

ANONYMOUS

Witness Name: GRO-B

Statement No.: **WITN0296001**

Exhibits: Nil

Dated: 18/06/19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 September 2018.

I, GRO-B will say as follows: -

PERSONAL AND CURRENT CIRCUMSTANCES :-

I am a 57 year old Male, infected with HIV. I live alone at an address known to the Inquiry.

My date of birth is GRO-B 1961.

I live by the means of state benefits.

I receive a payment from EIBSS due to having received contaminated blood products.

I take multiple medications in treatment of my HIV and other medications to survive, every day.

I receive the assistance of a carer at least once a week, for such things as Domestic help.

I also received aftercare assistance with post surgical procedures, when I had Coronary bypass surgery in May 2017.

I then had to have removal of wires from my chest due to complications in May 2018 and will no doubt be receiving help with my upcoming Hernia surgery in December 2018.

Both of my Parents are elderly, in their mid to late eighties. I also have a younger Sister.

Due to my ill health, I am unable to fulfil the role a Son should be able to, such as helping my Parents.

This is a constant source of worry and stress each day as things are not improving as time goes by, not only for my parents but for myself.

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HOW INFECTED :-

I was first taken ill in August of 1982 and was admitted to GRO-B Hospital.

I was anorexic, I was jaundiced, I was vomiting and coughing up green phlegm.

I had severely swollen glands in my neck, armpits and groin.

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I then went blue and needed an emergency Tracheostomy.
A short time after that, I was transferred to the Royal Free Hospital in Hampstead.

Tests were done and I was informed I had Hepatitis non A, non B. I recovered from this, only to be taken ill again on November 27th. 1982.

I was admitted to the Royal Free Hospital, Hampstead once again, for treatment.
I was diagnosed with Acute Lymphoblastic Leukaemia, Chemotherapy started soon afterwards.

During my treatment I suffered profuse bleeding from my rectum, so badly, that a large number of units of blood were used in a transfusion, along with Plasma and Platelets and other Blood Products.

I returned to the Royal Free Hospital in September 1983 to continue with the final round of Chemotherapy.

During this time I received transfusions of blood products including platelets.

As a result of these transfusions, namely the platelets, I was given HIV while I was in The Royal Free Hospital, Hampstead.

It was confirmed at a later date that the infection I was given, came from platelets.

Batch number :-978767W4. Delivered for transfusion on 05-10-1983.

I finished all of my chemotherapy by March 1986, in full remission and have remained so.

DISCOVERING I WAS HIV :-

In April of 1986 I developed pneumococcal pneumonia and was admitted to the Royal Free Hospital.

During this time bloods were taken and tested for relevant levels and I also believe tested to see if HIV was present.

This was done without my knowledge.

I was contacted by the hospital in June of 1986.

I was told that a blood test needed to be performed because I had received multiple amounts of various blood products during all of my treatment.

I asked exactly why.

They told me, it was to see if, I had received any blood products that may be contaminated with HIV.

I was also asked if I could present myself and current partner and a list of former partners since my first wife to the hospital to test.

My girlfriend at the time was also tested for HIV on the same day.

A few weeks later my girlfriend and I returned to the Hospital to obtain the results of the blood test.

We were given the results separately.

My result turned out to be Positive.

My Girlfriends result was Negative.

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DISCOVERING I WAS HIV cont'd :-

I believe I was told of this fact by a member of the Leukaemia team. I distinctly remember being told in a very blunt manner.

My first reaction to this was, to state that if I had HIV, the hospital gave it to me.

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The consultant at the time denied this, he stated that I could have contracted HIV prior to having Leukaemia.

I then responded with the question "Why did you call me into the hospital to give me an HIV test in relation to blood or blood products if that is your belief?"

He could not really answer the question, so I pressed him for an answer.

His response was "There would be no proof that the HIV came from our blood or blood products."

It was later confirmed that the source of infection was in fact The Royal Free Hospital, as I mentioned in the previous section.

I was told basic facts, what HIV was, from the knowledge available back then.

When I asked "What was I to do now?" the reply was "Nothing, go away and come back when you start to get sick."

The manner in which I was tested and advised left a lot to be desired.

I was stunned, completely shocked at this point. I did not know where to turn for further advice or help.

The only other advice that was offered to me was with regard to practising safe sex and warning me of the dangers of transmitting the HIV.

I was told that at some point, I may be offered some form of counselling. We then left the consultation.

From this point onward, I made sure that I practised safe sex with my girlfriend.

As a precautionary measure, my girlfriend had a second HIV test and that too was shown to be negative.

OTHER INFECTIONS :-

I do not believe I was given any other infections through transfusion or other means.

CONSENT :-

With regard to the issue of consent, it is my belief, The Royal Free Hospital did in fact test my blood for HIV earlier than June or July 1986 without my knowledge.

Therefore, without my knowledge would mean without my direct consent.

I have a blood test result sheet from May 2018 which states "Date first positive 27/01/85."

This has led me to believe that the hospital knew of my HIV status eighteen months before I was told in June/July 1986.

The first I was aware of blood specifically being taken for an HIV blood test would have been when I was called to clinic in the June, with my girlfriend as mentioned in the previous section.

CONSENT cont'd :-

As far as I am aware, any blood tests during my A.L.L. Treatments were to monitor relevant levels to do with that.

If my blood was used for research, I was not informed of it by anybody.

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However, bearing in mind the previous paragraph, regarding my date of infection, I personally, can not rule out the possibility.

IMPACT :-

Mental Impact :-

From the moment I was informed of having HIV, I felt like someone had died. Then I realised they had, it was me. My life, as I knew it, was changed forever, I was petrified, bewildered, numb. I personally, was of the view that my prognosis was dire. With the limited information that I had been given about HIV there was nothing more for me to think, meaning, that I may only have two or three years to live. The Doctor could not provide any better clarity or prognosis himself.

I felt like my life had been shattered into thousands of pieces. I was living with a Death sentence.

I can not emphasize enough, the sheer enormity of being told I was given HIV at a trusted institution like The Royal Free Hospital. It spurred the question at the time and every day until the present day "WHY WAS THIS ALLOWED TO HAPPEN?!"

Since that day I have had, constant feelings of Grief, Intense Sadness, Anguish, bouts of Depression. My Anxiety and Torment is a daily thing. It never leaves, there is no escape from it. Being scared is also a normal thing. It has been since being diagnosed. Whenever I got sick, I would wonder if this was the time I was going to die. Even now, although I know I take medication to help manage my HIV, when I get sick I feel very scared and think the same thing.

Due to the Stigma surrounding HIV at the time, HIV was being associated with being a disease that was mainly in the intravenous drug user community and the gay community. I was never part of either. As a heterosexual male I experienced an overwhelming sense of feeling dirty, contaminated and I felt ashamed of being HIV.

The loneliness of being alone with my HIV gave me a profound sense of isolation. That isolation has grown over the years and still continues to the present day.

I was unable to tell my parents about being infected with HIV because I was in remission. My parents thought I was in near full remission from my A.L.L. I was scared. I felt ashamed.

IMPACT :-

Mental impact cont'd :-

How could I bring myself to tell my parents that during my treatment, I had been given

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infected blood?

How could I tell my Friends that I was HIV?

I felt compromised because the hospital at this point, were still denying having given me infected blood or blood products.

The only way I could deal with it at the time, was self imposed estrangement from my own parents and Sisters.

I was forced to live a lie where my parents and the entire family were concerned.

This was deeply disturbing and extremely distressing.

I felt compromised as a Man and as a Son and Brother because of what happened to me.

At one point I did consider the fact that I lived in a flat on the fifth floor, the balcony was only five steps away, a swift way to end the suffering and avoiding telling my parents.

In GRO-B 1987, my youngest Sister was killed in a motor vehicle accident.

I was asked by a Nurse to view the body of my Sister at the hospital, to make sure it was appropriate for my Father to see her so he could make the formal identification.

At the time of viewing, I exclaimed to myself that it should have been me that died, not my sister.

I experienced no feeling of Loss, Grief or any other emotion. I was just as numb as the day I was diagnosed with HIV.

It had such a profound impact on me, that while I had no choice but to accept my Sister's death, it has taken me thirty years to begin to come to terms with it.

This is how being HIV through contaminated blood made me feel at that moment in time and still does to this day.

Due to being infected by the N.H.S. I have hardly any trust in the service, even though I have no choice but to rely upon the N.H.S to keep myself alive.

When I have had surgeries, I have had to remind health care professionals to put gloves on as a precaution, while cleaning wounds for example, even though I had previously informed staff of my HIV status and it was on all medical records.

This can lead to difficulties between staff and myself.

I have typically felt ostracised on some occasions for being honest with regard to my HIV status.

Four months after the tragic death of my youngest Sister my father found out I was HIV positive.

Not from myself.

This occurred while I was seeking treatment for a Left ophthalmic Herpes Zoster in A&E at the Royal Free Hospital, on the GRO-B 1987.

Upon seeing the initial doctor in A&E, I had made it clear about my need for strict confidentiality with regard my HIV status, in particular, where my family were concerned.

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IMPACT :-

Mental impact cont'd :-

This was especially important as my Father was going to be meeting me at the hospital.

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He then informed me I would need to see a colleague of his as I needed to be admitted as a patient.

His colleague entered the area and simply said "Hello Mr [GRO-B] you're the patient with HIV."

He then proceeded to examine me.

I believe, it may be possible the second doctor was not informed of my express need for strict confidentiality.

This was said in a curtained cubicle and my Father was present by this time.

This was absolutely devastating for myself.

I was extremely distressed at the fact that my Father had to find out in such a way.

I saw the look of devastation on his face. I will never forget that look.

It was made more difficult because of the recent sudden death of my youngest Sister a few months before hand in the [GRO-B] of 1987.

It was roughly three months after this had happened that my relationship with my girlfriend came to an end. Things had become untenable between us.

IMPACT :-

Physical effects :-

The physical effects of being HIV are very apparent in my appearance. I am very skeletal due to the severe Lipodystrophy I suffer with.

By the early 2000's my facial appearance had become gaunt. Even my consultant mentioned my appearance to me.

He also mentioned how thin my skin was becoming on my body but even more so upon my face.

He asked me if my appearance affected me in any way, such as "Did it prevent me from going out?"

I told him of my concerns about how I appeared and how I dealt with it.

I told him that it is easy enough to cover my body, make myself look bigger, but I could not hide my face.

My consultant put me forward for the "Newfill" program. This was a form of cosmetic surgery to deal with facial lipodystrophy.

My consultant recommended the treatment for two main reasons.

The first reason was to try and help me gain some confidence so I would not be so self conscious of my facial appearance.

The second reason was from a medical point of view. Should I receive an injury to my face, there would be, hopefully, sufficient mass for stitches or similar repairs.

IMPACT :-

Physical effects cont'd :-

It was hoped that the "Newfill" would help me maintain mass in my face.

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It was known that patients who had been infected for many years less than myself, also with far less lipodystrophy, gained benefit from this and maintained mass.

I received the "Newfill" treatments over a three year period, roughly.

Each year I received three treatments over a five month period, roughly.

After two years, there was a definite improvement but after three years the "Newfill" had lost its physical effectiveness.

It served its purpose quite well for the time it lasted, which was in total, two or three years, inclusive of treatments.

I have low bone density because of the A.R.V. medications I currently use and have used over the years. I was prescribed Colecalciferol 20,000 IU Capsules. One capsule to be taken once a week. This has been ongoing since my investigations in 2015.

Anorexia makes it difficult to even have an appetite. The smell of food cooking and the preparation of food gives me Nausea and prevents me from preparing and eating.

For that reason, I mainly eat preprepared, reheated meals.

My nutritional intake is not good and I have to use supplements, that I buy at my own expense, to assist with that.

This is a daily struggle.

IBS is a constant problem. I also get recurring and sporadic diarrhoea.

As a consequence, I must carry a discreet bathroom kit with me at all times when going out.

This includes a change of underwear, Loperamide tablets and Buscopan tablets, should a situation occur.

Insomnia is a constant major problem, it has been for decades.

I have suffered with "Night Sweats" since being HIV.

Chronic fatigue is a constant feature. This affects most things I do.

As a result of my fatigue it takes me a long time to recover from carrying out my daily tasks indoors.

When I go out, I have to rely upon Taxis to travel between Hospital appointments and Doctors appointments.

Because of my fatigue, walking is limited to going to my parents house, my sisters house and the local shops.

The typical distance walked is no more than one and a half miles, during which time I have to stop several times.

IMPACT :-

Physical effects cont'd :-

I was started on ARV therapy in 1994 and that has ranged from Saquinavir/AZT/ddC at

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first and other combinations over the decades.

I currently take the following ARV drugs :- Abacavir/Lamivudine 600mg/300mg
Atazanavir/Cobicistat 300mg/150mg

I also have to take the following medication :- Acyclovir Hydrochloride 1000mg daily.
This is to prevent Shingles, which always returns when the dose of this particular drug is lowered.

I must take this drug for life.

Along with the ARV medication, I was prescribed a Statin tablet to be taken once a day.
This is to help control my liver functions because of the side effects from the ARV medication.

I take Loperamide tablets as and when required, this treats the Diarrhoea. These I had to start taking in 1988 before I presented at HIV Clinic.

I also take Buscopan for help with the IBS, as and when required.

For pain management I take Paracetamol. This I take usually twice a day, most days.
This is for my low bone density and other pain.

I was prescribed sleeping tablets when I started my ARV treatment as Insomnia became increasingly worse at this point.

I still today have to take two types of sleeping tablets to try to deal with the Insomnia issues.

I also had to start taking Lorazepam medication to help manage my increasing anxiety and depression.

A large proportion of my anxiety is due to, in my belief, the ARV medication.

My anxiety has been present since the day I was informed of being HIV.

It has only become worse over the years.

Around 2010 or soon after, I saw my consultant in the HIV clinic.

I told him how I was feeling and the type of thoughts I was having at the time.

He informed me that I was suffering with severe depression.

He gave me two options.

They were to take medication to try to help or to see the psychotherapy team.

Due to the trust issues that I have, we both agreed, medication was the only option for me.

The trust issues I mention are detailed under the section titled "Counselling."

I was prescribed Citalopram tablets.

These helped me immensely for the first twelve months but then I felt that they were holding me back from being able to continue with my daily activities.

Not only did the tablets affect day to day things, but also, from being able to write music and play music.

It was because of this, I managed to come off the medication in the proper manner.

I was on anti-depressants for roughly eighteen months.

IMPACT :-

Physical effects cont'd :-

As mentioned earlier, I have low bone density. This causes pain in my Neck, Shoulders,

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Lower back, Hips and Ankles.

For pain management at the time, Ibuprofen was prescribed by my HIV consultant. This was prescribed over many years and I found it very helpful in managing my pain levels

In 2013, I began to experience abdominal pains. I saw my HIV consultant and was then sent for a series of tests.

These revealed that I had signs of Diverticulosis and I was also diagnosed with IBS.

In 2013, I gave up smoking Tobacco, due to my increasing anxieties about my health, I was smoking at least two packs a day. I had no choice but to stop smoking Tobacco.

In 2015, I saw my HIV consultant because I was still experiencing severe abdominal pain. Upon examination it was shown that I had two Hernias in my extreme lower abdomen. As the Hernias became problematic it felt like I had problems with circulation in my left leg. I was sent for an MRI scan.

The scan revealed that I had a problem in my lower abdominal Aorta. There was some blockage.

This in turn meant that I could not have the Hernia surgery.

The doctor was very concerned about my circulation.

I had to have an Angiogram to investigate the circulation problem. This revealed further blockages in my arteries.

I was told I had to have a CABG operation. This took place at the end of May 2016.

I was immediately prescribed Aspirin for life and now I take other heart medications for life.

After my CABG operation, my pain management medication had to be changed from Ibuprofen to Paracetamol.

I am now only allowed to use Ibuprofen, for extreme cases of pain and only after speaking to my doctor.

I have no doubt that the medications that I have taken and do take have caused problems over the years and continue to do so.

I have experienced allergic reactions while trying to take new ARV drugs.

I broke out in a dark purple rash which covered almost half of my body. It felt like my skin was on fire.

I had to stop taking the ARV and reintroduce it at lower dose in the hope that I could take the drug and increase the dose successfully.

At that time, I was very anxious and scared as I must take the ARV drugs to stay alive.

IMPACT :-

Physical effects cont'd :-

In 2004 or thereabouts, I started to notice strange sensations in my lower limbs and also in

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my fingertips and face.

I saw my HIV consultant at The Royal Free Hospital. He sent me for some tests. The tests showed that I was suffering with the return of Peripheral Neuropathy.

I was quite surprised at this, since I had not noticed any symptoms of my previous peripheral neuropathy since shortly after my chemotherapy treatments.

My consultant told me that the peripheral neuropathy was being caused by the ARV drugs and the fact I had been taking them for a long time.

Subsequent tests showed that my symptoms of peripheral neuropathy were getting worse as time went by.

After having my CABG operation I was prescribed Gabapentin for the nerve and bone pain. This was to help the affected areas. As a result of my CABG operation I now suffer with Peripheral Neuropathy in my left leg far worse than I have experienced before.

It now also affects my entire left chest area.

The Gabapentin dose was adjusted by my HIV consultant to improve my pain management after my discharge from the hospital. This helped with my Peripheral Neuropathy at the time and still does immensely.

For these reasons, Gabapentin is still prescribed.

I had to wait for eight years after being given my diagnosis before I suddenly became sick and started ARV treatment.

Twenty five years of sticking to a very strict regime of taking my ARV drugs and other drugs prescribed for the side effects, has definitely taken its toll.

Where other treatments are concerned, such as attending to dental needs, I could not bring myself to see any dentist as most people would.

It would mean disclosing the fact I was HIV and with the stigma attached, it was not an option.

I received basic dental treatment at The Royal Free Hospital until such time that the service was stopped.

The department was closed down.

I was given a list of Dentists who accepted HIV patients if they had the room on their patient list.

I was fortunate and found one that accepted me.

IMPACT :-

Private, family and social life, living with the Stigma :-

There is information that you need to know with regard my family which will help explain

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why things were very complicated, both for myself and my Parents.

Unfortunately, my Parents were told that they could not conceive naturally so, as a result of that, they chose to Adopt.

I was given up at birth by my birth mother and father.

As an adult, my Parents told me that I was born in Scotland. Upon arrival in the care home in London, I was black and blue and not feeding, just weeks old.

My Adoptive Parents were informed of my state of health and poor chances of survival and so, My Parents insisted that they adopt me.

My life was saved by my Parents.

Later on, my Sister arrived, also adopted, the family was growing.

Then, in 1967, against all odds, my Mother fell pregnant and my youngest Sister GRO-B was born.

Moving forward to the time of being told I was HIV, mid 1986, as mentioned earlier, my life as I knew it ended.

I simply locked myself away not knowing what was going to happen to me, physically or mentally.

I thought I was going to be dead in a couple of years. I was extremely Frightened.

My turmoil was deepened at the thought of telling my Parents and Sisters.

What would I say?

How could I tell them?

I had, and still have an overwhelming sense of Shame because of being HIV.

I was only ever going to tell them if I had to.

I could not face telling them at the time. I thought they would find out inevitably as my HIV progressed and my health failed.

As far as I was concerned, my future was short.

In GRO-B 1987, my youngest Sister, GRO-B was killed in a road traffic accident.

Naturally the family were devastated.

My Mother suffered a nervous breakdown.

I went to identify the body of my Sister so as to ensure it was appropriate that my Father could make a viewing.

When I viewed my youngest Sister I remember saying out aloud "That should be me laying there."

I felt that way because of my HIV status.

The death of my Sister left me with a profound feeling and sense of Guilt within my Grief for her loss.

It still does to this day.

A beautiful young lady with her life ahead of her, robbed of it in an instant.

I on the other hand, HIV through contaminated platelets am allowed to live.

I don't believe I will ever fully understand this.

IMPACT :-

Private, family and social life, living with the stigma cont'd :-

In GRO-B of 1987, I was at the Royal Free Hospital and had seen a consultant before

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being admitted.

He sent another consultant in who blurted out "You are the patient with HIV."

This was in the presence of my Father.

He looked Horrified at what the consultant had said.

After the consultant left, I had no choice but to confirm this to him.

His exact words to me were "You can't tell your Mother, it will kill her!" I understood why he said this to me and I agreed.

We then argued about what happens when I get ill later on.

Who was was going to tell My Mother? My Father said that he would, if need be, but he didn't like to lie.

I believe My Father felt very compromised at the time.

It was natural for my Father to think of his Wife first, due to her condition because of the recent loss of my youngest Sister.

It was at that point that I realised that the fact I was HIV, now directly affected my family.

It caused the need for secrecy and living a lie for many years for both my Father and I.

This has simply not sat well with us, at all.

From that moment onwards, it was a matter of self estrangement from my parents.

The only contact was by telephone unless absolutely necessary.

I would avoid going to any family functions, it was easier to make an excuse and stay away rather than meet relatives and be asked "How are you?"

Did I tell them the truth?

Not back then, not with the level of ignorance and stigma, I felt I had no choice.

I can not imagine how my Father felt at finding out that I was HIV, let alone in the manner to which he found out.

I know he would have felt compromised of not being able to tell my Mother of my situation.

To this day, I do not know when my Father first spoke to my Mother about my HIV status.

I just know that by being infected with HIV has had far, far reaching effects on my Family and those that are close to us.

Soon after this, late 1987, the relationship with my girlfriend broke down and ended.

This is the point that I felt truly alone. No job, no girlfriend, no life.

I was going to die because of something that someone had given to me at the hospital, namely HIV, while saving my life.

I struggled to cope with that then and still do to this day.

During my treatment for Leukaemia, I discovered that Cannabis helped me to manage the treatment and the side effects successfully.

I maintained the use during my remission and continued the use of cannabis through my HIV diagnosis.

It helped me sleep when I used it with my sleeping medications. It certainly helped me in terms of the side effects from HIV drugs, by preventing Nausea and boosting my appetite.

It further enabled me to cope with my Anxiety and Depression until I started my HIV treatment.

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IMPACT :-

Private, family and social life, living with the stigma cont'd :-

I currently use CBD Oil and concentrates to help supplement and manage my pain,

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depression, anxiety and insomnia. I find this helpful.

I purchase these products from online health shops and high street health stores, at my own expense.

Living with the stigma of being HIV is nothing short of an absolute nightmare.

I feel like a Leper, an unclean person, like some kind of filth is running through my veins.

In the 1980's, the only knowledge and awareness people had was from the television "HIV" advert featuring John Hurt.

The Tombstone at the end was a close reality for me at the time, literally.

I was verbally abused while outside.

I had been threatened on the street.

I was told things like "You need to be put out of your misery."

Upon my front door, someone had etched into the paint, deeply, "FUCKING AIDS FREAK!"

This is the reality of some people's level of understanding, this is what I had to live with at the time.

I had a fear of leaving my home in case I was seen or worse, physically assaulted.

I would actively avoid people I knew while outside.

I would cross the street to avoid them and turn down a side street, even if it meant a longer walk.

It would prevent awkward questions.

Even to this day, I make a point of being extremely cautious as to whom I mention my HIV status to, then it is usually only medical staff.

I feel morally obliged to do so, it is also, I believe, my legal responsibility to inform them so as to avoid contamination during treatment.

Not only do I face the stigma of being HIV, but also my family has to endure it too.

My parents are very careful as to what they say to people if they are asked "How is GRO-B?"

They are all too aware of how the stigma is transferred just because of association. It is just as much of a burden for my family as it is for me.

As rumours circulated back in the 1980's about my status, friends began to disappear.

If I visited people, I would always be given the same mug to drink from.

Furthermore, at one person's house, it was kept by itself on a separate shelf.

You notice these little things as time passes.

For reasons such as that, I locked myself away.

As damaging as that may have been for myself, I felt it was the safer option.

I still do today to a degree and I have very few people that I trust.

IMPACT :-

Private, family and social life, living with the stigma cont'd :-

At that time an old friend from my teenage years visited me at my flat. She took the time to

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ask why I had been isolating myself.

We ended up in a relationship after some time and during which, she was helpful in encouraging me to go out to places and be a little more sociable.

I had completely locked myself away for three years before this point.

The lady had a two year old daughter.

We went out on day trips like a family would do.

In time they were both introduced to my parents.

My parents accepted my girlfriend and her child as members of the family.

Not only did my girlfriend's daughter help me, but also helped my mother and father.

The presence of my girlfriend and girlfriend's daughter was very uplifting for my mother and father since the loss of my youngest sister.

It was because of all of this, my sense of self worth returned to a degree and I knew that there was someone that truly cared.

As my girlfriend's daughter grew older, she became more aware. Naturally I began to question the validity of the relationship from a stigma point of view.

What if other children found out I was HIV?

What if her friends at school found out?

How would that affect her?

I could only conclude that it was not fair for her to be put in that position.

The decision was made to end the relationship, however this person and her family have remained present in my life until this day.

The lady is in fact now the trusted person who has taken over looking after me since I have been unable to take care of myself fully after my second wife left me.

Care is provided during the week at home and also other assistance, such as hospital appointments, as and when necessary.

EMPLOYMENT AND FINANCIAL EFFECTS :-

Before I became ill with Leukaemia, I was a Qualified GRO-B in full time employment and a married man and we were buying our own property.

My illness changed all of that.

I was unable to work, we were unable to carry on purchasing our property, eventually our marriage collapsed. We were in Debt.

I had to rely upon the state benefit system for financial support. I had to apply for social housing from my local council for a place to live.

Upon my HIV diagnosis, I could no longer perform my function as a GRO-B This would be because of injuries, such as cuts to myself that can occur while working GRO-B and the risk of infecting others.

My mental health was starting to become an issue at this time.

EMPLOYMENT AND FINANCIAL EFFECTS Cont'd :-

Since being diagnosed, I received benefits of some kind, but finally ended up receiving Disability Living Allowance (DLA.) higher rate, care and mobility.

It was awarded for life.

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Having to survive on the benefit system can not, in any way, be compared to having a job, an income and the freedom that comes with that.

In fact, it is the opposite, especially when you know you were infected with HIV while being treated by the NHS, left unable to work through no fault of my own.

I was raised by my Parents to view the benefit system as an absolute last resort after trying all avenues.

Being on the benefit system, was at the time shocking. It is a lot worse now.

Having to be on benefits, through no fault of my own, I find to be totally degrading.

When I was "Awarded DLA for life," it at least gave me some small feeling of financial security at the time. This was awarded for things such as help getting around and with care.

The DLA allowed me to maintain a reasonable level of care.

I was left horrified when I received a letter informing me that my DLA claim was being stopped.

I was told I had to apply for a new benefit known as P.I.P.

I was under the impression my DLA was for life.

It was a very difficult process to claim P.I.P. I felt persecuted. I was very scared.

With the cutbacks in my benefit amount, especially Personal Independent Payment, I can only say that my life has become much harder.

The sheer stress of having to fill out a form to basically state "Yes, I am still dying slowly." is still having a severe effect on my health, both mentally and physically.

A futile exercise that I have to go through every two years.

These people KNOW that my health is deteriorating.

It makes me feel angry and undignified that I have to justify to the DWP why I have not died or why my health has not improved from the N.H.S infected blood.

When you consider the fact I have to go through the same procedure for ESA, a matter of only months apart, I have to suffer the entire ordeal for around four to five months.

At my first PIP assessment, my money was cut in half.

I was and still am too scared to even think about appealing, for fear of losing any help I already receive.

I would simply not risk my health as I know there would be severe consequences.

It seems that under the current government that there is no compassion also a severe lack of understanding.

This fills me with a permanent intense feeling of dread and persecution.

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Every time I hear an announcement on television with regard funding for the services that I rely upon to keep me alive, namely ESA, PIP and other benefits, I am left with no choice but to fear for my future safety, especially where my health is concerned.

If the current cost cutting assault of the welfare system and NHS continues in such a manner, I believe I will be at risk even more so.

It is my belief and view that I have paid a large enough price already by being infected with HIV and having no choice but to take medication to stay alive so far.

EFFECTS ON THOSE CLOSE TO ME :-

In the early 1990's, I was extremely fortunate to start a relationship with a young woman. It was something that I had thought would never happen again because of my HIV status.

The relationship grew into something serious, eventually we married.

Things were good in my life at that point, by comparison to previous years.

I was no longer alone.

It is fair to say that although both my Wife and I did try our absolute best to maintain a good marriage, it was not to last.

As my health started to decline and I started my HIV treatment, it took its toll of both myself and my wife, mentally and physically.

Unfortunately, my wife started having affairs, which in turn left me no choice but to pursue a divorce.

As mentioned earlier, the effect on my relationship with my Father was deeply affected.

He is not the kind of man who likes to talk about these kind of things. Our communication was at a minimum between us. Things were not spoken of.

Up until about ten years ago my Mother and Father did not talk to me about these things.

It is my sincere belief that they found it too distressing especially after losing one child.

They would focus on my well being, as any good parents would do.

Things have improved in the last eight to ten years with my Father. As we have both aged and gained more of an understanding, there is more of a bond.

This is true for my Mother and I too.

In the early days of knowing I was HIV, I reacted to my Sister in the same way. I thought it was best to say nothing.

I believe my Sister found out through the rumour mill at the time. Not an ideal way to find out anything, let alone something as serious as my HIV status.

My Sister understands my HIV status and what it means. She is as helpful as she can be while running her own family home and maintaining her job.

We do speak of my status, I inform her how I am in general, but she finds the details of my illness very distressing.

Her husband also shows an interest and is very supportive.

EFFECTS ON THOSE CLOSE TO ME Cont'd :-

Like myself and others, they are both very distressed because of the injustice that has been allowed to go on.

All my Nephew was aware of, was that "Uncle GRO-B was not a very well man."

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I believe he was told more information around the age of thirteen or fourteen.
Where my Nephew is concerned I stayed quiet about my HIV status.
It is very difficult to explain to a young man how you became infected with HIV from a Hospital.

Within my immediate family, there is an unspoken understanding in general with regard my HIV status.

My parents have a basic understanding so far as my blood counts and a good understanding of the implications if they rise to high level.

The friends who are aware of my HIV status have a very good understanding of my condition.

There are two people that are particularly close to me, they have both known me for a very long time.

My being infected had a profound effect on this couple.

One thing they do have trouble with, is the fact I was contaminated by the NHS.

This makes them Livid with Anger.

They choose to ensure, no matter what, they are available to help me in my life.

This they have done for decades and continue to do so.

Another couple that got to know me very well are also very understanding of my HIV status.

Some years after the divorce of my second wife, I was in a particularly bad mental state.

My friends saw this and offered to help by inviting me to their home for a respite holiday.

They were of the view that getting out of my house for a few weeks by the coast would be helpful.

They were right.

This happened for a number of years and helped me regain a little confidence in myself.

Over the years we have had conversations with regard my HIV status.

One thing that is very clear is the anger.

Not towards me, but at the Injustice of the whole affair.

They are disgusted by the attitude of previous governments and they believe that the Government are knowingly treating infected and affected people without compassion.

My Family and Friends would like answers as much as I would like answers as to why this was and is allowed to happen.

TREATMENT, CARE AND SUPPORT :-

I would say that the treatment I received between 1994 until 2013 was excellent.

This was when I was under my consultant Dr Mervyn Tyrer at the Royal Free Hospital.

After a long period of time of dealing with each other we were able to build a rapport and

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an understanding.

This actually helped me in restoring a tiny amount of trust for someone within the NHS who was caring for me.

The care consisted of usual monitoring of blood counts that are pertinent.

The monitoring of things like Lipodystrophy, peripheral neuropathy and other problems as mentioned previously with regard to my side effects from ARV drugs.

Since 2013, due to funding cuts being made, the certain monitoring of things has ceased to be on a regular basis and is now only annually or bi-annually, if at all.

While at one time, my monitoring and tests were done "in house," under one roof at the Royal Free Hospital, arranged by my HIV Consultant.

It has since changed so as to pass responsibility over to My G.P for other monitoring services.

This in turn takes longer to be treated in some cases.

My GP then has to correspond with the HIV department at the Royal Free Hospital, to which, then means, in some cases I get referred back to the HIV department to receive treatment.

This may suit the bureaucratic system, but not the health system unfortunately, not where my care is concerned, considering how I received HIV in the first place.

The fragmentation and fracturing of both systems makes me feel that my access to treatment is becoming more difficult.

COUNSELLING :-

When I was informed of my diagnosis and prognosis there was no proper established type of counselling services such as there are today.

My girlfriend and I were offered at the time, I use the following term very loosely indeed, counselling.

This took place at a centre in GRO-B

Within the building we were lead into a room, which consisted of three people, one of the people was the doctor that told me of my HIV status and the possibility of counselling at a later date.

There was a video camera set up on a tripod. I was quite alarmed at this fact.

I was under the impression I would be meeting a counsellor, not a video camera.

I asked what the purpose was behind the recording. I was told it was for future reference for myself.

A recording of my thoughts and feelings on being infected with HIV while I was still of sound mind and body.

It could also be used, if need be, later on, upon my death, to find out my wishes.

COUNSELLING :-

Counselling cont'd :-

I was asked such questions, as was my girlfriend, "How did I feel about being HIV?"

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"Have you told your parents?"

"Will you tell your parents?"

"What does your girlfriend think about you being HIV?"

"Will you tell his parents?"

"How do you feel about **GRO-B** being HIV?"

It felt like I was under scrutiny.

It was more like a monitoring session for their benefit, rather than mine or my girlfriend's. This type of "counselling" I found most intrusive and it only deepened my suspicions as to the deniability as to the source of my infection.

I found this whole experience very disturbing and based upon my experience in that meeting, I would never again ask to see any other type of counsellor.

It left me with a deep mistrust as to how counselling was carried out.

I still feel and think the same way about counselling today.

In fact, because of that counselling session, it only fuelled my distrust of the NHS and Psychologists and Psychiatrists.

I was under the impression that they were there to help me, not hinder me.

I was left feeling very misguided. My girlfriend felt the same way.

After that experience, combined with what I had seen in the media, I was filled with pure dread.

I was left thinking that I would die by breaking out in black sores, or worse still, losing my mind.

Having stated my experience of so called counselling at the time, I can only say that adequate does not even begin to describe what was on offer, even taking into account the limited knowledge of HIV back then.

After my experience with the counselling and the way I had been told I was HIV, I felt like I had no choice but to try and help myself to some degree, with what I had available.

This was because of my extreme distrust of the NHS.

I began to keep written notes of thoughts and feelings as they appeared, something that I still try to do, but find increasingly difficult.

I also pursued an interest in music. I learned to play the Bass Guitar.

I found that playing music and writing has been far more useful in preserving any degree of stability than offers of counselling ever were.

FINANCIAL ASSISTANCE :-

In May of 2006, I received an envelope through my front door.

It contained an anonymously sent letter telling me to get in touch with "The Eileen Trust." It

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had contact details.

I made enquiries about it, I was very sceptical about the letter, it could have been some kind of cruel action by somebody.

Fortunately, it turned out to be genuine information.

During my initial contact I asked why I had not been informed at the very start of the trust. Simply put, it turns out that at that time I was "Missing presumed Dead."

This is in no way any fault of the Eileen Trust.

I believe, that in some way or another, communication was bad between governmental departments.

I say this because I was in receipt of benefits.

I may well have changed address and I did inform the necessary benefit departments, so as a result, I was still "on the system" and my claim was active.

I started receiving ex – gratia payments from The Eileen Trust. I began receiving regular payment from June 2006.

In December 2006, I received a one off payment in lieu of not being in the trust from the start.

A winter fuel payment was made once a year on top of monthly payments. This is now included into the total yearly amount managed by EIBSS.

The process of applying for assistance from the Eileen Trust was quite straight forward.

I was visited by the senior case worker from the Trust.

Details were taken, also means of verification of my claims and HIV status.

Letters were provided as evidence of benefit claims and a letter from my doctor at the time from the Royal Free Hospital.

On occasion, an auditor would send a letter asking for confirmation of funds provided by the Trust and levels of expenditure.

The level of payment has been at the rate that was fixed by the Trust and was paid by them into a bank account every month.

Should any further assistance be required, certain grants were available.

I found it a very straight forward procedure to apply.

Grants would typically be for things that would help a person with their daily living needs, such as white goods like a washing machine, or a new cooker.

This would typically be because of a sudden failure of an old appliance.

On one occasion I needed to replace my washer dryer immediately. I paid for it myself.

I contacted the Trust to tell them and they agreed to refund the cost.

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FINANCIAL ASSISTANCE :-

Financial Assistance cont'd :-

The Trust did provide the means for an annual respite break for myself to accompany my

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elderly parents on holiday.

I would give them the information needed about the cost of the holiday in suitable accommodation and the Trust would have given me a grant to help cover my share of the expense.

The Trust did run an annual respite break, which in later years, when my health deteriorated, I did attend.

This would be in a hotel, usually for a three day weekend.

There would be facilities including swimming pool and sauna as well as being provided with our own holistic therapy team.

This was always a good thing as all of those that could attend could meet up and talk in person.

I personally found this of great use to me as I knew I did not have to explain myself while I was in the company of others from the Trust.

It was not until I had met people in The Eileen Trust that I had met anyone else that had been contaminated by the NHS.

People actually like myself, contaminated with HIV only through blood OR blood products.

I then realised that I was in fact, one of only a very small number of people that made up The Eileen Trust.

No more than a dozen people and their carers, or so it appeared, judging by the attendance at the annual respite breaks.

During the last five year period of The Eileen Trust, I knew two friends that died.

Their loss was and still is especially felt as we were like a family when we met up for the respite break.

Unfortunately, since The Eileen Trust was dissolved it's members have been swallowed up within the other former trusts, now run by EIBSS.

This important connection between members, sadly, no longer exists.

While away on a weekend with The Eileen Trust I was told that we were a group added to the bleeding disorder trusts.

The Haemophiliacs who had also been infected with HIV and or HEP C through contaminated blood or blood products generally disassociated themselves from us.

The Eileen Trust supported other groups in their plight for justice.

It never seemed to be reciprocated in the same manner, even though we were all infected with contaminated blood or blood products.

It was made clear that differences were made between "whole bloods" and "blood products" by the members of the other trusts.

FINANCIAL ASSISTANCE :-

Financial Assistance cont'd :-

Since all the Trusts have been dissolved and EIBSS have taken over the responsibilities of

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payments to the infected and affected, I have seen great unrest between individuals and the different groups on social media.

This is because of the different level of health and medical statuses and the difference in the level of financial assistance paid to individuals by each of the former respective Trusts. This is apparently causing even greater problems and hardships now that it is being run by EIBSS.

In relation to the amount of money paid by the various trusts, that was a matter for each trust.

I received what I did because of HIV Contamination from the Government.

What is the "correct amount of money?"

The money will not cure my HIV, nor will it make things better.

It helps me to help myself to continue to survive from day to day, but certainly no more.

OTHER ISSUES :-

In approximately 1993, I was contacted by H. Grant Prentice, the consultant who treated me for my A.L.L. at The Royal Free Hospital.

It would appear that through a count back, The Royal Free Hospital had infected me with HIV and two other patients from the same blood batch.

The government were making me a financial offer of £43,500 on the undertaking that I sign a waiver.

This would mean the offer came with no liability against the government.

This happened very fast indeed, as apparently there were only thirty days until the deadline to sign.

The actual payment was received in April 1994.

I felt at the time that I had nothing to lose by accepting the offer.

I was supposed to be dead by this time, but I wasn't.

I wasn't sure as to how long I had to live. I still don't.

In 1993, under the advice of a solicitor, I attempted to take Legal action against The National Blood Authority.

It was during this action that I discovered the Batch numbers pertaining to my HIV contamination.

It was further confirmed by the then, Dr M Johnson of the Royal Free Hospital.

I have some correspondence pertaining to these facts.

OTHER ISSUES :-

Other Issues cont'd

A long time was taken gathering relevant information for my case. During this time, my

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health began to deteriorate and I started my treatment with ARV medication.

The whole process was very stressful.

I was hopeful at one point about the case however, legal aid ceased.

Ultimately, the legal action did not come to any fruition because I had previously signed a waiver.

This in turn lead me to feel wary and mistrustful of seeking further legal advice.

I had been informed that the waiver would make no difference to my particular case, from the start of receiving advice.

It only left me feeling let down by the legal profession.

I would like to close my statement with the following :-

Support from the government via the benefits system, specifically ESA & PIP, in my experience, has been reduced.

This means the cutting back of PIP payment I receive.

The PIP award is not for life, as was my DLA, it is reassessed as they desire.

I now no longer have the small sense of security I had when I was receiving my D.L.A for Life.

This in turn is very detrimental to my health, both physically and mentally.

Under the rules for P.I.P I feel that I am penalised. Although I have mobility, because of Low bone density, Lipodystrophy and Peripheral Neuropathy, I suffer extreme discomfort and pain whenever I walk.

This is shown by the reduction in my award of PIP.

I believe that no credence was really given to my HIV status during my P.I.P assessment.

The side effects of ARV's are almost as much of a problem as the virus itself.

They cause serious problems which were largely ignored by the assessor.

HIV is classified as only a "Chronic" illness now.

This may apply to people contracting HIV nowadays and by using the latest medicines to control it.

In my case, I was infected 35 years ago by contaminated blood given to me by the government.

The type of Medicines used in early treatment has had serious long term effects on my health.

There is no comparison between fresh cases and myself.

I am Terminal, this WILL kill me.

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OTHER ISSUES :-

Other Issues cont'd :-

The system used for payments to the infected and affected, EIBSS, is just as convoluted

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as the benefit system.

It leaves me feeling very vulnerable.

With The Eileen Trust, there was a sense of support.

You could make a telephone call and matters could be addressed in a simple and personal manner.

By contrast, EIBSS, in my belief, is run in a way to provide the minimum amount of help available.

It is run exactly like any other benefit that you have to apply for.

EIBSS is a faceless and nameless body.

At one time, I could contact The Eileen Trust and talk to a person.

That person had an awareness of the person calling and their circumstances.

EIBSS is the complete opposite. Everyone is no more than just a number.

I believe the government is aware of this fact.

All of my benefits, ESA, PIP and EIBSS, appear to be under attack as part of a cost cutting exercise, with the sick, disabled and poor paying for it.

I have felt very unsafe living in this country with the systems that have been in place by successive governments.

It has felt like those infected with contaminated blood, also those affected, despite at least thirty years of campaigning and pressure, have been denied.

I am not getting better as time goes on, but more unwell.

I did not cause my HIV infection, this makes me have to rely on benefit systems and EIBSS.

This makes me feel persecuted for something I am not at fault for.

I take my medications to keep myself alive yet I feel punished for doing so.

The benefit system and the changes that took place within it show this by the cuts made in my P.I.P. Payments.

After being informed I was infected with HIV it has had a life long effect on me.

I have not been able to live or lead a regular life since that day.

I have been Robbed of any chance of a regular life because of contaminated blood.

As a consequence of all of the aforementioned, I am just as traumatised today as I was in 1986 when I was first informed of being HIV.

I live in Fear.

I would like my identity to be treated anonymously.

Statement of Truth

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

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Signed

GRO-B

18/06/19

Dated

18/06/19

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