

IN THE INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF PAUL [GRO-B]

Introduction

- (1) My name is Paul [GRO-B] I live in [GRO-B] and I was born on [GRO-B] 1964.
- (2) I am a 54 year old man living with severe haemophilia A, and HIV infection. I have had a number of joints replaced due to haemophilia related arthritis. I have been infected with HBV, HCV and HIV from contaminated blood products. I have recently had successful treatment for my HCV. I have had no children due to HIV/HCV. I was married for over 13 years but my wife and I are now separated. I am self-employed as a garden designer. This has been a recent career change. I am currently in good health. I have campaigned for most of the last 30 years for the truth of our infections to be told.

How Infected

- (3) I have severe Haemophilia A. I had a number of blood products to resolve internal bleeding and external cuts throughout my childhood and teens. At first I had Cryoprecipitate as treatment in hospital settings. I developed inhibitors to FVIII, and my inhibitor level increased after cryo, so I wasn't aggressively treated initially. The thought was that the longer I went without cryo, the lower the inhibitor level would be and the better the prospect would be if I had a major/life threatening bleed. I was treated with ice packs, bed rest, splints, analgesia and gentle physiotherapy for a large part of my childhood with cryo only for occasional bleeding episodes. In 1976 I was referred to Oxford Haemophilia Centre. This was because Dr C Rizza was involved with a study on Factor VIII concentrates and patients with inhibitors. I was started on prophylaxis NHS products in the summer of 1976 which my parents were taught to inject at home. By November I had a USA commercial product. By April of 1977 I developed HBV. I was not treated prophylactically after that. I was only ever treated on demand, when a bleed required it. But I had a range of all factor VIII manufacturers over the preceding years, both NHS and commercial.

(4) Cryoprecipitate Plasma 1966-1981

I first had Factor VIII concentrates in June 1976. My notes state that I had no cryo or Factor VIII since 1974, due to inhibitors.

(5) Factor VIII Concentrate 80-85

Product	Batch Number	Date used	Units
KOATE	C1085	23.01.80	5000
KRYOBULIN	09M00179	12.02.80	1122
KRYOBULIN	09M00179	21.07.80	4990
HUMANATE	1805	06.03.81	400
HUMANATE	1805	30.11.81	2000
KRYOBULIN	09M04680	20.12.81	2104
HUMANATE	1805	25.03.81	4000
HUMANATE	1805	04.04.81	800
NHS	HL2684	04.04.81	1820
FACTORATE	U12608	27.07.81	5690
FACTORATE	V36504	16.12.81	5040
KOATE	NC8347	29.12.81	3500
KOATE	NC8347	01.01.82	1000
KRYOBULIN	09M06881	26.02.82	971
FACTORATE	N64401	02.06.82	2625
HEMOFIL	810527A006A	25.10.82	5740
HEMOFIL	811023A010A	27.10.82	750
HEMOFIL	811023A010A	23.10.82	4500
FACTORATE	W78605	25.10.82	3540
NHS	HIB3094	11.01.84	2450
KOATE	NC8495A	11.01.84	4700
CUTTERS		11.01.84	1410
CUTTERS		12.01.84	1980
NHS		13.01.84	490
CUTTERS		14.01.84	940
CUTTERS		09.02.84	470
CUTTERS		10.02.84	470
CUTTERS		20.04.84	470

KOATE NC8495A		30.04.84	2820
NHS		26.05.84	940
KOATE NC8495A		26.05.84	470
CUTTERS		02.06.84	470
CUTTERS		22.06.84	470
CUTTERS		18.07.84	470
CUTTERS		18.07.84	470
NHS		18.07.84	480
NHS	HLB3160	27.07.84	1068
KOATE NC8455A		30.08.84	2300
ARMOUR	X41606	11.09.84	2500
NHS		11.09.84	430
ARMOUR			3540
NHS	HLB3209	19.03.85	1715
NHS	HLB3209	20.03.85	2450
NHS	HL3212	25.05.85	4500
NHS	HL3234	18.09.85	960
NHS	HL3266	07.10.85	1140
NHS	HL32608	07.10.85	555
NHS	HL32608	07.10.85	1850
NHS	8Y3289	15.11.85	1000

- (6) Koate and Cutters are the same brand they have just been recorded differently on some notes. Armour and Factorate are also the same brand.
- (7) The records with batch numbers came from an email request to my hospital in 2002. The ones with no batch numbers I took from medical notes recorded by LCHB on a memory stick.¹ All of these state "home treatment" so I am assuming the ones with batch numbers were administered in hospital. It seems a little strange that there are no notes of factor usage for the whole of 1983. The UKHCDO records show me as having Armour products but do not list amounts or batch numbers. I don't seem to be

¹ These are in the possession of my solicitors

able to locate these anywhere. I had a retrospective² HIV test which showed I was HIV negative in 1979.

Details of the haemophilia centres, and hospital under whose care I was under at the relevant time

- (8) Nottingham University Hospitals Trust, QMC Campus, Derby Road, Nottingham NG7 2UH: Dr. Bletcher, Dr. French (1960's-1989) Dr G Dolan (1989-2016)
- (9) Oxford Haemophilia Centre: Dr C Rizza (1976-77) (by referral) ³
- (10) Prior to 1977 all treatment was undertaken in Nottingham Children's Hospital, Forest Road Nottingham. This closed down in 1977.

The dates given infected blood products.

- (11) I developed acute HBV on 21/4/1977. The red star started appearing on my blood tests results. I only started using Factor VIII concentrates the previous year. I believe that it could have been any of the products that I had used in the previous 6 months. I used a US commercial product in December of 1976 and NHS products before that.
- (12) With regards to HIV, I am aware now that retrospective blood tests confirmed I was HIV antibody negative in 1979. I was tested on 19th April 1985 for antibodies to HTLV3 and was found positive. Therefore any of the products I had received from 1979-1985 could have caused my HIV infection. My HCV infection could have originated in any, or multiple treatments from 1976 to 1985, when heat treated/solvent detergent products were used.
 - a. Information or advice provided to in the event of infection

² The only stored sample of blood that the hospital said they had was from 1979. In the late 1980's they tested this stored sample for HIV and found the 1979 sample to be negative

³My doctors at Nottingham referred me to Dr Rizza at Oxford Haemophilia Centre to discuss factor VIII use and my inhibitors as he was seen as the leading haematologist in this area of medicine. My Nottingham doctors arranged an appointment for me and my family to see him.

- (13) I am unaware of any risks and no warnings as to risk were given to me or to my parents at the time. There seems to be nothing in my notes which indicates that we were advised of any risks at the time.
- (14) My parents were involved with the Haemophilia Society and local support group (Notts and Derby Haemophilia Group) for the sole purpose of gaining information. I suppose we must have been alerted to *possible* risks after I was infected with HBV in April 1977. I started using Factor VIII concentrates in the summer of 1976 after advice from Dr C Rizza at Oxford. My notes show a letter dated 17.6.76 from Dr Rizza to my doctor, Dr French. In it he states.. *"it would be wise to try, as far as possible, to treat him with the NHS concentrates.....As a last resort I think it might be justified to put him onto one of the commercial factor VIII concentrates"*. I had started using commercial Factor VIII concentrates by the end of 1976. Armour and Cutter were used in December 1976 according to my hospital notes. However, I only remember being told I was unlucky to have got HBV four months later. The risks couldn't have been explained because I continued to be prescribed commercial factor concentrates after my HBV infection. My father has said he doesn't remember any notification of risks other than I was unlucky to have contracted HBV.
- (15) The first warning of the risk of contracting HIV/AIDS came in a World in Action programme around 1983/84. I only remember my doctors (Dr. French and Dr. Bletcher) stating that the programme was sensationalised. They played down any risks. My parents sought information from The Haemophilia Society, which in turn was being advised by Haematologists, UKHCDO and the Pharma's. The Haemophilia Society's information booklets "Haemofact-AIDS" were my parents, and my, only source of information. They stated:
- (No.3 May '84): *"retrovirus has been isolated from the lymphocytes of a patient with haemophilia B who had AIDS. These reports should be received with optimism. The obvious benefits...would be the provision of a blood test....and development of a vaccine. Thus the incidence is less than 1 in 1000 patients at risk. It is possible that the immune suppression produced by repeated exposure to clotting factor concentrates lowers the threshold for infection with the putative AIDS agent."*

- (No.4 Sept.84): *“most haemophiliacs have antibodies to a variety of different viruses in their blood, probably as a result of repeated exposure to small amounts of these viruses in transfused blood products. The presence of antibodies is usually taken as evidence of immunity to infection and perhaps one reason why the risk of AIDS in haemophilia is so low (around 1 in 1000).”*

(16) With this information from the only patient organisation, and the advice from UKHCDO haematologists, we all accepted that the risk was minimal. No one was saying anything different at the time. My doctors were still advising continued use of factor concentrates, even advising me to take factor more regularly on the same day that I was unknowingly tested for HTLV3.

(17) When I was told in June 1985 I was HTLV3 antibody +, I again thought I was unlucky and I was one of the 1 in 1000's they talked about. There was no warning with HCV other than my personal knowledge of hepatic infection with HBV (which was an acute episode which I recovered from after a some months), and sporadic mentioning of Non A non B hepatitis in the late 1980's. By the time I was informed I had HCV in 1992, I was told this wouldn't be a problem for me because I would die from an HIV related illness long before HCV would cause me any concern. There was no mention at the time of increased morbidity rates of the co-infected. My notes show, on 17.09.92: “Hep C study ... Anti HCV pos..” However my notes from a clinic meeting on 31.10.92 do not mention anything about informing me or how I was to be informed.

How infected

(18) I was infected with all of those viruses; HBV, HCV and HIV. (I believe I am also on the national nvCJD register although I am not aware of having received any linked batches).

(19) I was called in for an appointment to discuss some blood results. This was in July 1985. The letter I received prior to the appointment on 24th June 1985 related to bloods taken on 19th April. It stated “.....I would like to briefly discuss one or two of these results with you personally. Could you please come to see me for a short time one day next week.....” The letter was written by Dr Bletcher, who saw me in clinic on 19th April and directed that the blood tests be performed without telling me what he was

testing for. I was seen by Dr French who told me I was HTLV3 antibody positive and that this virus develops into AIDS. I remember asking him whether I had antibodies and if this meant that I wouldn't get it. He told me that I had it and that that meant I would need to avoid intimate relationships and that I shouldn't tell anybody. He also said it meant that I would probably only have a couple of years before I developed problems and that I may only have a few years left to live.

- (20) With my HBV infection in 1977, I probably received better information as to how to manage the infection than that which I received following my HIV or HCV infections.
- (21) Following my HBV infection, my whole family were tested for the virus. We were given advice about hygiene and infection control. I was advised to have different towels, facecloths, cutlery and eating/drinking utensils. As far as I am aware, this was explained to the whole family. As this was an acute infection, I recovered after a few months. My family and I thought that I had just been unlucky and that it was just another episode of ill-health that I had bounced back from.
- (22) At the time of my HIV diagnosis, I was given no information other than that I probably would only have a few years left to live; that I should avoid sexual contact, or intimate contact with others and that I should not discuss my diagnosis with anybody due to stigma. This wasn't adequate information in helping me to understand or manage my condition. The contents of the letter referred to above (prior to my appointment on 24th June 1985) show that my doctors had not thought about the consequences of my diagnosis and had not considered how they could help me understand how I was going to manage. How could a doctor who had treated me for years, seen me grow up from childhood to adult, test me for the AIDS virus without my knowledge, and then only want to "*briefly discuss*" my result and only want to see me for a "*short time*"?
- (23) I remember thinking it was odd that they didn't ask for my girlfriend at the time, or my parents or siblings, who I was living with at the time, to be tested. They tested all my family when I had HBV, but there weren't any checks or advice for my intimate partner and family members on my HIV diagnosis. This confused me at the time.

- (24) I didn't receive any support or guidance as to where I could obtain advice, from the doctors or hospital. It was 2 years before I saw a counsellor in my first HIV clinic, and that clinic was mainly involved with supporting gay men's issues, and seemed out of their depth in supporting me. I remember being told I was "*brave*" at that first meeting which only angered me. It was 5 years after my HIV diagnosis that I saw a psychologist who helped me deal with, by then, some dark thoughts of dying and of living with a death sentence, and the burden of having a highly stigmatised contagious disease.
- (25) As referred to above, when I was diagnosed with HCV in 1992, I was given minimal advice. I was told "*not to worry about it too much as my HIV would cause my death a long time before the HCV would cause me any concern*".⁴
- (26) I think that advice should have been given about the risk of using Factor concentrates in the first place. Any risks were underplayed and factor use was encouraged. It always felt to me as though the doctors stuck their heads in the sand and hoped we wouldn't get infected, rather than giving us educated and considered advice and information. With HIV I think I should have had more time for the appointment when I was informed of my diagnosis. I was just told I was HTLV3 antibody positive, and then the doctor asked me if I had any questions. I was like a "*rabbit in the spotlight*". I was numb. I didn't have any questions that I remember because I was just taking it in. It was a surreal moment. I didn't want to believe it. They knew we were infected months before we did. The time delay between the doctors knowing and me being informed could have had disastrous effects for my intimates. The doctors should have at least have come up with a list of "*frequently asked questions and answers*". They should have given me time to consider the implications and talk through with me the information that I ought to have received, for example concerning; lifestyle; emotional support; how I should tell my girlfriend; how I should tell my parents; what support my parents should have; what I should do about my work and workplace; what to expect with my health; where to go or what to do if my health changed; what symptoms to look out for; how to avoid transmitting this to others and a range of other things that kept me awake

⁴ Conversation with Dr. **GRO-D** at time of diagnosis

for many years to come. They offered me nothing in the form of information and it felt like the doctor couldn't wait for me to leave the room after he had told me. He didn't even look me in the eye. He told me whilst looking at my notes. The advice I did receive was due to my finding out about THT and other mainly gay support organisations that I could call and go through my issues.

(27) I believe the way the results of tests and information about the infection were communicated was very poor. They didn't prepare me for the test result in any way. I didn't even know I had been tested for HIV. Testing without consent or even knowledge that I had been tested meant that I had no opportunity to prepare myself to ask questions. Compared to all my hospital appointments, the appointment where I was told of my HIV infection was the briefest, most unprepared and most uninformed I had ever had. It was also the most devastating news relating to my health and longevity that I had ever had. The letter asking me to make an appointment stated it would be "*brief*" and "*short*" meeting, and the appointment itself only took minutes and the doctor couldn't make eye contact with me. I wasn't even given phone numbers for support organisations, condoms or an opportunity for a follow up meeting to discuss any questions I had.

(28) I remember being told to avoid sexual intimacy and close contact with others. They didn't tell me how I was going to do this. How I was supposed to not kiss my girlfriend; how I was to avoid sexual relations; how I was to suddenly avoid close family contact? They didn't tell me how I was supposed to tell my intimates. They left that up to me, even though they had known for many weeks of my infection before informing me. Anything could have happened in that time. I felt very alone and very isolated. I was given no guidance as to how I was to live my life after that diagnosis. It was up to me. I felt an enormous sense of responsibility, coupled with a dark sense of my own morbidity. They never gave me any advice or information for me to pass on to my intimates.

Consent

(29) My treatment with Factor VIII concentrates was obviously with my knowledge. My parents administered my home treatment when I was a child and this was always done with my knowledge and consent. The risks associated with this treatment, however,

were not relayed to me or my parents, so I do not feel the treatment was given with adequate or full information. I feel it was the opposite. I feel risks were underplayed. The testing for HIV was done without my consent. I had no idea. My medical notes from that day - 19th April 1985 - only talk about discussions around internal bleeds in my left knee and the encouragement for me to use more factor. There was no discussion or information about the doctors having tested me, or the reason for the blood tests that day. I had blood tests at every appointment for inhibitor levels, full blood counts, heamaglobins etc. It did not register with me that I was being tested for HIV/HTLV3 and no one told me. If I had been informed, maybe I would have prepared some questions for the appointment so as to learn whether I was infected.

- (30) Research, I believe, played a major part in our infections. With inhibitors to Factor VIII, I was advised not to use factor unless for major bleeds or life threatening injuries. This was documented on a number of occasions in my medical notes.⁵ This all changed when a Dr C Rizza from Oxford Haemophilia centre was conducting a study on inhibitor patients and using the new factor VIII concentrates in 1976. (29/9/76 letter from Dr French to my GP: "*Dr Rizza, however, at the Oxford Centre has been finding recently that some patients with inhibitors do benefit from regular treatment.*") Over that summer I was referred to him and put on regular Factor VIII concentrates for the first time. My parents had been trained to administer it at home. (In many ways I now think that the doctors felt they had reduced responsibility and guilt because the factor was being administered by my parents and I and not by them. They didn't have to think about the risk because they were not present when the factor was pumped into my veins.). It states on my notes that I was to use Elstree/NHS concentrates only. By December of 1976 I was using Koate/Cutter and Armour/Factorate, both US commercial factors. Why was I put on factor VIII if I had inhibitors? I realize my parents wanted the best for me. They were saddened by my constant knee bleeds and the pain I was in. However, they would never have agreed to give me those products if they realized there was any risk, greater than the knee bleed itself.

⁵ For example, 6.3.75 ("*only dare to use Factor VIII to treat Paul in the event of severe or dangerous bleed*").

- (31) With HIV I believe we were part of a larger study. AIDS was a new virus that many medics knew little about. We, as patients, represented as an ideal opportunity for them to “*make their name*” in the developing world of AIDS. We know now that the “*chimpanzee*” letter was an example. We were cheaper than chimps and easier to monitor over a long time. Why else would they have given it to PUPS? Dr Christine Lee recently stated in a Radio 4 interview that she was working in studies and research. I believe she was, and we were the study group. I also believe there was coercion from the pharmaceutical companies to use as much factor as possible in the early 1980's as destroying it would have cost them and their shareholders money. They knew people with haemophilia in the US were exhibiting AIDS related symptoms, so why did they keep exporting it, if it wasn't profit driven?

Impact

- (32) As I was first infected with HBV in the acute form, I was ill for only a few months, but took a number of months to get back to normal routine. I was 13 years old at the time. I missed a lot of school, but this was normal with my haemophilia issues and bleeding. I had daily nosebleeds, nausea, lethargy, loss of appetite, weight loss and no energy. I remember being told I was unlucky to have contracted this, but also remember my parents' attitude changing. My whole family had to be checked and undergo blood tests. I also had to have “*barrier*” protection at home, with my own towels, facecloths, mug, plate, knives and forks etc. I could only have minimal contact and protection from those around me at the time. This was difficult for my parents as I was having daily nosebleeds and there was a lot of blood spilled in the family home. I have a brother and sister, both younger, whom my parents were concerned about. My haemophilia was by now a “*normal*” condition - and my younger siblings had grown accustomed to it - but the HBV infection changed things significantly. It was the first time I felt different in the family. I felt dirty. I couldn't eat fried foods for about 5 years after diagnosis because they made me feel sick. I was 13, developing as a teenager and later bounced back to my normal life. But this episode made me realise that my haemophilia treatment had its risks. From my medical carers, however, I was simply told that I had been unlucky. I believed them.

(33) With my HIV infection this was very different. Obviously, AIDS had been in the news and the stigma attached to it was intense. The haematologists were still prescribing factor concentrates, and the literature and information given to patients were stating that only 1 in 1000 were at risk. I wasn't taking regular factor on a weekly prophylaxis basis so I didn't perceive myself to be at risk. I was 21 with the world at my feet. I had a good job, a girlfriend and an active social life. I managed my haemophilia quite well and had very few complications other than a knee that bled fairly often and early onset arthritis in a few joints. I had no preparation for the appointment when I was told about my HTLV3 diagnosis, so I had few questions to ask at the time. From that day on, my life changed forever. I was told I had the virus that causes AIDS and that I may only have a few years to live. I was told to keep this to myself, not to tell others and to avoid intimate relationships and sex. My mental state changed from that day on and I don't really know now, looking back, how I coped. I was obviously traumatised from knowing I would die soon. I would die from some very horrible infections and illnesses attached to AIDS. The thought of my parents losing me and seeing me die horrified me. Hadn't they been through enough pain seeing me grow up and seeing the pain I suffered through haemophilia? For them to see me die from this virus, that they themselves may have had injected me with, traumatised me as well as them. From that day on I became a liar. I lied to my friends, my wider family, my colleagues and also to myself. When stories about "*gays, drug addicts and haemophiliacs infected with AIDS*" began appearing in all the tabloids, I lied about my diagnosis when I was asked. I lied to myself because I was partly in denial that it would kill me. I went from being a fairly carefree person who enjoyed life to someone who was frightened and very scared of the world around me. I was petrified of infecting others around me and became very isolated avoiding any personal contact. My relationship soon ended when I insisted on only using condoms and made every excuse I could to avoid any intimacy. I stopped sleeping well, and instead lay awake all night with my head full of fears. Fears about dying, fears about infecting others, fears about getting illnesses that would ravage my body. Instead of planning my life around my career, or the hope of settling down and having children, I lived the nightmare of death and planning my funeral. I had suicidal ideation as I thought the option of ending my life would at least keep the stigma of AIDS away from my family when I got ill. I saw suicide as something that would cause less stigma and heartache than an AIDS-related death: that gives some idea of where my head was at the time. I became very angry and bitter towards the world. The

doctors had given me this virus (the very people I trusted to make me well) and they couldn't answer my questions. They couldn't be honest with me or look me in the eye. The pharmaceutical companies had made their money. The government had messed up somewhere, but all I was being told was keep this to yourself. Don't tell anybody.

(34) I tried to keep it together and pretend to the wider world around me that everything was OK. I told people, when they asked, that I had been one of the lucky ones and I had escaped the virus. Mostly I was believed. It made me into something I wasn't. It changed the person I was. I continued going to work and socialising, but with different agendas in my head. It wasn't just the thought of dying, the getting ill or the massive burden of responsibility of not infecting others, it was the horrible stigma and attitudes of the world around me. AIDS was perceived by the public, reinforced by much of the media, as a dirty disease. It wasn't just the ill-educated Sun readers; or the homophobic and uncaring part of our society. It was everywhere. James Anderton, a senior police figure, stated publicly in 1986 that Aids patients were "*swirling in a human cesspit of their own making*", (he was supported by Margaret Thatcher and he was later knighted becoming Sir James Anderton for his work). Church people, councils, politicians all had something negative to say about the disease. It is difficult looking back today and trying to understand the level of hatred that people had for anyone living with the virus. I had to live in this life. The thought of dying never left me. I closed my bedroom door at night and my world collapsed. I was very fragile inside by now and would breakdown. I cried a lot at first, always alone and always when I knew it was safe to do so. I had been given this virus and I hadn't been given any tools to know how to deal with it. I kept it to myself and it stewed and rotted me away from inside.

(35) Some 5 years later when I was introduced to a psychologist who I felt comfortable with, I started talking about my fears and the mess that was inside my head. I talked and talked and the hour appointments seemed like only minutes each time. She set up a self-help group for infected people with haemophilia in my area. This group met in a safe room in the basement area of the hospital, with no windows and no sign on the door. We talked. There were about 10 of us and people were more ill every month we met; people got thinner; had more health complaints; scratched at their skin; were unable to talk properly as the virus had affected their mental capacity. They cried as

they told their stories and month by month the group got smaller and smaller. I started going to their funerals after a while. I couldn't at first because it was too much for me to cope with, but after a while it strangely gave me some kind of strength. It was always acutely sad and I cried for every one of them. I cried for the children they left behind and the widows they left behind, some of whom were unable to tell the truth of how their loved ones had died. I cried for them and for the lives they could have had. The anger in me just got more intense. Maybe it was the anger that gave me the strength. I started writing to politicians - the first being Margaret Thatcher. Her response was so negative and insulting to me that I soon realised that there were very few people out there on my side with this. All they were bothered about was negligence or the risk of fault being laid on their doorstep, not helping me in anyway. How could any of this help with my mental state and the way I dealt with living with this virus? By now I had acquired a deep mistrust of the medical profession, the pharmaceutical companies and the politicians - institutions I had been brought up to believe were on my side if anything went wrong. Those institutions had become the problem.

(36) Over the years, I had a number of HIV related illnesses: coughs and colds that took months to go away, diarrhoea, **GRO-B** lethargy, night sweats, rashes, thrush, oral hairy leukoplakia (which drove me mad), lymphedema with golf ball size lumps in my groin, and so on. I refused treatment in the early days as I just did not trust the people administering them. The people telling me to take the drugs were the same people (as I saw it) that told me Factor VIII was safe. I didn't trust anybody anymore and I became a "problem patient". I only agreed to take my HIV medication when my CD4 levels had dropped to 5 and my viral load was approaching 1 million. By this time, I could only stay awake a few hours at a time and my quality of life was extremely poor. I am very lucky to have lasted until the drugs became effective.

(37) I was told about my HCV infection by a haematologist at a clinic in 1992. I didn't really see the relevance at the time or understand the implications. They had already ruined my life with HIV, so how could it have been any worse? My doctor at the time told me not to worry about it too much because my HIV would kill me a long time before HCV would start to cause me any concern. I was told to have a drink of alcohol when I wanted if it helped me to relax or sleep. I just saw this initially as another slap in the face. My mistrust in my doctors had just increased and I started to research HCV and

its implications. I did worry about alcohol and stopped any recreational drinking when I could. I learnt about the increased morbidity rates of being co-infected and it made me more proactive about my health and lifestyle.

- (38) I wanted to live and I wanted to beat these viruses. I didn't know how much I could take physically or mentally. I kept on going to the funerals of those I got to know and then went on to die. I kept the anger inside me fuelling my reason to live. If it wasn't for me, it was for them that were no longer here. It was to tell their story. Something had gone very wrong with our treatment and still nobody wanted to take any responsibility. And then I got a letter stating that I may have the nvCJD prion: "*Mad Cow disease*". My anger at this point was counterbalanced by my despair.

Further medical complications or conditions have resulted from the infection

- (39) As above in the main- coughs and colds that took months to go away, diarrhoea, **GRO-B** lethargy, night sweats, rashes, oral hairy leukoplakia, thrush, lymphodemia with golf ball size lumps in my groin.
- (40) The treatment(s) which you have been given for HIV, HCV and/or HBV (or for any consequent medical complications or conditions);
- i. HIV-Triple Combination Therapy- Lamivudine, Zidovudine and Nevirapine. This had to be changed when I started HCV treatment due to drug interactions.
- (41) I am now on Triple combination therapy Emtricitabine/Tenofovir Disoproxil (Truvada) and Dolutegravir (Tivicay).
- (42) As to HCV, after many years of fighting for treatment – and being refused trials due to my HIV or to not being seen as a priority under NICE guidelines - I eventually had the new oral medications which comprised a 3 month course. I am happy to say that this "*cured*" my HCV infection. (I do not recall the names of these drugs at present).
- (43) I felt that the HCV treatments were seen as a financial issue for Health Trusts and Government funding, rather than the focus being on their treatment value for our

condition. I spent many years fighting for treatment for my HCV before I eventually got it. In many ways I am glad it took so long as the treatment did get better as time went on. Nevertheless, I found it very hard to bear the fact that although I had been given the virus by the NHS, I was being denied treatment for it because I didn't fall under the NICE guidelines. I was just a number on a list, not a person.

- (44) With HIV, it was different as the doctors wanted me to have medication many years before I agreed to use it.
- (45) I consider the HCV medications ought to have been made available to me but were not. There were many obstacles due to funding, NICE guidelines, and also my HIV status. The idea seems to have been: what's the point of treating me for one illness and wasting resources, if I am only going to die of another? I knew other people with haemophilia who were not considered for liver transplants because of the same reasoning. Even alcoholics could have a new liver if they stopped drinking, but a patient with haemophilia and HCV would only go on to infect that liver as soon as it was transplanted. The HCV wouldn't leave the person. And if they had HIV as well, then was it viable to give a scarce resource to a potentially terminally ill patient?

The mental and physical effects of the treatments received

- (46) With HIV, it took me a long time to accept that the drugs would work due to my mistrust in doctors and pharmaceuticals and also from my experience of seeing patients on AZT monotherapy and some of the earlier drugs in the early 1990's. I saw many people with HIV over this time and the body fat changes and the body shape changes that occurred in some people on some drugs scared me. I didn't suffer from any of these in any dramatic way personally, as I was lucky to leave it until the drugs had improved. However my pill burden was fairly heavy with 3 drugs twice a day initially. I used to feel dread filling my weekly pillbox knowing that all these toxins and drugs would be going through my system and were being processed by a liver already impaired by HCV. I was also aware that this was it for the rest of my life, forever. Accepting my illness and accepting a lifetime of daily medication placed its mental strains on me. I had to talk myself into believing that the drugs were good for me.

- (47) With HCV treatment, I was happy to finally get it. I had a lot of support from the HCV specialist nurse and although I had a heavy pill burden, it was only for 3 months (not for ever as with the HIV drugs). They worked and they eradicated my HCV. However, they were potent medications and I had a range of side effects with them. These were mainly insomnia (only getting 2-3 hours sleep a night), I became a bit manic and had a lot of nervous energy, talking and too much physical energy, which was not normal. I became very short tempered and angry and also suffered from anxiety. I lost weight during this period. The side effects wore off after I stopped the medication apart from the anxiety. This was not a normal reaction for me, but I still do suffer from bouts of it. The main issues are having people around me, and people talking to me too close and too loud. I find this very intimidating and I often walk away from social situations if I can. If I am invited to any social function, my automatic response is fear and panic rather than previously happiness and a sense of inclusion and belonging. I spend more time on my own since my treatment and always look for an escape route in busy public spaces. This wasn't my old self. However, I feel a massive sense of relief to finally clear the HCV.

How infected status has impacted upon my treatment, medical and/or dental care for any other conditions

- (48) This was probably more of an issue in the early days when even the medical profession had their stigmas around HIV. I was refused orthopaedic surgery for arthritic joints by one surgeon as it was stated he did not want to expose himself or his staff to unnecessary risks. It seemed I was always put at the end of the list for any orthopaedic surgery so there would be no risk to patients following me. I felt like a "*hot potato*" which no one wanted to hold for too long. Dental treatment had always been an issue with my haemophilia, so I didn't notice too much about the infections as I always had an NHS/hospital dentist and was always seen in hospital settings for dental work. The first extraction I had after my HIV diagnosis was a very negative experience, as I was sent to a ward with high infection procedures. It was a specialist ward with double metal doors, a side room with a sheet on the door stating my diagnosis and stating high risk. This was very different to any procedures I had had before and no one explained what I was to expect. I had an argument with my haematologist about this on the day. I had no preparation for this and felt stigmatised by this kind of treatment.

- (49) I have experienced many incidences of medical staff taking “*over the top*” procedures in relation to my infections. It wasn’t uncommon in a shared ward for the nursing staff to wear gloves all the time with me for simple routines such as observations (temperature, blood pressure etc) when they were not wearing them for other patients. I had a dietician come to see me once in hospital and she wore a plastic overcoat, gloves and a face mask just to sit at the end of the bed and ask me questions about my diet.

The impact of being infected with HIV/HCV/HBV on your private, family and social life

- (50) I cannot answer this question as fully as I would like. The passage of time, and the mind’s ability to shut off traumatic thoughts over the years has softened the depth of feeling I have had over the last 30 years or more. I think I have touched on a lot of this in previous questions above. For me, my infections have had a massive detrimental effect on my private, family and social life. How could they not? I became 2 people. The one the public saw was me trying to be as normal as possible. No one would think I had the viruses, and that I struggled with everyday life. I was preoccupied with death and dying for many years. It consumed my thoughts. When would I get ill? When would I die? What horrible infection would I die from? Would I infect others around me? I had very morbid thoughts. I also had a lot of anger, resentment and feelings of unfairness for all the other people I knew who had died: those other people with haemophilia who hadn’t been as lucky as me. They were normal, nice people who had their lives snatched away. This made me into someone I wasn’t in the past. This experience changed me and the way I was in the world. I lied to my friends all the time. I went many years without a girlfriend or any intimacy in my life. I grew to learn to pull away from any situations that would lead to any intimacy for fear of infecting others, or anyone finding out about my HIV. I had a plan before that I would have children. I get on well with children and thought I would make a good dad. This was taken away from me. I saw this as a very cruel twist to my infection. I couldn’t give my mum a grandchild. I couldn’t lead a normal family life. This was only mitigated by the fact that I was constantly told, and believed, that I wouldn’t have long to live. Would I want to have brought a child into this world knowing that I would die at any time? Would that have been fair to any child? What mental trauma would that child have to live

through? It hurt me emotionally that I couldn't have children, or any hope for a normal life. I became very scared around all the children in my life (my friends' children and my nephews and nieces) that I might infect them. The person I was changed due to my infections in many ways.

- (51) My parents suffered more than anyone else in my family. My mum had carried enough guilt around with haemophilia being passed on by the female line. Both my parents had been proactive in getting their son the best treatment available. They didn't want to see me in pain. They wanted me to have the best opportunities available, like any well-meaning parent. They both injected me at home. They both had pressed down the syringe that may have given me HIV. As for any parent wanting the best for their child, the knowledge that they may have injected a contagious, deadly, highly stigmatising disease broke their hearts. It made them both angry. But they couldn't talk about it to anyone.

The impact on me and my family of the stigma associated with a diagnosis of HIV/HCV/HBV

- (52) The stigma in the mid 1980's through to the mid 1990's was one of vile hatred and fear. The fear of anyone finding out about my status filled me with dread. Nobody seemed to be on our side. The tabloids, the general media, the politicians, the church, the police -they all hated us. Stories of catching AIDS from kissing, holding hands, coffee cups and toilet seats didn't help our cause. The negativity of the patient groups was constantly reinforced. It gave fuel to the homophobes that gay love was wrong, rather than accept the tragedy that was unfolding. It gave fuel to some religious fanatics who stated it was God's way of cleansing the earth. It made every drug user look evil and dirty, rather than expose the poorly funded services that didn't provide clean needles and support. The people with haemophilia were amongst them. We were all part of the *"great unwashed"*. *"What are they moaning about, they only had the factor to save their lives in the first place"*. The stigma from all walks of life all made everything seem dirty and evil. I was so afraid anyone would find out. I knew other people with haemophilia and HIV that had told some of their friends and the gossip spread to lots of others. They had told their bosses at work and the next day desks were moved and coffee mugs replaced with paper throwaway cups. They had

told their children's Headmaster and suddenly their kids no longer got invited to their friend's houses or parties and their kid's friends were no longer allowed to come to their house. There was a stony silence at their local pub when they visited. Their friends stopped inviting them for dinner, or made excuses for why they couldn't come round. In my home town one of the swimming baths that had a regular gay swim night closed down and refused entry to gays because other members of the public didn't want to swim in the same water. Co-op funeral services refused to handle the corpses of deceased AIDS patients. I was absolutely terrified about anyone finding out that I had this virus. I felt I had enough dealing with the mess my head was in living with a deadly contagious disease. The stigma and resentment by many members of the public didn't have to reinforce to me how dirty and unwashed I felt about myself at the time. When Princess Diana publicly on TV held and touched a patient with HIV, I felt this was the first sign of any hope for all of us. It was a defining moment for me.

- (53) I heard all the jokes about AIDS; the hateful comments from people; the jibes and piss-taking of people with AIDS, and I pretended to go along with it at times. This was wrong, but to object, to my mind, would be to give my true story away. This was a story I didn't want to tell anybody.
- (54) In 1994 I had a job in a school. I told them about my haemophilia at my interview. I always told my employers about my haemophilia - it could save my life one day. After some months of working there, I had an unstable internal bleed in my knee and was hospitalised. After a few days of being there, the Head from the school came to visit - not with grapes, but to find out when I would be back at work. I tried to explain that haemophilia wasn't that simple and could she just pass that on to my colleagues, pupils and parents. She told me, in the hospital, in an open ward, *"I don't want haemophilia mentioning in my school, and I don't want you letting anyone else know. If they hear the word haemophilia they will all think AIDS and I don't want my school to have any link with AIDS"*. This was in 1994; and those words were from a school headmaster, employed by the County Council, who operated under anti-discrimination procedures. I went home and handed in my notice.

- (55) The day I received my diagnosis I told my Mum and Dad. They had been an intrinsic part of my health care and life and we had always discussed my health openly in the family home. I regret in many ways doing that. It broke their hearts. Hadn't they had enough to cope with over the years? Apart from the heartache and emotional devastation, they too were thrown into a world of stigma. They knew no one could be told; they too turned into liars. Lying for their own protection, the protection of my younger siblings and the wider family. My Dad only told me recently that they never told any of their friends, other family members or colleagues. They never had anyone to talk to except each other. They did this only in bed at night in whispers- when the door was closed and their children asleep, where no one else could hear their fears and living nightmares. The only reason they couldn't talk about it was due to the stigma. Once disclosed, you can't un-disclose.
- (56) With HCV, I felt more comfortable telling people. For some reason, it didn't seem as bad as HIV. And it gave me an excuse for telling others around me why I was careful with blood spillages and general hygiene. I already had lived with HIV for 7 years before my HCV diagnosis. It was the stigma around HIV that was scary. By the time I had my HCV diagnosis information about pharmaceutical blood collection and prison donors was coming out. I saw HCV as a means to educate people without disclosing my HIV status. However, people would nearly always say *"that's the virus that drug users have isn't it"*.
- (57) I would also like to add as an example of the stigma attached to HIV from a personal experience. I knew a person, Stephen, with haemophilia and HIV/HCV coinfection. We used to meet up in the mid 1990's. We met through the hospital. Stephen died due to his infections. I went to his funeral. I didn't know his family, only his girlfriend, and the vicar invited everyone back to the family home. The service talked about Stephen's troubled life and struggle with haemophilia. They stated that he died of liver failure. I wore a small enamel red ribbon badge on my suit lapel. As soon as I got to the house, his brother asked me to come round the back into the kitchen where we were alone. He then demanded I take my red ribbon off or leave the house. He didn't want anyone in the family knowing about Stephens HIV infection, or that he had any connection with HIV. Stephen was a campaigner. He supported other people and he wore a red ribbon

at all times. He didn't even get the support from his family, and now he was dead the family could also bury the stigma with him.

Educational effects

- (58) I was 21 when I was diagnosed with HIV so any schooling issues in the past were due to haemophilia, not my viruses. I did return to university. In the late 1980's, I embarked upon a teaching degree. I was terrified of telling anybody, and didn't mention it once during the 4 year course. I struggled through some course components whilst dealing with a golf ball size lymphoma in my groin, erratic sleep patterns and night sweats. But I didn't tell them why I was underperforming. I went back to university in recent years, to undertake a horticultural course. I was quite happy to tell my course tutor everything about my health. There was no hint of any stigma and I was just offered support if I needed it. Times have changed.

Work-related effects

- (59) Work was a different issue for me. When I was diagnosed, I was working for a high street bank. I had been there for 2 years and I was working my way up the ladder with a potentially successful career ahead; one with future security and support, and one in which haemophilia wouldn't give me problems. It was a nice steady office job with a lot of potential for me. After being diagnosed, I didn't sleep well. My head was full of thoughts about death, dying, illness and infecting others around me. I wasn't being productive at work and standards were slipping. I couldn't tell my boss. I knew that nothing was ever secret in the office. If I knew of people's affairs, alcohol issues, illnesses in their families, dodgy dealings out of work time, they were bound to find out about me. It wasn't really a supportive place. Staff members told AIDS jokes in the staff room and office without being challenged. There was an air of competitiveness amongst workers, and there were many discriminatory remarks about many bank customers too. I didn't feel it was at all supportive and I didn't feel safe telling anybody. After a year of pretending everything was alright, I came to the conclusion that if I was going to die either sooner or later, it wasn't going to be in a suit "*working for the man*". The carrot of future financial security and career potential had long left the room. I had a life-threatening virus. I didn't have long to live. By now I wanted to see the world before I died.

(60) I worked as a school teacher for a short while. As described above, I left after the Head told me not to mention haemophilia, as people would associate it with AIDS and she didn't want her school having any links to AIDS. I left that job. I worked for a number of years at the Citizens Advice Bureau in the 2000's. I told most of my colleagues there. It was a supportive atmosphere in many ways but it was never straight-forward. The boss was a gay man and he was very supportive of my health issues and the political dimension. The deputy manager told me that attitudes had changed, and if she was honest she wouldn't have felt comfortable with me and HIV in her office 10 years ago. I had to tell her I had had the virus for 20 years at that time. Her husband was a vicar.

(61) I am currently self-employed. My boss is OK with me. I just don't tell my customers.

Financial effects

(62) This is an unknown, as if I had stayed at the bank I may have had a very lucrative career and financial security. Job security and options for any person with severe haemophilia were always going to be limited, but I thought I had done well at the time. Having to wade through the benefits system when I was out of work was very daunting and the benefit system itself wasn't free of prejudice or stigma, and there was no guarantee that workers within the benefits system treated information as confidential.

(63) The MFT helped a bit but it just felt like a begging bowl. I had to justify any application I made. All funding was linked to rules and restrictions that didn't seem to fit my lifestyle. The money was there because of financial hardship: to have to jump through hoops to justify hardship and then be restricted by their regulations never sat well with me. It was and always has been an unfair system. The ones with fewer scruples, a scanner, half a brain and a good hospital support worker got the most out of the MFT. The very needy probably saw the least. The Government's ex gratia payments were just enough to buy a car or a few nice holidays. They only came after legal pressure, and I only accepted them on the basis that it was presumed I wouldn't live very long.

(64) I have never felt so comfortable with money than in this last year and half; that is, since England has come into parity with Scotland and its infected haemophilia population. I do not feel like it's a begging bowl and I feel it is enough for me to live my life, with a

full fridge, the utility bills paid. I can put the heating on when I want and I can take a holiday. But this has only been a recent change. The last 25 years have been very challenging with finances.

Other infection or infections other than HIV, HCV and/or HBV as a result of being given infected blood products

- (65) No, not that I know. However how can I rule this out? It has always been a fear, and one that increased with nvCJD. I was later informed that I didn't have any blood products from a donor who later went on to develop nvCJD. I was also told that because of the risk factors, I was put on the CJD register. I have never been informed that I have been taken off that, so I presume I am still on it. I cannot rule out being infected with any parvoviruses or other viruses or infections. I had multiple blood products made from thousands of donors each time. Those donors were mainly people in ill health. I will always have concerns about what I have actually injected into my veins in the past.
- (66) Difficulties in obtaining treatment, care and support in consequence of being infected with HIV/HCV/HBV
- (67) I have mentioned that orthopaedic treatment and operative surgery was only available from surgeons who were happy to work with infected patients. Some refused to put themselves at risk. Dentists have always had to be hospital/NHS dentists. In the early days when I did have orthopaedic surgery or hospital admissions, these wards did not know how to deal with HIV+ patients and the range of care and concern would vary greatly; from complete barrier protection and a side ward, to an open ward and being treated like any other patient. I have had nursing staff that have wanted to spend as little time as possible with me, and some that I have spent hours with as they have educated themselves about HIV/HCV and haemophilia and have shown a genuine interest. I have had some nurses that have put full barrier on to take my observations and one who asked me out for a date when I was discharged. The differences have been upsetting and also uplifting.
- (68) I think the biggest obstacle has been accessing HCV treatment. In the past, I was refused treatment when pegylated interferon was introduced (this was more effective

than the last) because my HIV was a barrier to entering trials and to initial use. When the newer oral based treatments became available, and my hepatologist/gastroenterologist and his team were getting excited about HCV care for the first time, I was refused it as I didn't fit under the NICE guidelines. So the years of avoiding alcohol when I could, eating a good diet and looking after myself didn't do me any favours. I was deemed too well for treatment. They didn't take into account my psychological state, my 2 decades of fear of infecting others, the endless trips to hospital for check ups, blood tests and scans. They didn't take into account the fact that they had infected me with HCV in the first place and I felt they had a duty of care to treat me for it. This really made me angry and I researched the possibilities of buying this from Australia on the Internet or travelling at my own expense to a clinic in India. They were both viable options at the time. Should I really have had to go to these extremes?

(69) Counselling and psychological support

(70) Support was never adequate at the time I needed it; that is, when I discovered I was infected and my head was like a blender on full speed, whirling round with dark thoughts about death, dying, infecting others, illness, emotions, relationships, fear, anger, bereavement.

(71) I saw a counsellor at my first HIV clinic two years after being infected. This was a sexual health clinic and the clientele was 99% gay men. I felt she was out of her depth with my issues. She pulled sad faces at me and told me I was brave. This didn't do me any good. I saw an excellent psychologist 5 years after my infection with HIV. This was extremely valuable to me at the time. I was able to talk about everything on my mind in a safe secure setting with someone who gave me practical advice about coping mechanisms. There were many discussions we had that would not be appropriate in today's climate, but at the time people were getting ill and dying on a weekly basis. The prognosis wasn't good; the HIV drugs consisted of AZT only (which I considered a poison) and most of our conversations were based on planning for death and enjoying what life I may have. It was necessary at the time. It was my only escape avenue. My only sanctuary to talk, to cry, to laugh at it all. It lasted 2-3 years. It was essential, but 5 years too late. I saw another psychologist many years later. My mum

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had recently passed away and by this time I had seen scores of friends die, been to numerous funerals and my life seemed preoccupied with death. Morbidity, suffering and sadness overwhelmed me at times. In a session I had with this psychologist, as I was pouring out my soul, I looked at her and she was in tears. I realise now she was human herself and had her own feelings. But I had to stop talking and offer her the tissues and support. I didn't go back to see her after that.

(72) I saw a counsellor recently, after my HCV treatment which left me with some depression and on-going anxiety. He helped me work through a few issues in my life and gave me a different perspective to think about.

(73) My parents were never offered counselling, psychologists, or support.

The impact of being infected on those close to me

(74) My parents suffered the most, I feel. As I have stated above, they were heartbroken. They always supported me and were proactive around haemophilia care. They were a large part of our local haemophilia support group. They went to Haemophilia Society meetings. They always came to my appointments with me and wrote letters to the hospital requesting the best treatment for me. They sought advice. The haemofact leaflet from 1984 stating the risk to be only 1-1000 stayed in my mum's bedside drawer until her untimely death in 2001. I think it was her way of trying not to blame herself. A doctor had told her the risks were low, and they were not. My mum had given me my factor VIII. She, like my Dad, had put that needle in my vein and pressed that syringe that may have been contaminated with all my viruses. Their son was infected and dying from one of the most horrible and devastating diseases that our generation has seen. When I ever tried to talk to my mum about my feelings around HIV and my life choices because of it she just cried. We didn't have those conversations until many years later, when she was on her deathbed with cancer. It broke her, she never recovered from the news of my infection. She put a brave face on, like we all did, for everyone else's sake. I talk to my Dad about it more now and the anger he has still inside him about why I was infected has never gone away. But it is something he is unable to change. My parents never got any support or advice. They just had to get on with it. "*Sink or Swim*" was one of my dad's mottos and the family kept their heads

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above water and tried our best not to sink. Nobody could throw us a life ring, because we couldn't tell anybody.

(75) My brother and sister were told by my mum and dad a few years after my infection. They have never really had a proper conversation with me about my illness and infections. They are always there for me but I feel they are ill equipped to deal with any of my issues. They have their own lives. Living with a brother who had haemophilia messed up their early childhoods. I don't blame either of them for just getting on with their adult lives. They have always known that I have dealt with my issues in my own way.

(76) One of the most pressing issues for me after my diagnosis concerned intimate relationships. I had an overriding fear of infecting others. Relationships, especially sexual ones, were something I thought I would never have. I had to write off the notion of being a father. This was deemed impossible for many reasons at the time. I felt very lucky to have met a woman who wanted to share my life. When we met and it was obvious that we had an attraction and sex would be on the menu, I had to tell her my story. She was accepting of this and it didn't put her off. We always used condoms and practised very safe sex. However, the relationship was based on the fact that I didn't have long to live. This wasn't being over sensational. People I knew with haemophilia and HIV from my childhood were dying. Many had already died. No one told me anything else at the time. So I was dying. I wanted to see the world, or some of it, before I died. I wanted someone to do this with. My partner, I felt, put her life at risk by being with me and having intimate contact. I told her I may only have a few years to live. I am obviously still alive. Looking back, it is an unsustainable basis for a relationship. We were together for over 25 years. We were married for 13 of those. We loved each other once, but this love was based on the immediate future, not a long-term plan for future happiness. She never had children. She fell in love with a man that didn't expect to live very long and then did. She accessed support when she struggled dealing with living with my viruses and me. She met other partners of people with haemophilia and HIV, and witnessed the heartache when their partners died. She came to some of the funerals of my friends, who became our friends, with me. Our mutual support networks were very fragile. We lived through some very dark times. We were there for each other for most of that. Looking back, my viruses dominated

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our relationship. The bad times and the fear of uncertainty were down to my health most of the time. However, the money I did receive from ex gratia payments and legal avenues paid towards the roof over our heads and some wonderful travel adventures. It was like a life of extremes. Live life to the full because it may not last. But that has a burn out time, and we both got burnt out with it, grew older and wanted different things in life. HIV meant we had no right to a normal family life or to any normal expectations.

Financial assistance received

- (77) I really do not know with any accuracy. The payments system of the ex gratia schemes have changed many times over the years. I remember getting an initial payment of around £20K in about 1990. The Macfarlane Trust then paid a small amount each month, around £200 per month I think, with the possibility of applying for hardship grants (which I saw as begging and went against my principles at the time). The amounts changed over the years and the payment structures changed. I really have no idea what the payments were, other than that I received monthly amounts that gradually increased (due to pressure and on-going political and legal avenues by campaigners). The Skipton Fund paid another £20K many years later. It is only in the last year and half that payments have been in line with Scotland and this is the first time that I have felt I have any financial security.

The process of applying for financial assistance

- (78) This whole process through the MFT was ill thought out. For many of the years during which the MFT was in existence it had some very poor staff who were ill equipped to take on the role. A number of them were related to each other which made any complaints procedures irrelevant and worthless. Every year, just before Xmas they would send out an income and expenditure form which we had to complete along with evidence of bills and council tax and other expenditure. They would then assess what level of payments to make to us in the following year. This was demeaning and insulting, but if it wasn't done we didn't get anything. I felt this just justified many of their roles in an office. I never understood why a charitable organisation which just administered ex gratia payments to a patient group had to have expensive offices in London with well paid chief executives. I think when the government, set up the MFT, they only did so on the basis that we would all die in a few years. It was arms length

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from the government and the DOH, so in a way it took the onus off them and placed it on to the charity itself.

- (79) The hardship funds that we could apply for had stringent rules and regulations. They stated what we could apply for and what we couldn't. If we needed something, such as a respite break after a period of illness, we had to jump through hoops. We had to provide a letter from a doctor or a senior specialist nurse to prove we had been ill and needed respite care. An income and expenditure form had to be provided to prove we were in hardship along with at least 3 quotes from different respite venues. They would then only pay towards some of the costs and they had geographical limitations, such as only UK, or only Europe. They took away our independence and treated us like kids that should be grateful for anything we received. Payment in respect of household repairs were subject to stupid rules. For example, funds might be provided for replacement double-glazing but only for certain rooms in the home such as the main bedroom or the lounge since, as they saw it, this is where we would spend most of our time because we were ill. We had to get 3 quotes from "*reputable*" double-glazing companies. So a pantomime of salespeople would need to come to the house, measure up and give the hard sell. They would phone and call and send information for years to come once they had my details. The trust wouldn't accept a mate down the road could do it for half the price and that he wouldn't hassle me.
- (80) The MFT registrants were all different and in some cases they were treated differently by the trust. Some people just phoned up, sounded in distress, cried down the phone and a cheque was in the post that day. Some would have to jump through hoops and prove their need. Some would not lower themselves to begging and go through life without their grants, but with their dignity intact. Some forged quotes and hospital letters and sent in multiple grant applications and worked the system. We were all supposedly dying and most of us felt a massive sense of injustice and anger. Why didn't the Trust change so as to just pay us a sensible amount to keep us financially afloat and treat us like adults with a bit of independence? It was a very paternalistic way of treating us. It was unfair and unjust.

Difficulties in applying for and/or obtaining financial assistance

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- (81) As outlined above, I was refused any financial support for a respite break that was not in Europe. I wanted some winter sun to give me a break. They said they would only pay for a European break as they didn't want to take the risk of me being too far from home if I was ill. I did not apply for anything for many years as I felt it was demeaning and begging. I assumed that only the very needy and the very ill ever applied, as this was the message I was getting from the Trust for many years.
- (82) There was a time when they gave respite break payments. I applied to the Trust stating that I would rather have weekly on-going uplifting respite rather than a one-off break. I suggested that they paid for a health club membership instead of a respite break. The membership was actually cheaper than any of the respite break fees, or grants that they were giving. I stated that it would keep me fit with swimming, spa, sauna for my aching arthritic joints. It would also give me an appetite and help me sleep well, as well as get me out of the house, and that it would be generally good for my well being. I could attend as many times as I wanted in any week, and I could go when it wasn't busy. This was refused as they decided they didn't want to set a precedent on health club memberships. They never gave me any flexibility or independence.

Preconditions imposed on the making of an application for, or the grant, of financial assistance

- (83) There were so many changes over the years. For example there was a time when you could apply for funds for counselling, but it would need all the usual letters of support from the hospital and then the Trust would only give it for a specified number of weeks only.

US Litigation

- (84) I received money from the US class action, working with a US legal team Lief Cabraser Heinmann and Bernstein. After a 6 year legal case, involving 26 countries worldwide, we were offered an out-of-court settlement of \$32,000 (about £23,000). The case reached the point where the onus was on us to prove exactly what batch of Factor VIII had infected us. This was impossible. We had to sign a waiver to say we would not mention the pharmaceutical companies by name in any legal setting. Our legal team said they couldn't push the case any further, after the offer of a settlement. Without any legal representation to pursue the legal claim, I felt that I had no choice but to accept what was offered. My thinking was that as someone infected with HIV and HCV,

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there was no telling how long my luck was going to last. It seemed the best in a bad situation to simply take the money, hoping it would make a decent dent in my mortgage and provide me with a decent holiday.

Key documents

- (85) I have always felt that the Tainted Blood timeline documents and the archive of many of the documents related to the TOR gave a very good picture. I had a meeting with the Inquiry team on 28 January 2019 where I agreed to disclose all relevant documents to the Inquiry team via my solicitors. Please see Exhibit **GRO-B** (List of Documents inspected by Adesina Ojelade (solicitor to the Inquiry) and Wayne Thomas (Inquiry Investigator) on 28th January 2019) attached to this Statement.
- (86) I confirm I would like to give oral evidence to the Inquiry should I be required to do so.

I believe that the facts stated in this Witness Statement are true.

Signed:

GRO-B ...

Dated:

11.02.2019