time.
- 66. My education was a joint enterprise between the NHS and local education authority and I had to be either taught in hospital or at home by a tutor, but I also learned a lot myself, mainly through reading as it was the one thing I could do and could do it anywhere, home, hospital wherever.
- 67.I didn't enter mainstream schooling until I was six, a couple of years behind the other children, but did well as fortunately I had a high IQ. I did have to have some home tutoring to catch up with the others, and my schooling continued to be disrupted I once had to spend six months in hospital with GSD but I managed to keep up to date.
- 68. I was quite driven, determined to have a good future despite Von Gierke's, and working hard on my studies helped me deal with what could otherwise have been a most harmful childhood with my having to shuttle between home, school and hospital all of the time.
- 69. When it came to the time to transfer to a senior school, there was a problem. I couldn't go to a mainstream secondary school, as both the doctor and nurses caring for me and my parents didn't really want me to mix with large numbers of other children as I so easily picked up any infection they may have.
- 70. My parents considered it, but not for long, as they did not want to send me to what were then being referred to as 'special schools,' those for unwell or otherwise handicapped children. I had developed my own routine for education, which was proving successful, and they didn't want to disrupt it. So I carried on, technically being in school, but more often than not being at home or in hospital with teaching either being set for me to deal with on my own or through the input of tutors.

- 71. I do not believe that I missed out on much schooling, at least not in terms of its academic aspects, and even knowing that there was no cure for the condition I had, I took a view that I would press on, be the best I could be, and generally hope for the best.
- 72. In many respects I enjoyed having a double education whilst in hospital I would have to do schoolwork, and brought assignments home with me; and completed those on top of the home-schooling I was set. I also found that I was able to make friends, in spite of my spending so much time in hospital, and contrary to fears many held that I may grow up isolated from my peers.
- 73.I have already explained that my interaction with clinicians became secondnature for me (please see paragraph 62). I underwent my first liver biopsy when just ten years of age, as apparently a new drug from the U.S.A. for use in combatting GSD had become available and Dr Warren needed to conduct a biopsy to determine whether or not I'd be able to take it.
- 74. I then took the drug on an experimental basis, but found that I had to stop as it hadn't been working as had been hoped, and I had suffered with the most dire side-effects. However, what it did do was to accelerate my hitherto stunted growth, and I was growing up to 2" a month, highly abnormal even allowing for childhood 'growth-spurts,' and there were concerns that it was having an adverse impact upon my metabolism.
- 75. The combination of side effects, abnormal growth and metabolism issues meant that I was taken off of the trial but my parents and I had entered into it willingly, hoping for some sort of 'miracle cure.'

- 76. I had been under the care of Dr Warren as a child, but by the time I reached adulthood at eighteen, my care was to be moved on through St. John's Hospital to Broomfield Hospital. Dr Warren was quite reluctant to 'lose' me as a patient, he had become very close to my family and I over the years and had developed a superb understanding of my condition, so after I'd been moved into the care of adult services, he nevertheless maintained an active interest in my continuing healthcare which included his involvement with Dr Singh as regards the septoplasty.
- 77. I had been twenty seven years old at the time of the septoplasty operation and its resultant blood transfusion. About two to three months following my discharge from the hospital, I found that I was again developing rashes and contacted my sister Glynis. She was concerned that these were not typical of my GSD problems but a sign that something else was going on.
- 78. I went to my G.P. but he was unable to provide me with any positive diagnosis other than that I had developed an intolerance to sunlight on exposed parts of my body. It was not until I was diagnosed with Hep' C and under the care of Addenbrooke's Hospital that it was established that I was suffering from a condition called Porphyria Cutanea Tarda (also known as 'PCT') which is associated with HcV. This G.P. visit was a missed opportunity to have identified the relationship between the light intolerance and Hepatitis C, probably due to a lack of information given to G.P.'s.
- 79. PCT has had a major impact on my life ever since the initial reaction to the blood transfusion and I have to be ever mindful not to expose myself to the sun as a precautionary measure.
- 80. I was employed as a local authority (council) street lighting technician where the vast majority of my work was conducted outside, in the open. Although I had not been diagnosed with PCT at this time, it was nevertheless a major issue for me.

- 81. Initially, I tried to arrange my working hours so that I'd predominantly be working in the shade, e.g. if I were working on a road, I'd work on the shady side and wait until the other side moved into shade before crossing over to work there.
- 82. I developed coping mechanisms, such as that which I have described above, or by careful selection of clothing (keeping as much skin covered as possible and / or wearing a hat). Later, after the PCT diagnosis, I was prescribed a very high factor sunblock. This reduces the impact, but I am still limited as to the amount of time I can spend outside.
- 83. Unknown to me, and apparently unknown at that time to my G.P., PCT is a known symptom of Hepatitis C infection but Hep' C wasn't tested for or identified, which was a missed opportunity for its diagnosis at a relatively early stage. I do not think that at that time, sufficient was known of either HcV or PCT or of the connection between them for Hepatitis C to have been identified.
- 84. In 1985, for reasons unrelated to any of the health issues I faced, I stopped working for the council and started my own business. My brother-in-law, who was a leading physics and in particular chemistry professor, helped me to develop a particular window cleaning agent, so we had opened up a window cleaning business.
- 85. Leading up to this time I had suffered from a number of skin outbreaks and other infections, coughs, colds, 'flu etc., but I had attributed all to my having GSD and PCT, nothing more, nothing else was then known or had been identified.
- 86. My first wife and I had two children (a son and a daughter) and we saw to it that each was tested for GSD, but fortunately neither had inherited the condition. I had also been advised that the chances for inheriting the ailment were quite remote, unless you married a relative, so my wife and I weren't unduly concerned, but we nevertheless wanted to be sure so that we could put the right measures in place if necessary.

- 87. In 1998, I lost my first wife to ovarian cancer and became a single parent to our children. At the time our son had been thirteen whilst our daughter was just eight. The illness my late wife experienced posed additional problems for us as a family, and I worried as to my future and that of the children in addition to concerns I had always harboured as to my own health. It was an extremely stressful time for us all.
- 88. In spite of my issues with the sun and PCT, I continued to work in the window cleaning business which was doing rather well and I was additionally selling window cleaning products to others across several areas locally. However, with no wife and two young children to care for, and the added pressures this placed upon me, I had to cut back on my working hours and for the first time we found things to be a bit of a financial struggle.
- 89. In addition, despite having cut my working hours, for no apparent reason, I was also finding myself exhausted, and unable to work as many hours as I would have otherwise hoped, and as a result I lost customers which only increased the financial pressures I faced.
- 90. In 2000 I met Sue, and after a whirlwind romance, she became my second wife in August 2001. She tells me that when we met I had been very skinny I was only ever 10 stone in weight at my heaviest, but apparently I was a mere 9 stone at the time of our meeting, possibly a little less.
- 91. I had been going through a really tough time leading up to our meeting and was under a great deal of stress. The exhaustion I had been experiencing had cost me work, a loss of income and my once thriving business had been shrinking. I had continued to work, but felt physically drained all of the time, whether I had been working or not, and was quite lethargic which had never been in my nature.
- 92. I was still prone to infection, in particular suffering from chest infections like a wheezing cough, and was experiencing difficulty sleeping which is still the case today.

- 93. I do not know what part 'stress' or 'anxiety' played in this process, but it was also ever present with concerns for my health added to concerns for my ability to work and secure an income to support my family and I as a lone parent.
- 94.I do not know what part, if any, my weight loss had in the lethargy I was experiencing, or whether it was just all of the issues I faced coming together, but I coped as well as possible, and determined to improve my condition and outlook joined a Gingerbread Club, for single parents, the bereaved and / or divorced. However, this was not to my liking as I found the group I had joined to be more irritating than therapeutic, so I left.
- 95. I was really struggling but could not fathom out why. Hepatitis C had not been diagnosed, so I knew nothing of it and had no grounds to suspect Hep' C infection, but looking back with the knowledge I now have, it is clear to me that I was displaying many HcV symptoms and had been for some time but people kept telling me that it was worry, stress at having lost my wife, and I didn't then know any different.
- 96. Having turned eighteen years of age, my care was passed to clinicians at Broomfield Hospital. The care offered was not consistent and depended on which specialist I saw. After 1995 my care was left in limbo and my care through the hospital waned. I did continue to attend for ultrasound scans on my liver, but these were no longer regular, a matter of fixed routine as they had been, but sporadic and I was left wondering to whom the scan results were going.
- 97. Since 2012 I have been under the care of the metabolic specialists at the Addenbrooke's Hospital who are excellent and through whom I started having bi-annual scans at regular six monthly intervals.
- 98. I have experienced a number of periods of uncertainty concerning my health, such as the time spent 'in limbo' at The Broomfield Hospital or in 2003 when I developed a lump the size of a golf ball on my back and was concerned because this had always been a major fear that it may have been cancerous.

- 99. Fortunately, my second wife Sue had private medical insurance and I was able to 'fast-track' my being seen at The Broomfield Hospital by using it, but my fears were allayed when it was found to be nothing more unpleasant than a lipoma, a benign tumour of fatty tissue, not cancer.
- 100. Concerns from the past returned at that time. The lipoma was removed in hospital by a Dr Nigel Richardson who spoke to me before surgery to explain what he was going to do, how and why to secure my consent. I asked if I would require a blood transfusion, as once surgery had been mentioned, my mind was taken back to the septoplasty and the reaction I experienced to my having been given blood. He was able to reassure me that it would not be necessary, but I remained concerned all the same. Fortunately, the procedure passed without incident.
- 101. As part of the pre-operative assessment, I had to provide a blood sample for testing. Whereas I have no idea what it may have been tested for, presumably just to ensure that suitable blood was available in the event of any emergency, this was undoubtedly another missed opportunity for HcV to have been sought and diagnosed.
- 102. I believe that whenever an opportunity arises, where someone presents with the symptoms such as I had been displaying; or where there is a history of whole blood transfusion or blood product use, then their blood should be screened for both HcV and HIV as a matter of course.
- 103. I can only now think, rightly or wrongly, that this has not been done because of concerns for what it may reveal despite the clear health benefits for the person tested if they, like me, are infected but unaware of the same. I believe that a look-back exercise should be conducted to determine how many missed opportunities there have been to diagnose the likes of HcV and HIV, and to then ask 'why so many chances went begging?

- 104. Consideration of missed opportunities aside, I believe that there should be a screening programme to ensure that everyone who was given either whole blood by transfusion or blood products, between 1975 until 2000, has their blood tested for HcV and HIV to ensure that no one else finds out when it is already too late.
- 105. I worked hard to provide for my children, in spite of the adversity being faced, and found that once my son came of age and he was able to join me at work, the window cleaning business began to pick up again and our lot improved to a point where he joined the business as a partner. I trained him to take on more and more of the job so that I could gradually step my own workload down. Although tiring, we were able to keep the customers who had remained and expand afresh. Sue was working in Social Services, but was able to be at home of an evening which also helped lighten my load and enabled me to cope a little better.
- 106. I continued to experience flare-ups of the skin blistering and rashes, which sometimes were quite awful but at others minor, it varied and was just something I found that I had to live with. In 2012 the flare-ups intensified in both nature and their extent, sometimes covering my whole body in blisters and rashes, so much so that I could hardly leave the house.
- 107. I made an appointment to see a G,P, at my local surgery, now a group practice, The Robert Frew Medical Centre. I cannot now remember the name of the doctor I saw, but he was pretty dismissive of the problem and sent me home without any help, but the problem persisted.
- 108. Sue and Glynis persuaded me to see another doctor and so I decided to ask to specifically see a Dr Chakera at our practise who had treated my daughter previously for an unrelated skin issue and was a G.P. with a special interest in dermatology.

- 109. Dr Chakera told me that she had seen the same type of blistering and rashes before, and referred me to a hospital in Basildon for a blood test. She completed a form which I was to take with me, and I could see that she had asked the hospital to check my blood for Hepatitis C as she'd written, "please check for HcV" on the form.
- 110. The doctor told me the she suspected that she knew what the problem may be, but that she'd need the blood tests to confirm it before a diagnosis could be made she didn't let on what she suspected, and I didn't then know what HcV was. Unfortunately, she left the practice soon after this, but not before the results had come back.
- 111. A short while later, my blood having been taken at Basildon, I received a call from the surgery to come in for the results and went back to see Dr Chakera. I wasn't asked to bring anyone with me, but I hadn't thought that I needed to as I'd gone through a lot with my medical background and didn't need anyone to hold my hand, but I am glad that they didn't tell me why I needed to come in over the 'phone.
- I had been a little concerned as to what might have been going on, and hadn't told Sue what the doctor had written on the form, so my not having told her, and not knowing what HcV was myself, neither of us were prepared for the diagnosis.
- 113. In consultation, Dr Chakera told me that the blood test had confirmed that I had Hepatitis C, as she had apparently suspected. She asked if it was possible that I had become infected through my past use of blood or a blood agent and asked what I could remember of any such thing. I told her of the septoplasty, and what happened as a result, and she told me that it was most probably where the virus had come from, despite it having been so many years before.

- 114. I asked her what the effects of this infection could mean for me, beyond what I could see and had experienced already, and she spoke to me about my liver, already at risk because of the GSD, and now likely to have been impaired because of Hep' C.
- 115. Apparently, she knew that there were specialists at The Broomfield Hospital who dealt with Hepatitis C, and she suggested that I accept her referral to them for examination of my case and treatment if possible but she didn't let on what, if any, treatments may have been available to me.
- 116. Having travelled to and from this appointment alone, I then returned home to Sue to give her the bad news. She then researched the condition, as we awaited an appointment with the specialists, and told me what she had found, it is how we learned of this virus and how it can affect you, from the internet. Little or no information had been forthcoming from Dr Chakera, and is was apparent to me that she could do nothing other than refer me on. All the same, I am grateful that she saw it for what it was, Hep' C and had enough knowledge to be able to do that.
- 117. I cannot but think that G.P.'s have been given little or no information as regards Hepatitis C, what it is, how you can come by it, what it does to you or even how it can be treated. There was no literature available in the surgery, so we had to look it up ourselves this needs to change as a diagnosis like this needs to come with an explanation and treatment plan. In my case, it was just more worry, especially as it attacked the liver.
- The research Sue was able to conduct led us in the first instance to The Terence Higgins Trust and then on to the Hepatitis C Trust it was quite difficult as although Sue was quite adept at using a computer, you didn't have a start point and one site simply led to another, so you had to follow a trail with some being more relevant and / or easier to use than others. It would have proven even more difficult for someone without her experience of computer use.

- 119. An appointment to see a consultant at The Broomfield Hospital came through within a couple of months following the diagnosis, not ideal but after so many years with the infection, probably not an issue in the overall picture of things. I don't believe this was delayed other than by the sheer volume of patients trying to get an appointment with a haematologist at that hospital.
- 120. I was seen by a Haematology Consultant who immediately referred me to Addenbrooke's as he felt that he would not be able to treat my HcV due to my also having GSD and felt they were better placed to care for me, which turned out to be the case.
- 121. I think that it was then about three weeks before I had an appointment at Addenbrooke's where I saw a Hepatology Consultant, Dr Alexander, a wonderful man with extensive experience of treating Hepatitis C.
- 122. The only drawback with Addenbrooke's Hospital for us, living in Essex, is that it is 64 miles away and the first time we went it took about two and a half hours for us to get there as we didn't know the best way to go, exactly where it was and so on. Now, it takes about an hour and a half, each way, but it is still a considerable trek.
- 123. Having said that, I do not think that it is unreasonable to ask me to travel there for treatment which is absolutely first class and I am most grateful to have been able to be treated there as having been in and out of a variety of hospitals, I have always found them to be exceptional it's just a shame that hospitals closer to us cannot offer the same level of care or treatments.
- The consultant explained my condition and its prognosis and likely long-term impact. He explained that there was an available treatment, but that I would not be a good candidate for that treatment due to my underlying GSD. He explained that the available regime was a combination of two different drugs, the side effects of which were quite harsh, but that new treatments were then 'on the horizon' and could be more suitable for my use in the time to come.

- 125. He also explained that the new drugs which were available for HcV treatment were being rationed to those with the greatest need only, and that as such even when new medication became available, I may have to wait. Although at that time, waiting for the new drugs was advisable given my GSD, it would have been much better if these drugs had been widely available immediately, so I could have started straightaway and not waited four years to start treatment. This was purely an NHS cost-driven rationing exercise which is unforgiveable given that my HcV infection was NHS caused. I may have been better able to tolerate a new drug than those they were then using.
- 126. Whatever the case, I wasn't going to be treated there and then and would have to wait until something more suitable became available and then hope that I'd be found eligible to be given it. In the interim, my condition would be reviewed every six months.
- 127. In 2012, I was also found to have Diabetes, so Addenbrookes brought the treatment of all three conditions, GSD, PCT and Diabetes, together under the one body where I was under Dr Alexander for the HcV, a Professor Cox for the GSD and together with a diabetes specialist they consulted on my treatment. Addenbrooke's took this most beneficial holistic approach to my care for which I am most grateful as it is an approach which I don't believe a lot of other hospitals would have been able to replicate.
- 128. Between 2012 and 2013 I was very unwell. I had hoped to have been able to work on until I was sixty, but found that I could no longer cope with the physical nature of my work so in 2013 I had to retire. I hadn't given up my job our of choice but necessity, Sue and my daughter having had to persuade me to stop doing something which I actually loved. Fortunately, I was able to hand the business over to my son who continues to run it to this day.
- 129. Once I had stopped working, I had to claim sickness benefits which I found a most upsetting experience. Having worked hard to build up a business from scratch and to then fight to hold on to it in the most difficult of circumstances, it had gone and I found myself reliant upon others.

- 130. As a proud, hard-working man this was a difficult situation to accept and left me feeling quite down. Despite long-term serious health issues, I had worked all of my adult life. I felt shame at having let my family down, of not being able to provide as I should, for being what others may see as a 'sponger,' it was a very difficult position for me to find myself in or accept.
- 131. I found the sickness benefit administrative process truly horrendous. I had to apply to the Department for Work and Pensions (DWP) who were based in Newcastle, miles away, so most of the paperwork had to be completed online. I found the forms quite challenging and to a certain extent, intimidating and was most grateful for having Sue to help me work through them. I am fortunate, but there must be lots of people who do not enjoy ease of access to a computer or the support of someone like Sue, as I did.
- 132. It was a complicated process including my having to prove, repeatedly, why I was unable to work. I had to attend assessments, people who had absolutely no idea what GSD, PCT or HcV actually were or how they impacted upon a person and who simply didn't seem to care too much either as they seemed far more fixed on tripping me up than in impartially addressing what was before them and the help required.
- 133. I found the entire process extremely difficult and stressful, unnecessarily so, but despite the uncaring, unsympathetic, ill informed and generally obstructive nature of the assessors, my application was successful in so much as they accepted that I was unable to work.
- I was left feeling as if I was trying to steal money from the public purse, to be after something to which I was not entitled and wasn't considered 'worthy.' It was a dreadful feeling to have been left with and there were many times in the process when I just wanted to give up, they made it so hard for me, any sight error in the paperwork and it was returned.

- 135. On occasions I would have to 'phone them and would find myself sitting in a small cubicle at the local job centre where I'd have to wait for anything up to an hour just to speak to an advisor. I felt scrutinised all the time, less of a person for having sought help, and were it not for Sue I would not have seen it through or been able to cope.
- 136. Even for Sue, who having worked in social services and accordingly been accustomed to such people and their processes, found it challenging and saw how different it was for those who found themselves on the other side of the counter, like us.
- 137. I would not wish the experience I endured with the DWP upon anyone, and the irony of my being given such a hard time by a government department, having been out in the position I was by another, the NHS, is not lost upon me were they simply hoping that by giving me and no doubt many others like me, a hard time, that I'd go away. I couldn't, I needed those benefits to get by.
- 138. After about four years a more suitable HcV treatment became available, in the interim my general health continued to deteriorate and I developed other illnesses as I had before. Additionally now, not helped by the actions of the DWP, my anxiety and worries had increased and I was now experiencing episodes of severe migraine, stress related.
- 139. The new medication became available and I was offered it without ever knowing if I was one of those to whom it may have been 'rationed.' It was a combination of drugs, two different ones I believe, but I don't now remember their names. Addenbrooke's had been very good at maintaining contact with me, and they called me in, telling me that my name had come up on their list to be treated, so perhaps it was still being rationed, I simply don't know.

- 140. Whereas the treatment I received was 'sold' to me as being one of 'the new ones,' it still came with some quite harsh side effects. I found myself quite lethargic still, lacking energy and after only about two weeks into the treatment was found to have been dangerously anaemic, a direct reaction to what I had been taking, not helped by my GSD condition.
- 141. As a result, the medication dosage was reduced, and as such they doctors appeared unsure as to whether or not it would still work. I had initially been advised that I'd need to maintain the treatment regime for about 16 weeks, but having reduced the dosage after just two, no one knew what would happen which merely added to my own worries, would it work or not? There was a fear of the unknown.
- 142. I carried on for the scheduled 16 weeks, and blood tests were conducted at regular intervals to monitor its progress whilst also checking for anaemia, but I cannot say if they were looking for anything else.
- Throughout the course of treatment, one thing sat to the forefront of my thinking, something which had always been there with the GSD, an issue which had been reinforced by the HcV diagnosis and what we learned of its impact would I develop cancer? My late wife had suffered terribly with cancer before she eventually succumbed to it, and I did not want to have too go through that. I was quietly worried sick, but never aired my concerns with anyone else, not Sue, not the doctors, I kept it all to myself, which didn't help my mental state and anxiety.
- 144. Having completed the course, it appeared to have been successful, as a blood test showed the HcV viral load to have been reduced but it wasn't until early 2017 that I was informed that the blood test no longer showed HcV infection.

- 145. For eighteen months thereafter, Dr Alexander continued to monitor me, 'just in case,' but I was eventually discharged from his care, clear of Hepatitis C, but I remained under the care of Professor Cox as regards the Von Gierke's Disease.
- 146. Professor Cox retired, to be replaced by a Dr Deegan who continued my GSD monitoring with bi-annual scans of my liver. There had been concerns for cirrhosis developing and the impact Hepatitis C may have had on the GSD I suffered with. A major worry was that the HcV may have exacerbated the GSD leading to major liver problems.
- 147. In December 2020, I saw my G.P. about a lump which I had found to have developed in my groin. A scan revealed that I had an inguinal hernia and that a further scan would be required. This was done locally, and some form of what was described to me as having been a 'shadow,' nothing to do with the hernia, was apparent.
- 148. My G.P, contacted Addenbroooke's Hospital on my behalf, and within a few days Addenbrooke's contacted me and asked that I go in to see Dr Tan, one of the metabolic consultants there, who was part of the clinical team addressing my GSD. I was also asked to have further scans, including an MRI which took place on 27th December, 2020.
- 149. As a result of Covid-19 precautions being taken at the hospital, rather than go in, I was called by Dr Tan in January 2021 with the MRI results he confirmed my worst fears, I had developed liver cancer.
- 150. Dr Tan was very caring and considerate when breaking the bad news he had for me, and asked if I would like my wife to sit in on the call with me, which I did so she was with me when I found out. In some respects, I was happier to find out in the comfort of my own home rather than face-to-face in the hospital, it somehow felt better this way and I probably got the result a lot quicker than having had to wait for an appointment.

- 151. He outlined the available treatment options for me, and tried to put a positive to his comments, being encouraging as to my future, which was kind of him and provided some much needed hope. I was told that I could have a liver transplant, if necessary, but that in the first instance they would have to explore further to see exactly where the cancer was, its size and so on.
- 152. Further scans revealed that the cancer was inoperable. This decision was taken as the cancer could not be cut out due to its location and because of the ability of my liver to regenerate was very low, one of the effects of GSD.
- 153. However, there was also the option of them conducting a radio wave ablation. I took this option and in March 2021 it was conducted at Addenbrooke's Hospital. Four weeks later my condition was reviewed, and I was told that the ablation appeared to have been successful but there was no guarantee it would not reoccur. I was given the all clear, albeit tentatively as I would have to return on 22<sup>nd</sup> September 2021 for a further review. This would hopefully confirm the initial results.
- 154. Doctors are very careful with what they say and how they tell you things. In so far as I am aware, there is no longer any sign of the cancerous tumour on the scans, but until I have the result of the ones to be conducted in September (2021), I remain anxious as I was told that although the ablation appeared to have been successful and the cancer was no longer visible on the scan, I would have to return on 22<sup>nd</sup> September 2021 for a further review. This would hopefully confirm the initial results.
- 155. I have had an amazing period of treatment regarding this cancer. From the moment the shadow was first detected, I was contacted within a fortnight and things moved at pace thereafter. The kindness and care of the staff at Addenbrooke's has been outstanding and I cannot thank them enough for the way in which I have not only been treated but the steps they have taken to try to allay my fears at such a difficult time for my wife and I.

- 156. Throughout my married life, initially with my first wife Lorraine, and then with Sue, I have been unwittingly putting them at risk of contracting Hepatitis C. Looking back it fills me with dread to consider the dire consequences for either of them had I passed this dreadful ailment on. I believe that this situation, the risk of an infected person being able to pass the virus on to a partner or child, without knowing, needs to be highlighted and emphasises for me the need for all of those who may have become infected to be screened.
- 157. My lifelong concerns about cancer have rubbed off on my children, especially as they lost their mother, my first wife, to cancer. They had to sit and watch as she suffered, and I did not want them to have to go through that again, with me, but it happened and they were left having to come to terms with the fact that having lost one parent to cancer they may have lose the other it has been just as traumatic a time for them as it has been for me.
- 158. These worries extend to Sue, worried and suffering great stress at the thought of losing her husband, and even my grandchildren my daughter is terrified at the thought of losing her dad, and my grandsons fear losing their grandfather. The impact sends ripples out through the generations far beyond just the infected person
- 159. I do not believe that I have anything to hide in so far as my health is concerned now, or historically. I had always been unwell, it was nothing out of the ordinary and everyone knew that I was unwell and had been unwell from childhood, we made no secret of it and it was tenet I continued with beyond my childhood.
- 160. I have never found the need to be extra vigilant in any particular areas, once I knew that I had HcV even whilst working with glass and the potential for cuts and grazes that came with it. Due to GSD, I was a naturally cautious person, thinking carefully about what I did, and in particular how I ate, I just carried on in this way, being mindful of what I may have been doing, with what and how as regards Hep' C whilst seeking to avoid the sun as best as was practicable, for the PCT.

- 161. Since diagnosis (HcV) though, I have been very careful around my grandchildren, particularly in the period immediately following my having been told that I had hepatitis and then our learning of its potential for harm and means of transmission. Not knowing of the disease, I was very cautious, but then adapted and adjusted once we had found out more I just wish that more information had been available from the outset, from my G.P. or through the hospital, as soon as Hepatitis C was known or even suspected, rather than Sue and I having had to find out for ourselves.
- Due to the very late diagnosis, I have not had to endure the sort of negative approach to Hepatitis (and other ailments) which others with HcV seem to have experienced due to the stigma associated with its perceived origins. Although the stigma levelled at Hep' C is less than that for HIV, it still exists and remains to this day.
- 163. Over the past two to three years, whenever I have required dentistry, things such as tooth abstractions or anything invasive, I have had to obtain a document from Addenbrooke's Hospital to show that I no longer have Hepatitis C. Without it, knowing that I have had this virus, the dentists will not treat me.
- I have also experienced difficulties in securing insurance life insurance (in part additionally affected by GSD) and travel insurance. I do not think that enough understanding exists of the psychological impact not being able to secure services which others can, without good reason, has on the applicant. Your inability to secure insurance singles you out from others and makes you feel less valued and a risk, when this is simply not always the case.
- 165. I am supported by the England Infected Blood Support Scheme (or 'EIBSS,' and previously by The Skipton Fund) but believe the approach to supportive finance being provided is misguided. These are not compensation payments, which perhaps should be considered, but in my eyes funding for the additional expenses incurred by people like me who have been living with the consequences of another's actions.

- 166. In my case, I currently have to travel to and from Addenbrooke's Hospital around four times per month, which is costly, but the payments I receive help. I am therefore most grateful for them as in their absence I may struggle. But this does not mean to say that I feel the current financial package to be adequate when considering the various injustices people with HcV have experienced, such as a lack of insurance or their inability to secure a mortgage.
- 167. As regards mortgages, I have been rather fortunate, as each time it has been required, I have been able to get a mortgage, but on each occasion I had been in full-time employment and my Hepatitis C infection had ben unknown. I believe that I would have encountered problems had it have been identified earlier in my life.

# Section 6 - Treatment / Care / Support

168. At no time during the course of my treatment for HcV was I offered any form of counselling or other psychological support, but I did have a dedicated nurse specialist allocated to me, someone I could contact as regards the Hepatitis C infection, in particular whilst I was undertaking the Hep' C treatment, which I found useful. I was offered support at the point of the cancer diagnosis.

# Section 7 - Financial Assistance

- 169. I learned of the existence of The Skipton Fund by virtue of the extensive research Sue conducted once we had been told that I had Hepatitis C. I do not think that this is how I should have found out about them, we should have been told when the diagnosis had been made and the help which they may have been able to provide should then have been explained to us but there wasn't even a leaflet made available.
- 170. I sought assistance, but the fund wanted me to prove how I had become infected, and in my case that I had been given blood. I found this to have been a rather barbed request as, had my sister not stood up for me, to ensure that a record was made and then made available to my G.P., I would not have been able to prove that I had been given a transfusion and no proof meant that my application would be declined.

- 171. The above aside, I found the application process fairly straightforward, and Sue and I despatched the forms. However, the fund refused to accept a statement from Dr Alexander that he believed the source of my infection to have been the blood transfusion given immediately following the septoplasty procedure.
- 172. As a result, I went to my G.P. where, because of Glynis' intervention, I knew that a record would be held, and fortunately they were able to provide a copy to support my application (and didn't charge me for this service, as I believe other surgeries do).
- 173. The application was then approved, but the insistence of my having to provide evidence of the source of my infection was a stumbling block which I was luckily able to overcome, but I fear that many others would not have been so fortunate and accordingly have not been treated as they should have been by the fund.
- 174. Initially, I received a lump sum payment of £20,000- from The Skipton Fund, a figure I considered an insult for the length of time I had carried the disease.
- 175. The EIBSS then took over from the Skipton Fund and contacted me, telling me that I would have to reapply to fall within the scope of their remit, so the changeover from one provider to another was not automatic in my case, which I feel it should have been as nothing had changed.
- 176. I reapplied and was told that I would be eligible for a payment of approximately £300- per month, which was apparently at the lower end of some sort of scale they were using to determine payment levels. I appealed, providing additional evidence to my initial application demonstrating that I met the provisions for a higher rate of support. This was accepted, and I now receive a monthly payment of £2,390- per month and an annual £500- winter fuel allowance, a considerable amount over that which I had initially been offered.

- 177. Rather than help me from the outset, The Skipton Fund seemed to do nothing but try to decline or at the least delay my application. There should then have been a seamless transition from them to the EIBSS, but there wasn't. The EIBSS made me apply again and then seemed to want to do nothing but offer assistance at the lowest end of their scale, causing me to have to lodge an appeal. The conduct of these funds has left me with a belief, rightly or wrongly, that they exist merely to save money as opposed to providing it where it may be most needed.
- 178. At the time of my EIBSS application, I had not been diagnosed as having liver cancer. Once this had been found, a further application was made and I received a 'one off' lump sum payment of £50,000-.
- 179. Penny Mordaunt MP, when serving as H.M. Government Minister of State for Disabled People, Work and Health, announced that everyone who had been affected by contaminated blood or blood product use would receive financial support of up to £50,000-, I hadn't realised that this didn't mean additional funding to that which they may have been allocated, but was instead a cap on the amount people would be entitled to, with no one entitled to receive more than £70,000-. The reality of what was on offer was misleading.
- I have also experienced some basic administrative difficulties with The EIBSS, for example I did not receive one of my regular monthly payments, following on from a Stage Two allowance, so I called them to ask 'why?' An advisor explained to me that their computer system had taken me off of the list for payment as I'd been given a lump sum. I don't know why this had happened, it should not have done, but it did. The lady put me back onto the list, and I was paid a couple of days later, but it should not have happened. You are left feeling that they (EIBSS) are doing you a favour rather than providing a service to support you.

# Section 8 - Other Issues

- 181. In order to assist The Infected Blood Inquiry further, I now produce an extract taken from my medical record (as held by my G.P.) as documentary exhibit **WITN5907002**. This document is a copy of the note which shows my having been given four units of blood as a result of post-operative bleeding experienced as a result of the septoplasty procedure.
- 182. This record was created post-event, following the intervention of my sister as no record had been created at the time. As is evident, whereas the septoplasty took place in June, 1980 the note wasn't made until 10<sup>th</sup> October, 1980.
- 183. I believe that the whole issue of contaminated blood and infected blood products is an issue subject to a long-term systematic cover-up by both the NHS and successive politicians none of whom have been prepared to accept responsibility. My wife (Sue) and I watched with interest the appearance before the Inquiry of Lord Clarke, i.e. Ken Clarke, another former health minister.
- 184. We were both shocked and disappointed to witness such a lack of humility, denial of accountability and a general disinterested approach to the problems faced by so many people, many of whom are now dead. We had hoped to see a willingness to assist the Inquiry, someone who'd be prepared to locate relevant documents with an interest in getting to the bottom of the matter, but it simply didn't happen and it seemed to us that he simply 'couldn't care less.'
- 185. The people upon whom this whole affair has impacted need the government to accept that they are accountable, even where the root cause of the problem pre-dates their administration; to apologise and offer proper redress including adequate compensation and assistance.

# **Statement Of Truth**

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

Signed: GRO-C

Dated: 22 No November 2021