

**INFECTED BLOOD INQUIRY**

---

**FIRST WRITTEN STATEMENT OF MICHAEL O'DRISCOLL**

---

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 13<sup>th</sup> November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Michael O'Driscoll, will say as follows:-

**1. Introduction**

1. My name is Michael O'Driscoll. My date of birth and address are known to the Inquiry.
2. I currently live at my address with my wife, Yvonne, our daughter, Jessica, her partner and their three children. Jessica and her partner are residing with us while carrying out a major refurbishment on a property they recently purchased. Yvonne was an accountant and then a teacher, and has been retired since 2014. I decided not to return to my most recent job as a project manager for a mental health charity, following knee replacement surgery in January 2016. I have, since that time, devoted myself to freelance writing.

3. I was born in London in 1959 but not diagnosed with Severe Haemophilia A until 1965, by which time the family had relocated to Worcester. My diagnosis followed numerous bleeding episodes, particularly bleeds to knee joints that proved difficult to control. My recollection is that I was treated with whole plasma, and later, with cryoprecipitate. I was treated at Worcester Royal Infirmary, and once or twice at the Haemophilia centre at the Churchill Hospital in Oxford, I think for dental extractions and at the Children's Hospital, Ladywood Middleway, Birmingham from 1970.
4. In 1971, my parents decided to move back to GRO-C Ireland. From that time until June 1979, I was treated at St Finbar's Hospital, and latterly, the new Regional Hospital (now Cork University Hospital), both in Cork City. I had numerous bleeds throughout this period, requiring many in-patient stays, including confinement at the city's orthopaedic hospital. I also had dental extractions at a hospital in Dublin, I think in Harcourt Street, where the Haemophilia Centre was based. I was treated with cryoprecipitate.
5. I moved back to London in June 1979 and registered with the Haemophilia Centre at the Royal Free Hospital, Hampstead, London, and was under the care of Drs Tuddenham and Kernoff, and later, Dr Christine Lee, until moving to Swansea in June 1987. During this period I suffered numerous joint bleeds, particularly to the knees, but also to ankles and elbows, the majority of which required hospitalisation. It was during late 1981 that I was taught to self-administer Factor VIII and put on home treatment on an 'as-needed' basis. I do not recall the specific name of the product I received. As of 25th November, I have not had a response to my 2nd October application to the Royal Free for access to my medical records.
6. I met my wife, Yvonne in February 1981 in a pub whilst we were both living in London. We had a whirlwind romance and were married in August 1982. We both had good jobs with career prospects, with Yvonne being an accountant and I was the branch manager of a recruitment consultancy specialising trades and professional staff for the construction industry.

7. In 1984 we decided to start a family. We planned to have 3 children - Yvonne was one of four and I was one of nine children. Yvonne fell pregnant in February 1985.

## 2. How Infected

1. I was infected through treatment with contaminated blood products whilst under the care of the Royal Free Haemophilia Centre. To the best of my knowledge, after being informed in June or July 1985 that I was HIV+, I was told that retrospective testing of stored blood samples showed that I was sero-negative in late 1982, but blood samples from March 1984 onwards showed that I had been infected by then. Correspondence in my medical notes indicate that no blood samples were available for retrospective testing between these two dates. Given that reports were emerging from the USA in early 1983 of the risk of infection to haemophiliacs through contaminated blood products, I believe the Royal Free failed in their duty of care to notify me earlier of the risks of my continuing on Factor VIII treatment.
2. At this time I was unaware of the possibility of being infected by any other blood borne virus, nor was I informed of any such risk. I cannot recall when I was first told about the risk to Haemophiliacs from non A-non B Hepatitis, but in March 1987 I received a letter from Dr Kernoff at the Royal Free, asking if I wanted to participate in a new drug trial with interferon, for treatment of "nonA-nonB Hepatitis". This clearly shows that I had been exposed to Hepatitis C by this date. I did not take up Dr Kernoff's offer as we were about to relocate to Swansea In January 1993, when we were living in Swansea, Dr Ismail, the head consultant at the local haemophilia centre, spoke to me about Hepatitis C. The virus had been isolated by then and a new test capable of detecting its presence had been developed. I had been tested and the results confirmed that I

had been infected with Hepatitis C. I do not know the period in which I was infected.

### 3. Other infections

1. It was in 2004, I believe, that I was informed about the possibility of having been exposed to variant CJD through past treatments with contaminated Factor VIII. I believe Dr Ismail contacted Dr Christine Lee at the Royal Free to determine if I had been treated with any batches deemed to be 'high-risk.' It is my understanding that I did not receive 'high-risk' product, but that for public health reasons, I am deemed to be a risk for variant CJD. I have also been exposed to Hepatitis B though I can't recall the dates.

### 4. Consent

1. At no time was I warned of the risk of using Factor VIII by the Royal Free Hospital.
2. I cannot recall whether or not I was asked to consent to an HIV test in 1985. I suspect I was told, given that the clinical staff would have wanted to ascertain how many of their patients were HIV+, but I don't remember any discussion of what a positive test might mean. Similarly, I don't recall exactly when I was first informed of the possibility that I might be infected with non A-non B Hepatitis, (see reference to Dr Kernoff and offer of place on drug trial with Interferon in 1987, above) but I'm sure it was after we moved to Swansea. In January 1993, Dr Ismail spoke to me about Hepatitis C, informing me that the virus had been isolated and a new test capable of detecting the presence of the virus had been developed. I had been tested and the results confirmed that I had been infected with HCV. I don't remember whether I was asked to consent to a test for HCV, but I do believe I was given little information at this time about the long-term implications of the diagnosis.

## 5. Impact

1. It was during the early part of 1985, that I first heard about haemophiliacs in the USA becoming infected with HIV through contaminated blood products. The circumstances of my being informed that I had been infected were that in June or July that year, I received a letter from the Haemophilia Centre at the Royal Free, asking me to attend for a meeting with the Senior consultant. This was either Dr Kernoff or Dr Tuddenham. I do not recall receiving any pre-test counselling, though I may have been given fact sheets about the risk from contaminated blood products prior to my diagnosis. At the meeting, also attended by Riva Miller, a specialist social worker attached to the centre. I was informed that I was HIV positive and that my prognosis was terminal and that at best; I had two years to live . After being given this news, I received little in the way of ongoing emotional or psychological support.
2. I then had to go home and tell my wife Yvonne, who was about 5 months pregnant. We were both incredibly shocked at the news, not only at my diagnosis, but also by the very real possibility that I had infected Yvonne.
3. Our distress was compounded by the unwanted advice we received at a follow up meeting at the Royal Free Hospital, from River Miller, the senior social worker attached to the unit. This was that Yvonne, should have her pregnancy terminated. We were further advised that if we decided to proceed with the pregnancy, we should abstain from sexual intercourse completely until after the baby was born. Thereafter, we were told, we should practice safe sex. Yvonne was later tested for HIV and was found to be ser0-negative and we decided not to have a termination. Although I tried to remain upbeat, I struggled to accept my diagnosis, and both of us found it difficult to adjust to safe sex practices.
4. GRO-C who had haemophilia and was living in London at this time, was also diagnosed with HIV, and later, with Hepatitis

C. So we were able to talk about our problems and provide support for each other.

5. AIDS was very much in the news at this time, and public perception was quite negative and even hostile to those who had been infected. It seemed to mainly affect the gay community or drug users and I was neither, and did not wish to be wrongly pigeonholed. Both Yvonne and I were very much aware of the stigma surrounding AIDS and to avoid prejudice we chose not to tell anyone outside my immediate family and closest friends, of my HIV status. I was also very concerned that my employers might make a connection between my haemophilia and HIV, and that if they did, I might lose my job. This meant that in any job I applied for in the future, I did not disclose the fact that I was a haemophiliac, despite the risk to myself from any possible accident that might occur at work.
6. Our daughter Jessica was born in GRO-C 1985. Although it was a very happy moment, it was tinged by sadness. I could not help but think about the fact that I would not be able to see her grow up and achieve all of the normal milestones one associates with one's children in life. Yvonne took maternity leave from her job as an accountant. I was working as a branch manager for a recruitment consultancy, having been promoted earlier that year.
7. In April or May 1986 I had to take two weeks off work with flu-like symptoms. Given that I did not wish to disclose my HIV status to my employer, they were sceptical of my reasons for taking two weeks off work, expressing surprise that I would need this long to recover from a cold. Because of this, I returned to work before I really felt well enough. The stress of having to lie about my illness, coupled with the anxiety of having to adjust to my diagnosis, and to feeling generally run down, made it increasingly hard to cope with the demands of an already stressful job. My diagnosis increasingly impacted on my marriage, and to a large extent I was taking out my anger and feelings of helplessness on Yvonne. After a couple of months, we began a series of marriage guidance counselling

sessions and this helped to improve things between us. Unfortunately, it became increasingly difficult for me to work as effectively as I had done in the past, and after a number of absences, I kept thinking more and more about not seeing Jessica grow up.

8. As a result, in late 1986, I resigned from my job. So Yvonne returned to work while I stayed at home to spend time with Jessica. I was determined not to miss a second of her early years because I had been told that I would die so soon. I began to lose contact with many of my friends and became very isolated, I didn't want to see them as they may have asked awkward questions about my health which I did not want to answer
9. In May 1987, we moved from London to Swansea. We were struggling to live in London on one salary and believed that a move would be beneficial not only to my health, but that it would be better for our Jessica. It did mean a substantial drop in salary for Yvonne, who had been working as an accountant for a merchant bank in London. We also felt that we would get more practical support from Yvonne's parents, who lived locally in South Wales, particularly at times when I was ill. I registered with Swansea Haemophilia Centre at Morriston Hospital, under the care of Dr S. Al-Ismael.
10. By late 1987, we had discussed the prospect of extending our family. As I have said it had always been our intention to have three children. We decided, against the advice of medical professionals and despite our mutual fears, to have unprotected sex on specific dates to tie in with her cycle, to give us the best chance of having a child. Unfortunately, she didn't conceive and the subsequent stress and worry of waiting for HIV test results was too much of a psychological burden for Yvonne and so we abandoned further attempts at trying for a natural pregnancy. The fact that we took on such a risk is a measure of how desperate we were to have more children of our own.

11. By the start of 1988 I had suffered another couple of viral illnesses with flu-like symptoms. In January, and still hoping to have another child, we decided to begin a course of artificial donor insemination at a local private clinic in Swansea. Although Yvonne got pregnant at the third attempt in March 1988, she miscarried in May. This was devastating for us and we struggled to come to terms with this loss, but, having switched to a private London clinic, we persisted with donor treatments at a substantial financial cost. Yvonne continued a programme of treatments, none of which resulted in pregnancy.
12. In June 1988, I felt well enough to return to work and got a job in Swansea managing a small retail business. We sold our house in London and used this to fund a deposit on a house in GRO-C Swansea. In December I used my recompense payment of £20,000 (awarded to HIV+ haemophiliacs earlier that year) to part-fund the purchase of a video retail business that I owned and ran for the next five years.
13. My HIV status continued to be monitored at the Haemophilia Centre in Swansea, which was now based in Singleton Hospital. Monitoring mainly consisted of CD4 counts. There were no treatments at this time for the virus, but a number of prophylactic options were available for the treatment of AIDS related infections.
14. By early 1991, I was struggling to run the business, which was open 10am to 8.30pm, 7 days per week. It was an extremely competitive environment, and with large video chains moving into Swansea, the business began to run at a loss. I found it difficult to cope with the financial pressures, and eventually they began to impact on my marriage. In June, Yvonne and I we separated and I rented a bedsit in Swansea for the next six months. Dissatisfied with being able to spend so little time with Jessica, Yvonne gave up her job as an accountant to retrain as a teacher. In December that year, we reconciled and I moved back into the family home.



15. My HIV status was monitored at the Haemophilia Centre in Swansea, which was now based in Singleton Hospital. There were no treatments at this time for the virus, but a number of prophylactic options were available for the treatment of AIDS related infections. In November 1992, on the advice of Dr Ismail, I began treatment with Septrin as prophylaxis for Pneumocystis pneumonia, (PCP). After approx. 4 – 5 weeks, in December, I was admitted to hospital with suspected pneumonia. However, it turned out that my illness was caused by a severe allergic reaction to Septrin. Symptoms included fever, diarrhoea, rash, generalised lymphadenopathy, conjunctivitis, weight loss and nausea. These symptoms only began to recede following the cessation of Septrin treatment. I spent most of this time in a fever, and can recall little of my period in hospital.
  
16. In February 1993, I started a Humanities degree with the Open University. I applied for and received a grant from the MacFarlane Trust to help fund the course. I think it was early that year that I received an ex-gratia payment from the government, of £60,000. Due to repeated hemarthrosis, some of which required hospitalisation, I had limited mobility in my left knee and was in constant pain. By June, because of continuing financial problems, I wound down my business, using my ex-gratia payment to pay off an outstanding loan on the store, and had to re-mortgage our house in order to repay a business overdraft of £16,000.
  
17. It was around this time that I sold my first short story, having been writing fiction for about 4 years. I continued to write and sell stories, but could not make enough money to warrant writing full time.
  
18. In May 1993, blood tests indicated past infection with the Epstein-Barr Virus, which is associated with oral hairy leukoplacia, and enlarged spleen, both of which I have experienced. Exhibited as WITN2384002 is (Emergency Set, part 1, p.60)

19. In December 93, I was treated for symptoms of viral infection. I can't recall whether this required hospitalisation. I was treated for other opportunistic infections including Oral Hairy Leukoplacia and severe skin rash. In late 1994, still hoping to expand our family, Yvonne went to see a consultant to discuss the possibility of IVF treatment, but we were deterred from proceeding by the expense, as we had not been able to get help with funding from the MacFarlane Trust

20. I think it was in 1994 that I began a course of treatment with nebulised Pentamidine, another prophylaxis for PCP. By this time I had been living for 8 years with a diagnosis of HIV and was, to a large extent, living in denial and leading a self-destructive lifestyle—drinking to excess and neglecting my general health.

21. In Spring 1993, I was contacted by Tim Hunt and Nia Wyn-Jones, specialist HIV social workers attached to Cardiff Haemophilia Centre. They introduced me to members Birchgrove Wales – a Cardiff based, client-led support group of HIV+ haemophiliacs; and also to SWISH, a Swansea based client-led support group of HIV+ individuals. Over the next 8 or 9 years, I became closely involved with both groups, initially as a service user, accessing a range of alternative therapies like acupuncture, aromatherapy, Chinese Herbal medicines, meditation, as well as health advice, and up to date advice on HIV treatments. As an indication of how desperate I was to avail myself of any possible treatment for HIV and HCV, I, along with others at SWISH travelled to a private London clinic specialising in Chinese herbal medicine, once a month for a year. I stopped taking this treatment when after a years, it became clear that the herbal remedies were having no effect on either viral condition. Soon, I was more actively involved as a volunteer, going on to serve as treasurer of Birchgrove Wales, as well as being elected to the National Birchgrove Steering Committee and co-editing its quarterly newsletter. As part of the steering committee, I helped plan and organise national conferences in Manchester, Birmingham and Bath. Two years after starting voluntary work at SWISH, I was elected as a Trustee and Director of the charity,

eventually becoming chair of trustees with responsibility for line-managing the centre manager. Following a discussion with Yvonne and other haemophiliacs I had got to know through Birchgrove, I decided to inform my Jessica that I had HIV. I told her about its implications, but assured her that I was well. The time I spent working with these two groups was invaluable in helping me to overcome my isolation, recover and rebuild my self-esteem, and find a new purpose in life. I made a number of close friends through these organisations, some of whom I lost to AIDS. The loss of one friend in particular, a 39 year old Haemophiliac I had worked closely with at Birchgrove, to AIDS related illness in January 1997, was very hard to take. I struggled subsequently with depression and was generally run down and prone to infections, requiring treatment with Ciproxin and Erythromycin.

22. In April of 1994, on the advice of Dr Ismail, I started 6 months of mono-treatment with Interferon for Hepatitis C. Though I completed the course of treatment, the side-effects of Interferon—stress, depression, mood swings, anger and lethargy—my relationship with Yvonne suffered. We sought help from Relate and attended sessions with a counsellor for approx. 3 months. My state of mind only really began to improve after I had completed the course of Interferon. However, the treatment had no effect on my Hepatitis. The failure of the treatment upset me more than I had anticipated. In part, this was because having lived for so long with haemophilia—an illness that shaped my early life, limiting the choices I could make about my future—I had developed an emotional resilience when faced with adversity that, at least in the early years after my diagnosis with HIV, allowed me to cope. When I was diagnosed with Hepatitis C, I didn't see it as being as serious as HIV, and it was only after going on treatment for it, and seeing that treatment fail, that I saw, in retrospect, that I hadn't been coping as well as I thought. It was at that time that I began to see clearly the extent of the impact of HIV and Hepatitis on my career, marriage, and general wellbeing.

23. In April/May 1995, I was in hospital suffering with severe and fulminant bacterial infection with fever and swelling of the left side of my face (Cervical lymphadenopathy), requiring intravenous antibiotic treatment. I also had a left knee bleed whilst in hospital. I suffered with pyrexia for over a week and during this time, Yvonne was told by medical staff that had my condition not improved, there were no more treatment options. She and my family thought I was about to die. In July I tested positive for Adenovirus.

24. In 1996 I struggled with Seborrhoeic dermatitis and Jaundice, and was treated with Daktacort ointment. In July I was treated with Ciproxin for a chest infection.

25. In June 1997, I was referred by Dr Ismail to the GUM clinic, under the care of Dr Yoganathan, for management of my HIV. Because of my low CD4 count, Dr Yoganathan advised me to begin antiviral treatment. I started on AZT (Zidovudine) and DDI (Videx). I was also taking nebulised pentamidine at this time. I can't recall how long I was on these drugs but I struggled with side effects including severe diarrhoea, fatigue, loss of appetite, and skin rash.

26. I believe it was in the Spring of 1997 that we investigated adoption as a route to expanding our family, and embarked on a series of interviews with the local authority with a view to being accepted as adoptive parents. The process went well over a number of sessions, until near the end, when I told one of the interviewers I was HIV+. Subsequently, we were informed that as I was likely to die in the short term, we were no longer considered suitable candidates. At the time, this felt devastating, as it seemed to put an end to our hopes of having any more children.

27. In 1998, my left knee had deteriorated to the extent that I was put on the waiting list for a total knee replacement. I was in chronic pain, necessitating daily use of voltarol, and had very limited range of movement in the joint. In September 1998, my treatment regime was changed to triple

combination therapy of Stavudine (d4T), Lamivudine (3TC) and Efavirenz. Persistent side effects included skin rash, diarrhoea, poor sleep and depression.

28. Some time late in 1998, with the help of social worker Tim Hunt, we were referred to TACT, a private fostering agency, to discuss possibility of training as foster parents. After initial interviews and disclosure of my HIV and Hep C status, I commence training as foster carer, while Yvonne continues to work as a full time primary school teacher.

29. In June 1999 I graduated from the OU with a BA in Humanities, and in December that year, I had knee replacement surgery at the Nuffield Hospital in Oxford, performed by Dr Chris Dodd, with support from the Haemophilia Centre at the Churchill Hospital. I was back home for Christmas but early in the New Year, the knee wound got infected and I was admitted first to Morrision Hospital, then transferred back to Oxford. I was there for approx. a week and was discharged with a port-a-cath to allow me to treat myself with intravenous antibiotics. Following a few days at home I was admitted to Singleton Hospital on 21 January with high temperature, severe fever and skin rash, symptoms of what turned out to be a reaction to Teicoplanin. I remained in hospital until 1st February, with symptoms only easing after cessation of treatment with Teicoplanin. Blood tests around this time also show serological evidence of past Toxoplasma infection (Vol 2, part 1, pp. 83-85).

30. By April 2000, I was recovered sufficiently for our first foster child to be placed with us. Gradually, over the next 2 years, I cut down on my involvement with Birchgrove and SWISH, to be full time carer for our foster child, a seven year old boy. The placement, though challenging, lasted until June 2002, when it broke down irretrievably.

31. In February 2001, my HIV medication changed to Stavudine, DDI and Nelfinavir. It was around this time that I began a part-time MA programme with the OU. By July 2003 I was on Abacavir, Kaletra and Tenofovir.

32. It was in early 2003 that I began my second course of treatment for Hepatitis, this time taking Pegylated Interferon in combination with Ribavirin. This programme of treatment was managed by staff, including Dr Dosani, at the Arthur Bloom Haemophilia Centre at the UHW in Cardiff. Unfortunately, the treatment was unsuccessful and was suspended after 12 weeks, I think in April 2003, following only minor reduction in viral load. Whilst undergoing treatment, I had counselling to help with anger severe mood swings and depression.

33. In April 2003, we began a long term foster placement of two sisters, age 4 and 8. Yvonne gave up her job to look after the children. I started voluntary work as a literacy and IT tutor to adults with mental health/learning difficulties, in a mental health day centre. I was no longer involved with Birchgrove, which had ceased to exist at a local level and my involvement with SWISH was now only as a service user. In June 2004, I was awarded an MA in Humanities. My health was stable with my main difficulties stemming from haemophilia bleeds into joints.

34. Some time in 2005, the foster placement of the older girl broke down and she was moved on to different foster carers. The placement of the younger child was stable and she remained with us. Eventually, she made it clear that she wanted to stay with us permanently, and we applied for and were granted Special Guardianship, and Jamie became a permanent part of our family.

35. From Sept 2005 to June 2006, I completed a PGCE in secondary English teaching. In Feb 2006 I had a microlaryngoscopy & excision of a lesion from vocal chord. I don't recall the date when it changed but by 2006, my HIV therapy was 4 separate drugs: Abacavir, Atazanavir, Ritonavir and Tenofovir. This was the first regime I was on where the side-effects did not seem debilitating. Having struggled with diarrhoea and intermittent skin rash since starting treatment, these symptoms began to alleviate.

36. I gave up my voluntary work as an adult tutor in August 2006 and started full time work as a secondary teacher of English in Sep 2006. Initially on a 6 month placement covering maternity leave, and then on short term supply work. Although I was committed to teaching and enjoyed the challenge, at least initially, I found myself becoming increasingly exhausted and stressed. My symptoms deteriorated to the point where I became depressed, and I stopped teaching in April 2007 because of symptoms, which I attribute directly to Hepatitis C. I stopped teaching in April 2007 because of stress, exhaustion and depression.
37. In October 2007, I returned to voluntary work as adult literacy tutor with the same mental health charity. By October 2008, I was getting regular paid relief work, to cover staff sickness/holidays. In May 2011 I became a permanent member of staff, working as a part time support worker. I struggled with frequent bleeds into my right knee, despite prophylaxis, throughout 2010 and 2011. In Nov 2011, following repeated spontaneous bleeds into the joint over the previous year. I underwent a right knee embolization at the University Hospital of Wales (UHW) in Cardiff.
38. In 2012, I think in the spring, I had intraocular lens implanted in both eyes. In June of that year, I applied for and was promoted to manager of the Day Centre. August 2012, I had a fibroscan and consultation with Dr C L Ch'ng regarding new Hepatitis C treatments. In October, discussion and counselling with Clinical Nurse specialist Lisa Hodge-Johnson regarding new treatments for eradication of Hepatitis C.
39. In January 2013, under management of Lisa Hodge-Johnson at Singleton Hospital, I commenced a 3rd programme of treatment for Hepatitis C. This regime consisted of Pegylated Interferon and Ribavirin (for 48 weeks, and Telaprevir, for 12 weeks. Side effects of medication included depression – for which I took Citalopram—lethargy, rash, cough, poor appetite and shortness of breath. I also had problems with my sleep for which I took Zopiclone. By December 2013, at the end of treatment, I was virus free. In

July 2014, I had been free of Hepatitis C for 7 months. My HIV regime at this time was Ritonavir, Abacavir, Tenofovir and Darunavir. Not sure when I started this, but think it may have been December 2014.

40. I continued to manage the Connect project until April 2016, deciding not to return to full time work after a second knee replacement in January 2016, and instead concentrate on writing full time. In 2017, my HIV meds were changed to Genvoya.

## 6. Treatment/Care Support

1. I believe that both the Swansea Haemophilia Centre and the GUM Clinic did their best for me and to the best of my knowledge I was never denied access to treatment in relation to either HIV or HCV. There were a few occasions when I was hospitalised after first coming to Swansea, where I was kept in a separate room, and confronted with gloved and masked doctors, nurses, and ancillary staff, even when the reason for my being in hospital had nothing to do with HIV. In those early days, I felt isolated and stigmatised enough without having these feelings reinforced by the attitude of hospital staff. I faced difficulties getting dental treatment, when I was first taken off the roll at Morrision Orthodontics Dept, but was eventually able to sign on with Yvonne's dentist. I have nothing but respect for Dr Yoganathan, and gratitude for the care and treatment I have received whilst being his patient. He has always been concerned to look for and offer the latest treatments that might alleviate side-effects or have less contra-indications with medications I was taking for Hepatitis C.

2. We were never offered counselling while under the care of the Royal Free in London, and the first real emotional support we received was from the social workers attached to the Cardiff Haemophilia Centre in 1993, 8 years after my diagnosis. This was invaluable, particularly as they introduced us to other couples in similar situations. Any further counselling we received as a result of our own endeavours, through Relate or SWISH.



## 7. Financial Assistance

1. In 1988, I think, I was one of the HIV+ haemophiliacs awarded £20,000 in recompense with no admittance of responsibility from the Government.
2. I think it was early in 1993 that the Government, presumably through the Trust, made an ex-gratia payment of £60,000.
3. As for The Skipton Fund I don't remember when precisely it was set up, but I think it was in the early 2000s. Their purpose was to distribute ex-gratia payments to Haemophiliacs who had been infected with Hepatitis C through infected blood products. I don't recall when I received payments from them, but I did receive a lump sum payment of £20,000 at some stage, after 2003.
4. It was in the early 1990's that the Macfarlane Trust was established. I'm not sure when regular payments were first put in place, but I imagine it was shortly after the trust was set up. I received a regular monthly payment that was based on my HIV status, family and dependents. Yvonne and I were both working and we had one child. I cannot remember what my regular monthly payments were, but over the years I applied for various one off grants to fund various things including home improvements—upgrading central heating—a new bed, respite breaks, artificial insemination by donor costs, and OU fees (for my BA, not my MA). Whilst we did receive help with all of these, the application process itself was quite arduous.
5. Initial applications tended to be turned down if they did not fit within the narrow remit of things they decided they would fund. There wasn't much consultation beforehand about the kind of things they would and wouldn't fund. Thus, when, for example, I applied for funding toward my OU fees, and towards the cost of AID treatment, we were initially refused because

they didn't fall within the Trust's list of things they would help fund. We had to gather evidence and argue that furthering my education would significantly improve my employment prospects that had been damaged by my having been infected by HIV. Similarly, our decision to pursue AID—and later, to apply for funding for IVF, which was turned down, was not some whim, but based on the fact that for Yvonne to try to conceive naturally was to put herself at risk of infection. Having to respond to repeated questions of a very personal nature was both embarrassing and at times humiliating, and deterred us from applying for help with other things. I'm pretty sure that it was as a result of my application for help with my university fees, that the Mac Trust changed their policy to include higher education and retraining in their funding remit. Given the negative impact on people's education and career prospects as a direct consequence of having been infected with HIV, I would have thought this should have been included from the start.

6. I never had much direct contact with the Skipton Fund after applying for the £20,000 payment. When MFET took over my regular monthly payment from the Mac Trust, I think some element of the payment was to do with Hep C. I don't know when this change occurred, as my online bank statement only go back to December 2014. By this time my payment were coming via MFET.
7. As I explained Yvonne and I were well n the way towards very successful careers in London when I was diagnosed. We were both hard-working, ambitious and had aspirations to further develop our careers. Although I may not have stayed in recruitment, I do believe that I would have made a success of whatever management career I pursued, had it not been for the negative impact of HIV and HCV on my health and statement of mind. As a result of my condition we were not able to continue our careers and I now have to survive on Yvonne's small teachers' pension and my regular monthly payment from the Velindre Trust.

## 8. Other Issues

1. I was actively involved with Birchgrove Wales at a local level, and with National Birchgrove at a national level, from 1993 to 2000. I sat on the steering committee of the latter throughout that period and was co-editor and later editor of the National Newsletter. Through the Newsletter, National Birchgrove played a crucial role in disseminating information on a wide range of social, political, financial and medical issues as they related to haemophiliacs with HIV and/or Hep C. We also organised number of national events for haemophiliacs with HIV and Hep C, their parent, partners and children. Birchgrove was also very active in health promotion work, lobbying locally and nationally, and trying to increase public awareness about the particular issues face by haemophiliacs with HIV and Hepatitis C. to the Cardiff Haemophilia Centre.
  
2. I and my family found these groups to be very helpful and a great source of support for us.

Statement of Truth

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

Signed

GRO-C

Dated

18/2/2019