Witness Name: GRO-B
Statement No: WITN1190001
Exhibits: WITN1190002-6
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1963 and I currently live at GRO-B

2. My partner, GRO-B: P (born on GRO-B 1961) was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated Factor VIII (FVIII) blood products. He died on GRO-B 1992, aged 30.

3. This witness statement has been prepared without full access to P s medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. P had severe Haemophilia A, with a clotting factor of just 1%. He was diagnosed with haemophilia at aged 2 years. The diagnosis was

unexpected. His mother was adopted and did not know that she was a haemophilia carrier. P s younger brother died, aged 5 days, with severe haemophilia. P had two brothers without haemophilia.

5. P was treated with FVIII on an ad hoc basis as and when he needed it to treat cuts and bleeds and as a phrophalaxis.

6. P was under the care of the Oxford haemophilia centre at the Churchill Hospital Oxford from diagnosis to 1988. His consultants were Dr Rizza and Dr Matthews. He also attended his local haemophilia centre at Lewisham Hospital and Kings Hospital for dental work. From 1988 onwards he was under the care of St Thomas's (and Guys) Hospital. His consultants were Dr Savidge and Dr M O'Docherty. He was also included in the 1976 Dr Craske's research work".

7. P first tested HIV positive on 25th November 1985 whilst under the care of Dr Rizza at the Oxford Haemophilia Centre. **I refer to Exhibit WITN1190002** being a copy of his hospital record sheet. P had tested negative for HIV 7 months prior to the positive test on 10th April 1985 and "immunity study" is written (instead of usual haemophilia assessment/follow up). I refer to **Exhibit WITN1190003** being a copy of P s home treatment record together with **Exhibit WITN1190004** being letters sent to P in July 1986 seeking to recall the batches of Armour FVIII product P was given within the period preceding his first positive test.

8. I did not know P had HCV when he died. I found out that P had HCV very many years later whilst in the process of making a claim through the Skipton Fund. It was a shock to me to read in black and white a letter confirming that P was HCV positive and that HCV was a 'major contribution to his death'. I do not believe P knew that he had HCV. I have been unable to access a full set of medical notes and records. I have been informed that some of P 's medical notes have been destroyed. There is nothing within the limited records I have in my

possession about P having HCV until 28th August 1992. I refer to **Exhibit WITN1190005** being a copy of the letter dated 28th August 1992 sent by Dr O'Doherty to a GP surgery P had just registered with.

9. P died of liver failure at home, having also contracted tuberculosis, bronchopneumonia and encephalopathy less than one month after the date of that letter.

Section 3. Other Infections

10. P was first tested HBsAb positive on 16th June 1972 suggesting previous exposure to the Hepatitis B Virus. I do not know whether P was infected with anything other than HIV and HCV as a result of being given infected blood products. It is questionable whether the full extent of exposure to viruses and pathogens etc via factor products per se have been disclosed. I hope the Inquiry will be investigating this issue".

Section 4. Consent

11. I am unable to comment as to whether P was treated or tested without his knowledge or consent or without being given adequate information. I do not know whether P was told of his positive HIV diagnosis when he was first tested positive. I refer to **Exhibit WITN1190006** being an AIDS/3 form completed after P s death attributing the date of diagnosis to 18th October 1990. P only had HAART treatment for HIV between October 1990 and August 1991. He lost a lost of weight at that time. I can however say that he knew about his HIV status some time in 1986.

Section 5. Impact of the Infection

12. P and I met when we were teenagers at College in GRO-B where there was a vibrant music and subculture scene of which we were a

part. He more mod psychedelia, and me more punk. An unlikely match, and although there was something between us then, it wasn't until a few years later that we entered into a serious relationship.

13. We'd both moved independently to Colleges in London, I to study fashion and P film & media, and were working in our respective careers when we met up again. I was fiercely independent and was looking forward to a fulfilling and exciting career ahead. I wasn't looking for love.

14. P knew I was 'the one' for him, but I was astonished there was such a thing as 'the one' for me, and our previous flirtation was recognition that, but for timing, he was it!

15. P was the most positive person I have ever met, despite the hand that was dealt him. Joyous at the gift of the experience of life, he lapped it up. Adventurous, charming and irreverently funny – not always appreciated by everyone! He was also ambitious and determined. He had a passion for photography and his chosen career in filmmaking and, as a young film director he was accomplished in it.

16. With a shared adventurous spirit and outlook on life, we were ridiculously happy with each other.

17. P was headhunted to work in the Far East for a commercials production company. An amazing opportunity for his career, and for both of us it was a dream come true to travel. I think it also gave him a convenient distance to the growing public awareness in the UK that haemophiliacs had been infected with HIV via their blood products, and of course that included him. Whatever, it was the best decision we ever made [and we had a ball!]. We continued to have an exciting, happy and fulfilling life. My own freelance career there thrived, working in various media including: editorial, fashion shows, commercials, and for production companies on location from abroad, for prestigious names such as GRO-B, etc.

18. When P 's health began to alter we needed to relocate back to London where we continued to work in the creative industry we both loved. But as freelancers we had to rebuild our client bases and had returned to a difficult economic climate. So we took a financial knock, but as always we made the most of our situation and lived life to the full. [zooming around town in our GRO-B] We didn't dwell on the things that we couldn't have.

19. We booked a holiday to Egypt where P had secretly planned to propose to me by the Pyramids on NYE - did I mention he was a romantic -but he wasn't well enough to travel. So he asked me instead at a party in London, in someone's back bedroom, the only quiet place he could find, and I said yes. Funny that I think now, all the fabulous places we'd been to, and there we were just the same as all those years earlier in Devon, alone together in the quietest place we could find amidst the hubbub of a noisy party, when I'd first thought, er hello, what's this spark between us?

20. I can barely think, let alone talk of the physical and mental effects that the HIVirus [and hep C as I would later learn] had on P . It's too traumatic. So awful, that it comes to me in insufferable flashbacks.

21. I can't talk about the crazy stressful situations we found ourselves in, [the desperate dashes to get P home, sometimes from abroad] the difficult conversations with Doctors, the strain forced on to our relationship, P 's fear as it grew, and ultimately the sheer agony watching him suffer, watching him fade.

22. I'm deeply conflicted between wanting the terrible truth of the impacts known, and continuing to protect P s dignity and privacy. But it must be known that the effects on his body and mind were violent.

23. P party'ed hard and I urged him to slow down, but when the person you love tells you it's an escape from the increasing pain and fear, who was I to deny him. It just broke me knowing that's what he needed to do.

24. It became increasingly difficult for him to work. [Our industry demanded long hours, stamina, and often travel] but giving up wasn't in his nature. He needed an increasing amount of support. I was taught how to mix and administer his factor8 concentrate. My own work began to suffer as it became impossible to leave him alone for any meaningful length of time. He began to experience disturbing psychosis: a symptom of the virus or just sheer abject fear? I didn't know.

25. P couldn't get mortgage protection [although the Government would later argue that wasn't generally the case,*] and we were in a negative equity situation. Interest rates had hit an eye watering 15+% high. He was encouraged to claim for state benefits but we were forced to fight for them when they should have been given in good grace. I will never forget P poignantly saying [to me] that he'd be dead before he saw that money, and he was right.

26. I've never regretted upholding P 's wish to keep his HIV status secret, but it was tough at times. Friends and most family, including all of mine [to whom I was close,] were unaware. Only one of his two brothers knew.

27. It had became increasingly difficult for me to support P alone, and after a serious psychotic episode at an airport on a trip out to the US, I rushed him to St Thomas's hospital and I had to start informing some friends and family that he was seriously ill, but still not as to why. When he was admitted a few months later and we were told he was unlikely to leave, it was finally time to let everyone who loved him know the terrible 'truth'.

28. There was so much shock. So much grief. I watched friends and family reel. I don't know where the strength to support them came from as I was already on my knees, but somehow it kept coming. I was solid as a rock. And there was so much love between P and I which seemed to radiate out, and from our friends and family.

29. Reluctantly I visited an AIDS hospice with P's family. It was such a traumatic experience I still can't speak of it. A recent attempt with a counsellor, caused my body to convulse.

30. We brought P home from the hospital and I cared for him there. I barely ate and chain smoked to suppress my appetite. I hit approximatelh 7 stone, and have had eating and weight problems ever since.

31 P died at home in GRO-B 1992. He was 30 years of age. I was 28. He'd asked me if I could go with him.....

32. Just as the extraordinary power of our love had astounded me, so did the grief. It was raw and wretched and all consuming, In every cell of my being. The separation was cruel and devastating. To this day it can rip me apart and take me to depths unimaginable before his death.

33. There was some support from the Macfarlane Trust, but it was time limited, and although they tried to help me with my ongoing battle with the then DWP, there came a point when they cast me adrift with no expectation of future support.

34. It took me nearly two frustrating hair tearing angry years after P's death to obtain some of the state benefits, [including mortgage interest payments], that still remained due to him, causing delay to a difficult and protracted probate which I'd had to take on as Administrator. I vowed I would never go anywhere near the DWP ever again.

35. I'd returned to my family in Devon travelling back and forth whilst the flat was rented out to pay the mortgage and probate dragged on. I'd known when P had died it was inevitable that I would lose our home. It all compounded the grief. It was a desperately traumatic time.

36. I tried to continue working in London. Friends in the business were supportive, but in the early hours one morning I knew I needed to either call a friend or I

was stepping out of a third floor window. The friend came, and picked up the mess that I was. I'd cut off chunks of my hair.

37. Then In 2003, out of the blue, the MFT contacted me. They said they'd realised they needed to build bridges with the bereaved and asked me to try to trust them. I was shocked to learn they still existed. I'd been through a living hell in a 'wilderness' in those intervening years. Displaced from my home and my friends, far away from where my career was based, the stress had continued unabated. I'd struggled financially and worked myself into the ground. My career had long been destroyed but my ability to work at all had recently ended due to physical and mental ill health. Friends had drifted away, some unequipped to know how to deal with what had happened, others just busy getting on with living, establishing homes, families and careers. Good stuff, happy stuff. I wasn't a part of that, I was barely on this planet. New friendships hadn't been an option, the 'truth' had been reburied. No one said HIV or AIDS, including me.

38. Via the MFT, for the first time ever, I met someone else who'd been affected by contaminated blood products - 'A', who'd been infected with HIV. It was a deeply profound experience.

39. For a while the MFT appeared as it 'should' have been. Proactive, with a personal touch, There was access to a social worker, an OT and a financial advisor which we could speak freely to - unimaginable anywhere else. They appeared to be holistic in approach. It felt genuinely supportive. They'd begun organising bereavement weekends which filled up with damaged grief stricken families who'd been left in the wreckage, struggling and living in silence. I found a shared understanding. My pain wasn't alone any more, it was 'our' pain, 'our' grief, 'our' (unrecognised) trauma and it was such a distressing relief. I became a part of a community to which I sadly 'belonged'.

40. I attended a group counselling session where a trustee so moved by my story, turned to me and said, that but for the timing of P's death [ie under a different CEO] "I would never have been allowed to lose our home". I was

devastated to be told my decade of living hell needn't have happened. I returned home in a daze and broke down.

41. But there were unwelcome changes at the MFT and upheaval during my 'program' of support. I was angry with myself for having allowed them any where near me again.

42. 'A' had set up a blog and encouraged me to join. I met a small group of the guys who'd been infected ([consisting of H, G, A, P, M and A.] I started asking questions and they welcomed me in. The opportunity to share experiences was causing patterns to emerge. No longer could single incidences be seen as just that. Questioning of the governments narrative of events grew. There would be many painful and frustrating years of screaming into the dark to come, but the blindfolds were coming off.

43. So began my journey of discovery, a traumatising rollercoaster, where, as each new piece of the jigsaw puzzle as to 'what had happened' was hard found, and as each new revelation dawned I suffered the resulting grief. Again and again and again.....

44. GRO-B We attended 'PG' meetings with the Mft, where, the chairman Peter Stephens conceded to me they had "failed the bereaved". To this day, due to inconsistent policies and support schemes, the level of support available has been determined by the timing of a death. Bereaved Partners are still not treated as if this happened to them, with all the complex impacts recognised, but as unpaid carers passing through the lives of those infected, and who should have moved on.

45. As far as I'm concerned the consequences of contaminated blood products took both of our lives.

46. So my questioning turned to the MFT and its treatment of the bereaved, of being kept in the dark. I obtained the hidden trust deed* and found its object

at clause 4 obligated it to "relieve" our "need". Who knew, as we'd lost our homes at a time of grief and distress. I asked them what were the details of these (unknown to me) legal attachments* to MFT monies? but they themselves were unclear. So I worked with the new CEO Martin Harvey to find out, but we found official bodies including HMRC confused. Incorrect advise was given. I learnt of the vital difference between 'eligible' and 'entitled', which was at the centre of a fundamental misunderstanding of the MFT by many of its beneficiaries, with the former being applicable rather than the latter. Some had gone to their deaths wrongly expecting their families would be looked after for life.

47. More recent failures in the MFTs communications resulted in widows losing out on its 'income top up' scheme, including myself.*

48. Sadly by the end of 2006 all the years of unrelenting stress and struggle brought me literally to deaths door. The emergency hospital admission doubly traumatic for me, I came round to find an unknown [to me] drug being pumped into me and freaked out. It was a slow lonely recovery but I was left with serious long term health conditions. Dependant on others for care, but without my partner and any children, I was cruelly forced to turn to the State who I see as my abuser, where I've been owned by them ever since. It has been the most dehumanising experience of my life, exacerbating my anxiety, depression, panic attacks, and PTSD.

49. Housebound and unable to travel, I sat behind a computer in my pyjamas, day after month after year, continuing to contribute to the campaign battle to raise our profile and obtain a public Inquiry, and pushing the agenda of the bereaved. Latterly I set up a private Facebook group called GRO-B GRO-B for all infected and affected where I continued to communicate the Hansard record of political activities as I had done for many years [previously on the GRO-B website]. I'm also a founding member of the GRO-B GRO-B

50. In 2012, through yet another of the States many insensitive punishing exercises adding further insult to injury, this time the Skipton funds extension for applications from the bereaved, I received shocking information in a letter to me from St Thomas's hospital where P had been treated. Twenty years after his death I found myself reading that, not only had he been infected with hepatitis C but that "it was a major contributing factor in his death". Again the grief tore me apart.

51. The distressing DWP fraud investigations against myself and many of the MFT registrants, escalated. Despite the original legal protections of 'non disclosure'* of MFT monies, designed to protect the HIV status of the infected and their families, we were being forced to. The recent Legislation regarding EIBSS payments has cast it aside completely without any consultation with those whom it affects: it's payments must be disclosed,* solving the DWP's 'problem' rather than solving ours by taking the infected and affected out of the benefits system.

52. To this day I am fighting to exercise that right to non disclosure, and as a result my local care trust has terminated its funding towards my 35 hours per week care package.

53. At times I feel overwhelmed with the reality of it all: the scale of the devastation to me personally and beyond, and of the life I now live which is a million miles away from where I once was and all the potential it held. Chronically suicidal since P's death, I've struggled to survive the acute episodes. Recently I felt my resilience weakening and reluctantly reached out to the NHS who I have little trust in, for help, but was failed again. It refused me treatment for PTSD. The assessor simply didn't 'get it', preferring I continue to self fund the counselling I'd instigated due to the 8 month wait for their appointment.

54. The 'last straw' never was, they had just kept on coming, and now every bit of me is broken.

55. The States refusal to provide a public Inquiry for so many decades, forcing the infected & affected to themselves attempt to investigate what happened to them in such a painful & protracted manner, has been an act of inhumane cruelty. To say it has compounded the suffering is an understatement.

56. I now hope the outcome of this Inquiry will provide me with a 'release'. Not from the man I love, who I will do so to my grave, but from the vice like grip of the State, the unrelenting soul destroying battle to obtain the truth and for justice, and the endless grief. I feel only then, can I begin to come to terms with what happened to 'us' and be left in peace with P, the wonderful man who lit up my life.

Section 7. Financial Assistance

57. The MFT monies including SPT's had legal rights attached to them which were of financial value. They disregarded the monies for purposes of calculating an individual's entitlement to state benefits. They also gave the right of nondisclosure, for the purpose of protecting the individual and their family of the HIV positive status.

58. The DWP's inability to accommodate that legal right has resulted in decades of repeated fraud squad investigations against the infected and affected, causing further distress and trauma, amplifying the anger and injustice of those who've been forced to turn to the state benefits system.

59. It is obscene that MFT beneficiaries have been specifically targeted and punished by one government department (DWP) as a result of their receiving some financial support from another (DOH). It should have been the Governments problem not ours, and the benefits system should never have been used as the vehicle for beneficiaries main income.

60. As the social security legislation has been updated in more recent years, the inclusion of the right to non disclosure appears to have disappeared, either

intentionally or as a result of ignorance, with only the right for MFT payments to be disregarded remaining.

61. Currently the only legislation I have been able to find regarding the treatment of payments from the EIBSS which has recently replaced the MFT, states that it's payments must be declared, essentially due to the DWP's inability to accommodate the right not to declare".

62. The MFT had failed to correctly advise all their beneficiaries of these legal rights which were of potential financial benefit to them. Possibly affecting the bereaved and the younger infected individuals who had grown up, as they may not have been aware of them originally

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63. Many years after the MFT had watched me lose our home and then cast me adrift after the death of my partner, with no expectation of future support, I was shocked to learn of it's continued existence. I was further shocked when I discovered the trust deed and its object at clause 4, and the rights and responsibilities attached to the payments. The MFT had never provided me with that information and then appeared unclear of it themselves. To the credit of Martin Harvey the newly appointed CEO he worked with me to investigate the facts but we found official bodies seemingly as confused giving out incorrect advice.

64. To this day I'm fighting to exercise the right of non disclosure, and as a result my 35 hour care package funding from my local nhs care trust has been terminated.

Section 8. Other Issues

65. The Macfarlane trust made a number of amendments to its trust deed. At 29th May 2012 it deleted clause 5 in its entirety. In advance of its closure, the MFT offered a final grants application which dictated the criteria of what could be applied for. Was this in contravention of the trust deed? And, did the criteria put the bereaved beneficiaries at a disadvantage?

66. I was a founding member of GRO-B and have spent many years campaigning despite being ill. I am not academic but a creative person. I did not envisage that my life would be spent campaigning, lobbying, writing letters and reading legislation. I have a very strong sense of justice and I will stand up for I think is right.

Anonymity, disclosure and redaction

67. I wish to remain anonymous and would like my Statement redacted. I understand that this Statement will be published and disclosed as part of the Inquiry. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-B

27/02/2019

Dated

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness chronology has been prepared with limited access to P's full medical records.

16.06.1972	HBsAb positive
10.04.1985	HIV negative
28.01.1985	HBsAb positive
25.11.1985	HIV positive (first noted)
06.10.1988	Antibodies to HIV detected *(Virology)*
04.11.1988	HepB Surface Antigen: Not detected. HepB Surface a'body: Not detected *(Virology)*
20.08.1990	HepB Surface Antigen: Not detected. HepB Surface a'body: Not detected *(Virology)*
29.10.1990	The liver is slightly enlarged.... There are no enlarged lymph nodes seen .... The spleen is enlarged measuring 15.8 cms." *(Radiology)*
Dec 1991	Cervical tuberculosis diagnosis/large hypoechoic lesion
April 1992	Hospital
April 1992	CT scan reveals cerebral atrophy (consistent with HIV encelopathy)
	Planning a trip to the USA
01.07.1992	Hospital admission: Acute liver failure "as a consequence of Hepatitis C" *(letter dated 15.10.1992 Dr O'Doherty to Whom It May Concern)*