

Keep

Monday 21 May 2012

**Lord Morris of Manchester** asked Her Majesty's Government:

How they are marking the 50th anniversary of the extent of the effect of the use of Thalidomide by pregnant women becoming clear; and what recent contacts they have had with the families of those affected. HL122

**EARL HOWE**

The Government expects to receive from the Thalidomide Trust the evaluation of the second year of the three-year pilot study funded by a Departmental grant shortly, and will look to meet with the National Advisory Council to the Thalidomide Trust to discuss that report further.

GRO-C

21 ✓ 12



**blood.info**

Dying for your country is one thing, but dying-BECAUSE of your country is another..

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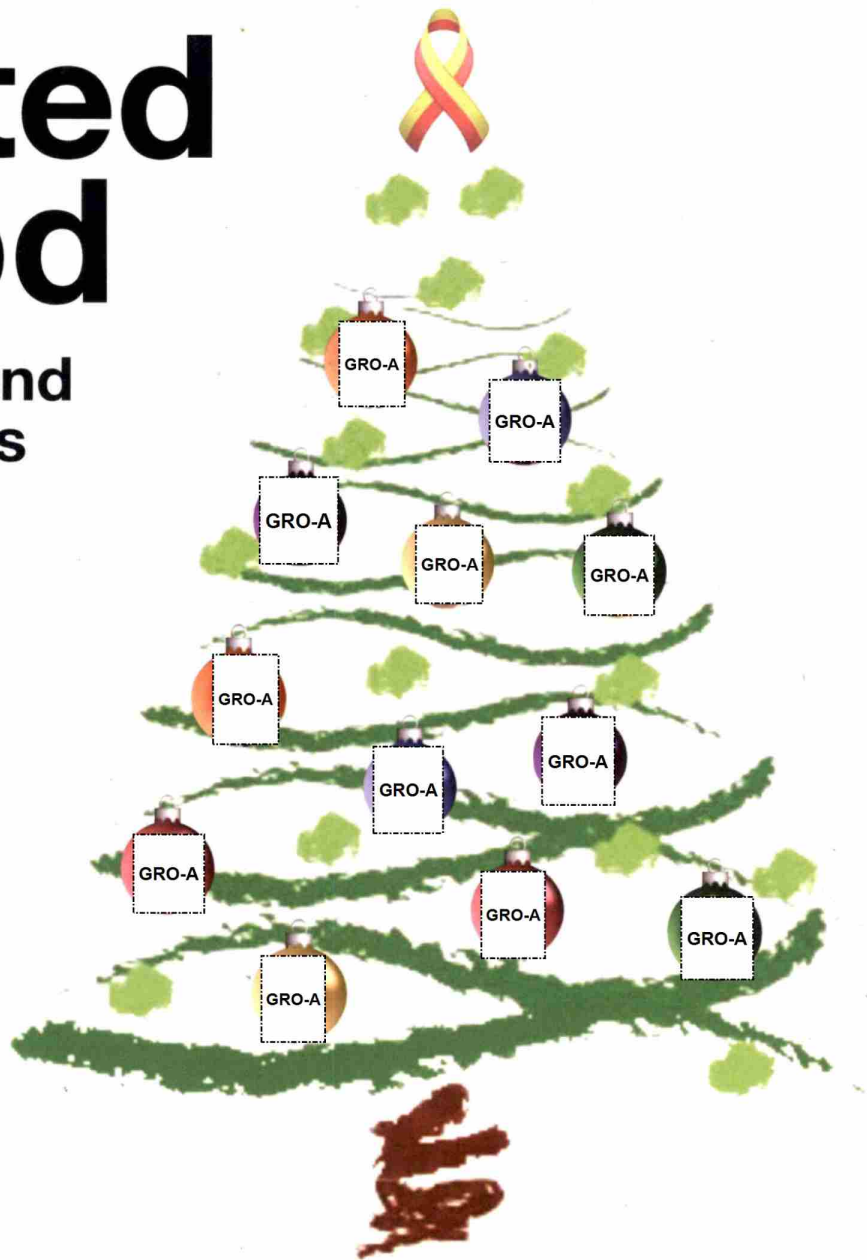
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GRO-C:  
Sue

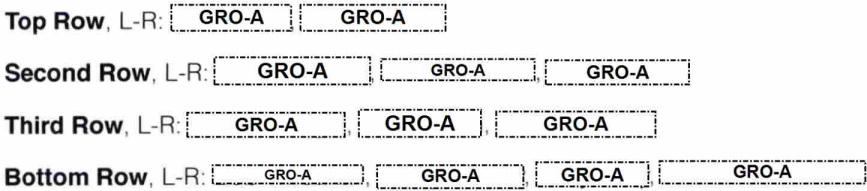
*With Compliments*

# tainted blood

Stories behind  
the statistics



# The Faces on the Tree



*Currently, on average, one or more of our group dies each and every month. Over 2000 Haemophiliacs have already been killed*



# Our people's stories

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**I was told at one stage by a council housing benefit worker to come off the treatment so I could get back to work to pay my rent...**

I would like to give a brief description of my life and how Hepatitis C has affected it.

Personally my life has been ruined by hepatitis C and haemophilia. My haemophilia was unavoidable and I accept that, but my Hep C infection was avoidable. I would like to tell you a bit about my life with haemophilia and Hep C if I may.

Throughout my school days in the 70's and 80's I was bullied on a daily basis because of my haemophilia. I was made to do PE with the girls' class because the schools didn't understand haemophilia and they thought that I couldn't do PE with the boys in case I got knocked and hurt myself. This made me an obvious target for bullies. Also in the early 80s there was the issue of AIDS and HIV, all the papers and media at the time were tagging AIDS to haemophilia and so this made me a very big target for bullies. Friends stopped playing with me and stopped inviting me to their houses and would not come to me in case they caught AIDS from me even though I was lucky enough to escape HIV infection.

When I was diagnosed with Hepatitis C in 1995 I was told that I had Hep C antibodies in my blood and that I would be ok but the doctors didn't really know much about it, I was scared and confused. I didn't know what was in me I had no counselling, nothing, I was just left alone not knowing anything. I decided to do some digging about my infection, I got all of my medical records and found out that I had been tested positive for non a Non-A, Non-B Hepatitis in 1984 and was not told until 1995 some 11 years later. During these 11 years I was a typical teenager and used to go out drinking weekends not knowing I was slowly killing myself because they had not told me of my infection. It makes me very angry that I was tested for this virus secretly and not told of my infection.

Hep C has had a major impact on my life since 1995. Socially it is not accepted and there is a big stigma attached to it I have lost friends because I have told them of my infection. They have looked at me as if I am some drug addict. Also the financial side has been awful; I drive a black cab for a living on a self employed basis so I can come and go as I please when I feel well enough. I only work a few hours a day just enough to get by on and pay my bills, I get very tired very quickly so don't do a great deal. People like the Inland Revenue and the benefits office don't seem to understand this because they see that I go to work so I must be ok.

I have been made bankrupt because I had a stage where I was off work for a long time and couldn't pay my bills but I didn't get any benefits because I don't earn enough to pay my NI stamp, it just goes on and on for us.

In 2007 I started interferon and Ribavarin treatment for my Hep C infection and during this time I was off work for about 6 months, I applied for benefit but because of the long process of them investigating my case I fell behind with my rent and the council took me to court for non payment of rent and charged me £100 in costs. I did not get any sickness benefit because the treatment was meant to be making me better so I couldn't be ill. The truth is that the treatment has some serious side effects but the benefits agency does not recognize this. I was told at one stage by a council housing benefit worker to come off the treatment so I could get back to work to pay my rent, my nurse wrote them a stinking letter about this. I finally got partial benefit two weeks before I came off the treatment. Incidentally the treatment did not work so I still have this infection in me.

I am now just getting myself straight again financially nearly 18 months after coming off treatment.

The Department of Health do not see this side to our lives; if they did would they still deny any wrong doing?

I got so frustrated a few years ago after writing to politicians and the Prime Minister Tony Blair at that time and being given no answers by them that I wrote to the Queen. I did get a letter back but she didn't seem interested either.

**GRO-A**

# Anonymous

We both would have loved to be parents

*I am a 54 year old haemophiliac who contracted HIV and Hepatitis C through my NHS treatment. I have since been exposed to vCJD and probably to other viruses and pathogens. I believe passionately that Lord Morris's Bill should be made law. After many years of trying to live and deal with these diseases I am not mentally able to cope with being at Westminster but I want my voice to be counted. This is my story as told by my wife* GRO-A

We cannot remember the date (summer 1985 we think), but we will never forget the day. Having been summoned to the haematologist by his secretary one week earlier by telephone with the fateful words 'It is nothing to worry about', we found ourselves waiting for two hours outside his door. When he finally went in he was given the news of his acquired HIV status as I sat outside, not being allowed in with him, which now seems incredulous, as at this stage we had been living together for 7 years. We drove home in shock and I then had to leave him to work a late shift, where I performed my duties as a nurse, that day solely on automatic pilot.

The first couple of years after this we watched bewildered as young men in the clinic with the same death sentence passed away. At this stage he was well and the full impact of the disease did not hit us until he developed shingles and was admitted immediately with great panic by his doctors to hospital. On that day the awful realisation hit home and the sick feeling of fright welled up within us as we realised that he could die so easily from any of these opportunistic infections.

That grip of fear in twenty five years has never gone away for us as so frequently one problem follows another or causes another. He spends so much of his precious life in hospital waiting rooms, as the doctors juggle with all his "NHS acquired" diseases. The doctors all marvel at his positive attitude and great ability that has managed to get him through so many close shaves with his life, but they do not realise how very frightened by the condition he is. So frightened that he cannot even speak to me about it in any detail after 30 years of being together, I suppose it becomes so real if you talk about it and then I do not think he could cope.

Some of his condensed medical history is as follows:

- Severe haemophilia, with reasonably controlled HIV disease at present, having had varying drug regimes for many years. At present viral load is just detectable.
- 1996 – due to his immunocompromised state he developed a bowel abscess causing peritonitis and was given at time 10% chance of survival. But survive he did and after four months in hospital came home essentially to die as a large open abdominal herniated wound from surgery was not thought repairable. Eventually after three months of intense pain and immobility a successful skin graft took place in London. Then followed years of a long and hard battle to recover. 14 years on he still has a large unsightly heavy abdominal hernia and a colostomy which they will not attempt to surgically correct because of his many health problems.
- In 2001-2002 Hepatitis C was officially diagnosed although present apparently for many years prior to being told. He has significant liver scarring but presently is clear of Hepatitis C active virus due to successful treatment with Interferon.

These illnesses and many others to numerous to mention have all taken their toll on David now. Physically and mentally, he is quite frail which is so tragic as before this he was always so strong and positive. Due to his ill health he has not worked since 1996, which is of great sadness to him as he enjoyed work and being with people in his job. He has found depending on me very hard and worries constantly about the pressure on me to work full time and care for him when he requires it.

He and I have been together 30 years and married nearly six years. We were in our twenties when he was diagnosed and we have spent our lives since then sitting on the outside of normality. We have watched longingly over the years as our brothers and friends have had their families and all the joys that ensue from that.

When he was diagnosed in the mid eighties there was no treatment available to safely have children, we were just told we could not have them. We both would have loved to be parents. Now of course as we are older we see our friends now as grandparents and how their lives are so full with love and purpose with their extended family which brings all the hurt and sadness back again.



In the twenty five years since his diagnosis the only people who know of his HIV status are his mother, my parents and our two brothers. None of our dear friends who have supported us through so much have been told and if they have guessed over the years they have never said.

This has been his decision from the outset not to discuss this and I have no choice but to respect this as this is the only control he does have on this awful disease, who he chooses to tell and who not.

However this has caused so many feelings of isolation for both of us over the years particularly at crisis time when you cannot tell people the real reason why you are tearing your hair out with worry.

The little energy he has left he tries to use on getting some sort of quality. He is not able to cope with writing evidence for this but is quite happy for me to write this statement which he has read and agreed with.

Having watched his great suffering and marvelled at his endurance over the last twenty five years I remain very angry that the people responsible for this tragedy have not appeared to comprehend the enormity of what was inflicted on these innocent people all those years ago.

With their great indifference to us it continues to this day to make us feel as human beings totally irrelevant and invisible in our society.

Thank you for reading this and to those of you who strive so hard for us for justice to prevail we thank you so much.



**This nasty, nasty, disease has completely shattered my life.**

I'm 44 years old and live in GRO-A Surrey with my wife GRO-A and two daughters.

Up until the end of November 2008, I had quite a senior position within United Biscuits (McVities) where I worked in the international part of that business. My team managed roughly half of the world and I was lucky enough to get to travel all over the place. I thoroughly enjoyed my job, had a great time and have made some truly great friendships along the way. Unfortunately, I was pensioned off at the end of 2008, on the grounds of ill health.

I was mild haemophiliac and was lucky enough to only require treatment as a result of sporting injuries or when I had surgery. Before my infection with Hepatitis C in 1982, I had only had 1 course of Cryoprecipitate. My liver function tests in 1982 prior to treatment with Factor VIII were perfect. Why I was changed from Cryoprecipitate to Factor VIII in 1982 is beyond me. There was no discussion, no dialogue, no consent. The three treatments of Factor VIII that I had prior to heat treatment being established in 1985 were for teeth extraction and minor muscle bleeds caused by playing football. None were for life threatening situations.

I found out that I was Hepatitis C positive in 1996 when I was 28 years old and already had cirrhosis at grade 5 (on a 5 point scale!!) I thought I was just unfit but didn't realise that my exhaustion was as a result of the Hepatitis C. I was lucky enough to be able to carry on working as thankfully, I was not in a physical job - the brain seemed to continue to be working, even though the liver wasn't!!

I was treated with Interferon and Ribavarin which did nothing except annoy me. I was injecting every other day so continually felt ill. I had the usual flu-like symptoms and felt generally ropery. Unfortunately this treatment didn't work and I was eventually told in early 2000 that I would need a liver transplant. I literally went to pieces. I had previously been a very active sporty, energetic type, despite my haemophilia and was now reduced to being a wreck.

I ultimately had a liver transplant was in 2000 and thankfully I recovered relatively quickly. I was back to work in 14 weeks post transplant and eased myself back into work. UB were fabulous to me during that time, and I was very, very lucky to have an understanding and caring boss. The transplant meant that I could do things I had written off being able to do. The family all learned to ski together. My daughter and I learnt to scuba dive. I started sailing, had a go at paragliding - in fact, I had a new lease of life.

All went more or less ok until the early summer of 2007. Lumps were found in my liver at a routine scan. I was put on the transplant list again as it was suspected that I had developed cancer. I was advised that it would take four weeks or so to get a liver as cancer patients went quite high up the list. Eight months later I had the second transplant, in April 2008. Surgery went well but the Hepatitis C came back very aggressively. Things were not looking good.

The doctors at Addenbrookes put me on peg Interferon and Ribavarin which has thankfully controlled the Hepatitis C for the time being. I came off the combination therapy in February 2010, which was 72 weeks of it. I felt like I had flu and was extremely tired most of the time. I also had an almost constant run of infections and minor complaints, which became very, very irritating. There are times when I struggle to get out of bed in a morning as I just can't be bothered.

As I understand it, I was the fourth person in the UK to have the combination treatment post transplant. One of the first three didn't make it, so as I mentioned, it wasn't looking good. The lumps were confirmed as being cancer after the transplant. Cancer cells were found in the blood vessels of the liver, meaning that they might have got out, circulated around my body and started again. I have a CT scan every five months to check to see if the cancer has returned and thankfully all is clear for now.

At the end of 2008 UB started the process to pension me off. I had the option to challenge this but given the circumstances and my state of mind, I think it was best for all that I took it. I couldn't work then and can't do so now, as I get too tired. Retiring was the only viable option that was open to me.

There is a huge difference between my salary when I worked, and my pension. We have had to change our lives from top to bottom. It now means that I cannot do what I wanted to for my family, but we are all still here, so I'll count my blessings. I also believe I am in a better position than so many others infected similarly infected, so I try not to go on about my lot, too much.

I am lucky that I did not get HIV. I am lucky that I was able to continue to work until relatively recently. I am lucky that I get a pension from the company which means that we can survive (survive, not live !!)

I am lucky that we have been able to stay in our family house although should the need arise we will have to sell up and move to somewhere less expensive. I am lucky to have a caring and supportive wife and family. I am lucky to have two great kids who just get on with things without seeming to let our circumstances affect them. I was lucky to have had two transplants – unfortunately I've been told that there won't be another should the need arise, but we'll fight that decision as and when.



This nasty, nasty, disease has completely shattered my life. I have gone from being a fit, active man to someone who can just about manage day to day. I have gone from having a senior role flying around the world and thoroughly enjoying life, to a being a retiree at the age of 42. I have gone from having a relatively good income to scraping about to make ends meet.

I have gone from being able to provide for the needs of my family to not being able to do so.

My eldest daughter is now at university and I am not be able to provide any financial support for her which upsets me tremendously. Realistically, if I make it to the age of 50, I will be lucky.

This is the impact that this wholly avoidable infection has had on my life.

Whatever the reasons are for changing me from Cryoprecipitate to Factor VIII when I was 15 years old, has had the impact of ruining my life.

**GRO-A**

There was no discussion, no dialogue, no consent.

This disease has completely shattered my life.

If I make it to the age of 50 I will be lucky.

**GRO-A**

- aged 45 - victim and campaigner

GRO-A

GRO-A was a valued and hard-working member of the Tainted Blood committee from 2007 until his death on 12th March, 2009. He was a haemophiliac and had been infected with HIV and Hepatitis C through contaminated NHS blood products.

He took on the role of treasurer and then dedicated himself to becoming full versed with the history of our campaign. He diligently read through many of the documents we accessed, determined to fully understand and interpret everything in them.

He often came up with incisive comments and a whole new slant on things. He never hid the fact that he was very angry about what had happened to himself and others, and was willing to do whatever it took in order to achieve truth and justice. Although Lord Archer's report was published before GRO-A died, sadly he did not live long enough to see everything he had fought so hard for come to fruition.

Hopefully he realised that we will never give up until we achieve our aims. GRO-A had a great sense of humour and until his recent ill-health our phones were often buzzing with his latest joke. The phones and the campaign are quieter and sadder following his passing.

Rest in peace, GRO-A

GRO-A

Greed and cutting corners for shareholders, only  
ever leads to one thing - the most vulnerable pay.  
...and in this case, with many lives !

GRO-A - died 2009

10 Tainted Blood

# A Wife's Story

The sister said that it would be preferable if [GRO-A] could be transferred off the ward for the safety of other patients.

I lost my husband, [GRO-A], just after his 35th birthday on [GRO-A] 1985. He was a severe haemophiliac and contracted the Aids virus due to contaminated blood imported from America by the British Government. I was widowed at the young age of 32 years, and left alone to bring up two daughters aged 11 and 9 years respectively.

I nursed [GRO-A] prior to his death, both at home and in the Royal Liverpool Hospital. In 1984 his health started to deteriorate, and he underwent surgery in the Royal. From then on his health began to rapidly deteriorate due the contaminated blood transfusions and treatment of Factor VIII. For almost two years I practically lived at the Royal Liverpool Hospital, on and off. I had no choice but to split my two daughters up and send them to live with separate relatives so that I could look after [GRO-A].

In the early days [GRO-A] was on a mixed ward and was suddenly moved to a side room on his own. When questioned about his sudden move, I was informed that they suspected he had contracted a virus and asked me to wear protective clothing.

The symptoms [GRO-A] started to display were: rapid loss of weight, vomiting and becoming delirious. When I questioned the Consultant at the time, he informed me that it was just a virus and they were testing him for salmonella and the side effects of the drugs were causing him to become delirious.

At this point of time, the Consultant requested that I also be tested for salmonella. Tests were carried out on me on three occasions.

I read a couple of articles in the national newspapers about the symptoms of the Aids virus and it appeared that [GRO-A] had all these symptoms. He was sent home from hospital for a short period, with a District Nurse in attendance. The nurse only attended on two occasions and then refused to visit the house and asked me: had the hospital not informed me of what [GRO-A] had got?

With this, I was left to care for [GRO-A] changing his clothing and bedding due to loss of body fluids. I realised [GRO-A] was deteriorating and called for an ambulance, and he was again taken to the Royal Liverpool Hospital where he remained in isolation in a private room. All visitors were made to wear protective clothing.

At this stage I made an appointment to see a Consultant and begged him to tell me if [GRO-A] had Aids. He informed me that he had not got Aids, and that there were lots of different viruses, and to desist from telling him his job, and stop being neurotic, to go home and get it out of my mind.

I decided to stay with [GRO-A] most of the day and night, due to the staff not wanting to go into the room to feed him and give him drinks. On occasions I was not present, drink and food was left on a trolley outside his room and [GRO-A] was left unchanged, lying in a dirty bed in his own body fluids.

One evening [GRO-A] had deteriorated and I asked a Ward Sister if [GRO-A] had got Aids, because I had seen Doctor Pinching from St Mary's Hospital in London, on television, describing the symptoms of Aids.

The sister said that it would be preferable if [GRO-A] could be transferred off the ward for the safety of other patients. A short time later a junior doctor approached me to inform me that [GRO-A] had contracted Aids and that he could not understand why I had not been told earlier.

That evening my life had been turned upside-down, and my brother-in-law and I drove down to London to see Dr Pinching to see if could help [GRO-A] and transfer him, but unfortunately he was attending an Aids conference in Brussels. I spoke to Dr Pinching by telephone and he confirmed that [GRO-A] symptoms were conclusive of Aids. Later, Dr Pinching contacted the Consultant regarding this matter and I was shunned by the Consultant for going to London.

All our lives have been shattered by [GRO-A] tragic death. Had I known the full circumstances and truth of [GRO-A] illness and the cause I feel I would have been able to cope and plan our lives a lot better. By keeping this knowledge of Aids under wraps it put me and my family at an unnecessary high risk.

I feel the way we have been treated by the British Government is gross negligence and betrayal. I have had to work hard all my life to put my two girls through their education, and I now have a grandson who is also a severe haemophiliac, bringing all the memories flooding back, hoping that history never repeats itself.

[GRO-A]



# A Daughter's Story

Dad's death, even today, evokes feelings of anger and sorrow, knowing that he died through pure negligence on behalf of the Government.

I was aged nine when I lost my father **GRO-A** **GRO-A** through contaminated blood products. During my childhood I spent much of my time visiting my Dad in the Royal Liverpool Hospital. When Dad's health deteriorated due to the HIV attacking his immune system, my mum decided that it was best I didn't see Dad in the condition he was in.

Mum considered my young age and how I may not understand what was happening to Dad. I was sent to stay at my Aunty's and I returned to a broken family when Dad died on **GRO-A** 1985, at the age of 35. Mum then had to cope with not only the loss of my Dad (her husband), but had to support two children, alone, at the age of 32.

As any young girl, I always wanted to have and do the things my friends were doing; not understanding that they had two parents to financially support them, compared to my one. Mum struggled, and it is only now, at the age of 33, that I myself can understand how hard it was. I am also now a single parent and have a four year old son with severe haemophilia.

Dad always wanted the best for us, including education. Mum struggled to financially support me through both of my degrees. As in many families today children are financially dependent on their parents for longer and I now, at the age of 33, often ask for financial help from Mum. Although Mum tried hard, working away and for long hours, I had to fall back on student loans.

I did achieve both Dad's goal and my own, becoming an art teacher. However, this career has had to be placed on hold. My son, **GRO-A** is now 4 and has severe haemophilia and I have to inject him three times a week with Factor VIII. I have had to become my son's carer and have to be on hand to treat him as required. It has been hard trusting the NHS and I sometimes feel uneasy injecting my son with Factor VIII after losing my Dad through contaminated blood.

Dad's death even today, evokes feelings of anger and sorrow, knowing that he died through pure negligence on behalf of the Government. I try not to research the contaminated blood issue, as I do not want to be consumed by anger, and I also have to support and reassure my own son.

My family have suffered so much financial and emotional stress, and I fully support my Mum's and other victims' fight to gain answers and deserved compensation.

**GRO-A**

## GRO-A

GRO-A was an active member of the TaintedBlood committee until his unexpected death in December, 2008.

After receiving HIV-infected blood in 1986, during his treatment for AML Leukaemia, GRO-A began campaigning for justice and continued to do so right up until his death.

His heart was weakened by anti-viral drugs, yet despite suffering two heart attacks he still worked tirelessly for all those infected and affected by HIV as a result of receiving contaminated NHS blood.

He was a particular ambassador for those who, like himself, who were not haemophiliacs. He gave evidence at the Archer Inquiry and was passionate about the Scottish Inquiry.

As well as being a strong supporter of TaintedBlood, and an active committee member, GRO-A was also Chair of the HIV Blood Transfusion Group and a member of the Eileen Trust. He once said: "We have been given a life sentence without parole, while those who are responsible have continued their high flying careers".

**Rest in Peace, GRO-A.**

GRO-A

We have been given a life sentence without parole, while those who are responsible have continued their high flying careers.

GRO-A - died 2008

**I told the doctors on 15.12.2003 that I didn't mind if I died and I asked them to stop all treatments**

I am a severe haemophiliac with less than 1% clotting factor and treated at Addenbrookes, Cambridge. There are not many people in this life who are put on to Palliative Care who recover and go back to the hospital get their notes and digest them. I am that person.

I am very lucky as I was not infected with HIV. My wife and I have four very healthy sons. I was born in **GRO-A** Scotland in 1952 on a poor council estate. My father was a railway clerk and my mother could not work as she had two severe haemophiliac children. I was treated at The Royal Hospital for Sick Children Glasgow and Glasgow Royal Infirmary until I moved to England for work in 1985. I had been a civil servant and was promoted but could not find a post in Scotland. I left the civil service in 1990.

My knees, ankles and elbows are wrecked with haemophilia and I walk on my toes. I have a 30 degree curvature in my left leg. Basically I can hardly walk and I have to go down stairs backwards. Standing up from sitting is difficult and I resemble a half shut knife. I am in constant pain and take Fentanyl patches and lozenges to kill the pain and these drugs are usually associated with pain associated with terminal cancer.

Unfortunately if I do not take them the quality of my life is very poor with the pain from my joints and walking. The pain is at its worst in the evening and night.

I was infected with hepatitis C at Glasgow Royal Infirmary. It eventually became chronic and in 1996 they wanted to treat me with blind interferon but on reading the side effects I said no. However by mid 2002 the progression had become so chronic that they wanted to treat me with Pegylated Interferon & Ribavarin which was the common treatment in 2003 and still to this day. It was put to me by the hepatologist Dr A that if I was not treated then I would probably develop Cirrhosis and he spelled out what that would do to me.

The side effects of Pegylated Interferon and Ribavarin are not at all nice. These are expensive drugs probably £20,000 for the drugs alone and I think you know that these come from Roche/Schering Plough.

The support in the UK is terrible from the hospital and non existent from the drug companies. The side effects they told me about were fatigue, pyrexia, headache, irritability, and nausea. These are the common ones and they wrote to my GP on 12th February 2003 saying that if I have side effects I should take paracetamol should these be a problem.

I am sorry to be sceptical but I have found that Roche Pharmaceuticals have Important Safety Information on their web site in relation to Pegasys and Copegatus combination therapy:

Fatigue/asthenia, headache, pyrexia, myalgia, irritability, anxiety, nervousness, insomnia, alopecia, neutrophenia, nausea, vomiting, rigors, anorexia, injection site reaction, serious and severe bacterial infections ( sepsis ), hypertension, cytopenia, thrombocytopenic purpura. Also that extreme care must be taken to avoid pregnancy.

Other web sites show Ribavarin to be Teratogenic even at doses of one six hundredth of those generally prescribed and even small amounts of seminal fluid could be dangerous. It is recommended that women of child bearing potential and men should use two forms of contraception during intercourse while undergoing treatment and for six months after treatment has concluded. Women of childbearing potential also should take monthly pregnancy tests and also for 6 months after. I was not told of these serious adverse effects or pregnancy risks and my wife was of childbearing age. The US Food & drug Administration has assigned Ribavarin to pregnancy risk X (positive evidence of human fetal risk outweighs any possible benefit )

My story is quite different. I am a survivor of Hepatitis C having been treated with Pegylated Interferon & Ribavarin and although the virus has

cleared the treatment had devastating effects which the hepatologists did not tell me about . Because so many haemophiliacs were treated with Pegylated Interferon & Ribavarin I think we should be heard. All of this was revealed as I inspected my hospital records at the Haemophilia Centre on 4th May 2007 so that I could write to the Archer inquiry ( I suspect that part of the records relating to hepatology has been removed and I wrote to them on 7th May 2007 asking to see these) The hepatologist never replied.

By the autumn of 2002 (26.09.2002) the hepatologist wrote to my GP saying that I had chronic hepatitis C on a background of haemophilia and that my liver tests over the last 12 months had been markedly elevated and more so in the past. I was of course HCA RNA positive by PCR. Ordinarily they would have wanted to perform a liver biopsy but this was not possible because of my high level of Factor V111 inhibitors. Here is what I am complaining about; that they did not tell us and still to this day are being fobbed off with statements such as: '...every drug carries some risks.'

In the US Schering Plough have nurse support lines, available 24 hours a day called "Be in charge" and Roche have a similar program called "Pegassist" enabling patients to speak directly with a nurse specialist regarding any difficulties they are having. We don't have that here in the UK. I am thinking we are the poor relations in the UK. I was started on the above treatment on 12.2.03. I visited the clinic every month and had my full blood count monitored. By



June I had lost 4kg weight and by July I continued to lose weight had haematuria and some nose bleeds. By September 2003 I was well but tired an ultrasound showed a normal size liver, no focal lesions, no ascites my spleen was 9CM. My right kidney was grossly hydronephrotic with cortical thinning. I was unable to obtain an erection.

In November 2003 I had very terrible haematuria and I had a bad fall and felt very low. Due to the fall I was so weak they gave me a blood transfusion but the Ribovaritin was not reduced as they thought the blood loss was due to the fall. On the 4.12.03 at the hepatology clinic I was tired but I told them I felt better after my transfusion. Things started going bad on 5.12.03 I felt most unwell and took to my bed and stopped eating. Over the weekend things got worse and I had spontaneous multiple major bleeds. Several times on the Saturday & Sunday I was so unwell my GP was called and gave me morphine injections.

Here is what happened then to treat my Septicaemia.

- Admitted to hospital by ambulance
- Joints painful & swollen – temperature 39.4°C
- Oramorph – Diazepam for muscle spasm
- Titrate diamorphine infusion
- Commenced IV Antibiotics – BenPen & Flucloxacillin
- 9.12.03 Palliative Care Commenced.
- Diamorphine titrated further upward
- Breakthrough dose of Oramorph 60mg

- Started on Clonazepam
- Entenox, Diazepam increased, Diamorphine increased
- Growing 2/3 gram + cocci in chains?
- CXR overloaded
- Platelets 88 underlined
- Tachypnoea up RR30
- Only few creps in chest
- Rheumatologists will aspirate joints post febrile.
- ITU outreach will transfer to HDU
- Continue benzylpenicillin
- On 11.12.03 the hospital sent for my wife and asked for her to come as soon as possible. The haematologist explained that I had septicaemia with thrombocytopenia and multiple joint bleeds and that I was being moved to the High Dependency Unit and that I probably had septic arthritis.
- 11.12.03 transferred to Neurosciences Critical Care Unit
- The Consultant thought I might not survive the next 24 hours
- I Responded well to furosemide.
- Transferred back to the ward
- Very ill and pyrexia until end of December 2003
- Told Doctors on 15.12.2003 that I didn't mind if I died and asked them to stop all treatments
- MacMillan Nurses offered and refused.

My hospital notes are voluminous. I have copies. They managed to get me out of the bed with a hoist about 20.12.2003 and by the beginning of January 2004 I was beginning to feel a little better and able

to get out of bed with a banana board onto a wheelchair for hydrotherapy. On 8.1.04 they moved me to a rehab ward and I recall being visited by two Social Workers about 10.01.04 who came to assess me. I overheard them saying to the medical staff that they thought I would never walk again and that I might have to go into a care home. All of my joints were still sore & swollen and I had on demand oramorph and MST 4 times a day.

My weight had fallen from 11 stones to 6.5 stones and consistently I refused every meal consuming only coca cola and eccles cakes from the hospital shop. I had unbelievable constipation having not opened my bowels since 25.12.2003 until 16.01.04. I had to be manually unpacked. I was so weak and joints so sore I could not stand. The R elbow bleed and the way I was lying in bed resulted in a claw hand which I could not open. It was very hard to get them to do anything about the hand as they probably thought I would not survive.

They forgot one thing and that life for severe haemophiliacs is a constant struggle and it has made this group of persons very stubborn and they do not give up. The rehab ward was the worst place I had ever been in my life I do not want to go into detail as it is so upsetting. I heard from patients it was popular for them to go home for the weekend and when I asked them they agreed to this in mid January 2004.

An ambulance, wheelchair, commode and bed in the living room were arranged but I could still not stand or weight bear. I had escaped – I did not return. my wife who is a Registered General Nurse working in Radiology but in a different hospital agreed to nurse me without any assistance. You will be wondering how I ever got back on my feet. Well there was a sofa near my bed and I dragged myself to my feet and gradually by the end of March 2004 I could walk with 2 sticks but permanently on my toes. My walking is now terrible for obvious reasons but I have not given up.

GRO-A

## After being discharged from hospital my life never was the same.

I was born in November 1970. In 1977 I was diagnosed with having Haemophilia A, which is quite unusual the Haemophilia Doctors said to my mum, that is because I am female, but I have the family history as my dad is a Haemophiliac. I was diagnosed because I had a large haematoma on my eye where I had an accident at school.

I loved school, had loads of friends at school and out of school, went horse riding, did ballet and loved riding my bike, I was so proud that I had learned to ride my bike without stabilisers, I also loved swimming I swam at school, and went to lessons out of school it was something I really got into, and excelled in.

In 1978 I needed a tooth extraction and the Doctors said I would need to be covered with treatment, I was treated with Cryoprecipitate, the tooth was taken out and I recovered well.

I started to suffer with perforated eardrums and I was in a lot of pain and discomfort, even now I remember my mum taking me to the GP and he gave me a tablet, and it took away the pain. Oh, I was happy not to have that pain for a little while. I was referred to an E.N.T. specialist and it was decided that I should have my tonsils and adenoids removed.

Whilst on the waiting list and waiting for a date for my operation, I was out playing football one afternoon, (Blimey... football, those were the days!) anyway I only went and slipped in some mud and broke my arm!

My parents took me to the Royal Free Hospital, for obvious reasons, and I had a collis fracture, so I had to have treatment, I had Factor VIII; quite a few hundred units of Factor VIII. I was in hospital for quite a few days, it was awful really, because the Royal Free is not 10 mins up the road from where we lived, it was a good hour's journey, so I didn't get many visitors, apart from my mum and dad of course. Actually I don't even remember my brother visiting; he was probably enjoying the peace!

Not long after being discharged I was admitted again into the Royal Free, and I had my operation, they said my adenoids were large, funny what you remember, anyway again I was treated with Factor VIII, nothing was said to my parents except the normal so to speak, having treatment to reduce the risk of bleeding, etc, etc.

I had quite a bit of treatment, thousands of units actually, fancy not informing my parents of the risks of the treatment they were giving me, terrible don't you think? I mean really how would you feel if that was one of your children?? At least you could have been given had the choice.



After being discharged from hospital my life never was the same. Remember earlier where I said what I liked to do? Well those things never happened again. No riding my bike, playing football, swimming, horse riding or general playing with my friends, no none of that, actually what happened to me you would never believe ( well the Doctors didn't anyway). I took to my bed, yes nine years old and I would sleep, I would come home from school and go to bed till the next day, I also had terrible skin patches and itching; God the itching was awful. I even blew up like a balloon never really understood that, as I was hardly eating because all I did was sleep every chance I could.

I had pale stools, felt sick all the time, as well as all that my school work went downhill and concerns were raised by the school, I couldn't concentrate and my memory was terrible. My mum was really concerned, any parent would be really. She took me back to the Haemophilia centre and asked the Doctors what had they done to me. The Doctors said they had done nothing, my mum told them all the things that were wrong with me and how I had been but they just shrugged their shoulders.

Mum never got any answers, but she took me to the Haemophilia Centre a few times wanting answers. The Doctors used to run in their office when they saw her. (All a bit obvious now) My mum knew her daughter was not right, (when it comes to your children you get a sixth sense.) but what could she do? Nothing really as you put your life in their

hands and trust them (not anymore and never again will I ever trust a Dr). As I said earlier about my weight, it continued to go up, I look back now at the photos before and after treatment and honestly it's like someone's stuck a bicycle pump in me and pumped me up, it's not even a normal looking fat child, I literally look bloated.

Because of my weight the hospital admitted me for the 6 weeks summer holidays, cruelty really but I wanted to be normal again so I went. Anyway I was ten at this stage and they put me on 500 calories a day. Some days I didn't eat; why? Because I would rather sleep. At the end of the 6 weeks I lost an amazing 3 lbs! Yes 3, you know what the hospital said to my mum and dad? "You must have been bringing her food in" Well fancy saying that to them.

Looking back now, they knew what was wrong with me, in fact they probably had me in hospital experimenting on me (Because they had done that already hadn't they?) It's all obvious now; I was a PUP (Previously Untreated Patient).

As the years went on I didn't change much, teenage years with me for my mum weren't too bad because I slept all the time. I would come home from school and sleep, the next morning my mum would wake me, I would get ready for school, then when she had gone to work, I would go back to bed. Most teenagers bunked off school to have a laugh, not me I would bunk off to sleep.

Oh, did my body hurt too! I really can't explain that, I actually suffer the same now.

Going through to adulthood I worked, it was a struggle but somehow I did it, I didn't have a great sickness record, but hey you can't have it all when you feel as bad as I did. I went to see the Consultant Haemophilia myself to say how terrible I felt, and do you know she put me down as being mad – well, having psychological problems; were the exact words. The same Doctors had documented the same words when I was 10; that's all after having Factor VIII.

Do you think that's an awful thing to say about a 10 year old little girl? I do and as I type this I'm crying because of the constant mental torture of what has been done to me, 30 years on and nothing has changed. Yes I'm bitter about it all – blimey, you can't blame me can you?

I had to have treatments as I grew up for various things, like bleeds in my arms and ankles, wisdom teeth out just to roll a few off my head, then in 1995 I was having treatment for an ankle bleed, my mum had seen on the news about Haemophiliacs contracting Hepatitis C, so whilst I was having my treatment I asked the nurse "Have I ever been tested for Hepatitis C?" she laughed and said: "You won't have that!" I'm losing count of how many times I've said this especially to the Skipton Fund. Back to the point... the nurse then gets my notes and says: "Oh, you were positive in 1991",

well I didn't really know much about it so I sort of said "oh, right". So that's 4 years never being told I had Hepatitis, actually I was never told that I was being tested for it, but what do you expect? I have Haemophilia so they can do what they want, least that's how they used to be. The nurse then arranged for me to see the Haemophilia Dr, who brushed in and said to me "you're Hepatitis C positive, but don't worry about it, as we don't really know much about it, and it might not affect you for many years". Like a fool I believed her.

I had bloods taken and that was it really; I carried on with my life as well as I could, taking time off work when needed due to not being well. Funnily enough I worked for the NHS and as there's a lot of sickness there so it wasn't really noticed.

In 1997 when I was having a review with another Dr at the Haemophilia Centre she took bloods for Hepatitis C, and they came back negative, she said I had cleared the virus naturally, lucky me, even with all I have and had suffered, I was lucky I never contracted HIV like many other Haemophiliacs had. I even remember in the early 80's when it came out about HIV/Aids, did you know it wasn't the thing to say you had Haemophilia because of the stigma attached to AIDS was terrible. I would hate to think about all those boys and men fearing for their lives, and then to top it all fearing what other people thought. Pig ignorant people were back then - come to think about it they're not much better now.

In the late 90's I met my husband to be, I told him all about what had happened to me and the Haemophilia, he was fine about it all and has been my rock, I had my daughter in 2002, and sadly she has Haemophilia, then in February 2004 when I was expecting my son, I got a letter through the post from the Royal Free Haemophilia Centre, It waffled on about vCJD, and then went on to say that I need to inform dentists etc for public health purposes, I put the letter away and thought to myself oh another thing to add to the collection, I was nearly 6 months pregnant when I got that letter, have to say the care side is none existent when you're a Haemophiliac, no airs and graces for us, not even treated like a human really. You do sort of get used to it, especially the bits when the Doctors and nurses roll their eyes up.

After having my son in May 2004 a bit later that year John Reid announced the Skipton Fund, I read about it and its criteria and could see that I met the criteria, so I made an appointment with my GP and he agreed that I should apply once the forms came I applied and my GP filled out the bits that were required, straight forward so I thought, the Skipton Fund wrote to the Haemophilia Consultant at the Royal Free, her name was Professor xxx, bit like a School head mistress I never did take to her, she was funny with me when I told her I couldn't urinate whenever I took Tranexamic acid, she told me not to be so silly, just another little example for you, still what would I know I'm only the patient, after all she is a Professor.

Basically she filled out the application form and wrote that I was a natural clearer, she didn't answer some of the questions, I will get to why I don't think she did later, but at the moment there is other stuff you need to know, I got a reply from the Skipton Fund and I was declined, yep the computer says no and all that. To say I was shocked was an understatement I couldn't believe it, how could this be? I met the criteria and they say no, still as the years have gone on I've noticed how good they all are at back tracking.

That was in 2004, what could I do? Well nothing really and so I sort of plodded on with my life and my family. In November 2004 when my little boy was six months old he had blood all over his bib where he was teething, the Royal Free did tests and he too has Haemophilia, its odd really as I knew the chances were going to be pretty high as he was a boy, I was still so devastated when they told me; two children both with Haemophilia, still I thought there are people worse off than me, and surely to God they will never have to go through what I have been through, all will they?

I was still searching for answers as to how poorly I always felt, then in 2007 I was put on steroids, I was finally diagnosed with undifferentiated connective tissue disease, I was put on different types of medications to help, but none did, so once again I plodded on, going on steroids every now and then to bring down the inflammation in my body. The Doctor told me my body is fighting something and



has now basically turned on itself. I'm not a daft lady, and I think anyone would have thought the same as I was thinking - can you guess?.

In 2008 I was looking on the internet about Hepatitis C, and somehow I came across Taintedblood, oh my was that an eye opener, I feel daft to say it now, but at the time you think you're the only one, I read the stories on the memories page; have you read them? My, that will bring tears to your eyes. The little boy called [GRO-A] how very, very sad. Why was I moaning when I read what had happened to so many, shouldn't I think myself lucky? I've thought about that, and I constantly run that question through my head, especially when another person has died due to contaminated clotting plasma products, the answer I come up with is, yes I may be more fortunate than others, but an injustice was done to me like so many others, I lost my childhood, and have not had much of an adulthood, so that's my answer.

I contacted a member of the Tainted blood committee. I spoke with this nice man called [GRO-A] [GRO-A] he is under the Royal Free too, and wow have I learned so much, and I still am. It was nice to talk to someone else who feels the same as me about the so called Professionals; it was also good that he knows exactly who I'm talking about. We talked a lot about the campaign and things in general; I like to think that out of all this terrible disaster, I have at least made some fantastic friends for life.

In 2009 I made an appointment with Professor Tuddenham he's one of the Haemophilia consultants at the centre, actually he was there when I was a little girl, so he's been about for a while. He did see me and I spoke to him about the Hepatitis and my health problems, I told him that I believe that my health problems now are all due to Hepatitis C, I was right, he told me that this was the case, and that sadly so much more is to come out that they don't know about. He said that he felt I had a good case for the Skipton Fund and that he would help me. He also apologized for the lack of follow up care I didn't have, and that I had actually been failed by them.

So off I go again; rang the Skipton fund and they sent me out another sheet, I filled my bits and Professor Tuddenham filled in his, he even did a letter explaining their mistakes, so off it went to the Skipton fund, and guess what? Oh yes, I got turned down again, the computer says no again! I didn't know whether to laugh or cry at this point, oh hang on I've just remembered I cried, I cried down the phone to [GRO-A] from Tainted Blood. It's the principle of not being recognised of what happened to me, and then the Skipton Fund back- tracking on their criteria, like moving the goal posts to suit them.

Funny thing about all this is that at the Appeal Court in November 2010 [GRO-A] lost her case against the Department of Health (Skipton fund) they said that "a natural clearer of Hepatitis C is left with no long term ill health affects", a day

later my letter from the appeal panel at the Skipton Fund, acknowledges that I am left with long term ill health problems. Make your minds up, do you see how it's made up as they go along? Why on earth would I believe a thing that comes out of any of their mouths?

In December 2010 I contacted the Skipton Fund to see why they had not taken into account the review sheet I had dated 95 saying that I was Hepatitis C positive; the response I got was that the Doctor who wrote it must have got it wrong, another sad fact that the appeal panel can ignore two professionals and evidence saying I am Hepatitis C positive.

I gave up with trying to fight as I was worn out with it all and not feeling too well. Actually in July 2010 I was diagnosed with breast cancer, and I've been trying to fight that, bring up my two young children and try and work. The funniest thing about the breast cancer was being told by the Haemophilia Doctors that I did not need treatment for my operation and the only thing my surgeon needed to know was that I'm high risk for vCJD. Funny how a month after my operation I needed Factor VIII to stop the bleeding, I'm not the only Haemophiliac to be treated like a second class citizen we all are, and even now the same thing is happening with my seven year old son.

I writing this as I would not want you to think that I as a female Haemophiliac am happy with anything successive Governments have done for those of us who have been multiply infected and exposed to different pathogens and viruses, I have received nothing, a big fat nothing, the only thing I have received is fear of what will happen next and which one of my dear friends is going to pass away due to the filth that has been pumped into us.

I want answers, not things ignored, brushed away and forgotten about; proper answers as to why a vulnerable group of people were chosen to be experimented on, why children were abused through the treatment, why our parents were not warned of the risks, and why nothing is done to help with the suffering we have gone through. I'm not interested in the counselling; six sessions is a laugh and I don't even qualify for that.

GRO-A

GRO-A



GRO-A

Born GRO-A 1982

Died aged 7 on GRO-A 1990

'That.' Said GRO-A, from his bed which was surrounded by beer cans and pizza boxes, 'was the best night I've had!'

Even then, not long before he died, GRO-A loved having fun. He loved his lego that littered his hospital room and in fact he banned the cleaners from coming in to clean in case they disturbed his models. His headstone is a car, complete with wheels, because he loved cars, both his toy ones and the real one he 'drove' round car parks sitting on his dad's lap. Most of all that day, though, he loved GRO-A. The night before, GRO-A had told us to go home for a rest, saying he would look after GRO-A - and he did, brilliantly. When we arrived the next morning they were fast asleep, cuddled up in bed together. GRO-A had had his first - and only - 'bloke's night in' thanks to GRO-A and he had loved every minute of it. He told GRO-A the next meal was on him, but it wasn't to be. They were great mates and would have got up to all sorts together if GRO-A had lived! GRO-A idolised him; they were like a mutual admiration society with exclusive membership.

GRO-A made people laugh; he never complained; he was a little boy who liked having fun. We never talked to him about dying, but we think he knew. Once, he turned to GRO-A, his brother and commented: 'You'll miss me, you know...', and of course, GRO-A was right; GRO-A does miss him, as do his other brothers, GRO-A and GRO-A.

He told his brothers they could have his toys - he obviously knew they would get to use them for longer than he would.

We like to think that GRO-A wasn't afraid. Once, after his grandmother died, he remarked that it was selfish to cry because: 'You know where she is.'

For his last Christmas, his greatest wish was to have a motorised car that he could sit on and drive. We knew that he was probably too ill but we tried to get him one anyway. We had problems in getting funding and tried to put it to the back of our minds. Then, one day, GRO-A turned up at the hospital with a shiny new motorised car. GRO-A was ecstatic - rather more ecstatic than the nurses actually, because GRO-A then proceeded to unhook GRO-A from all his drips, lifted him into the car and showed him how to work it.

He then took him out of the barrier nursing room and chased him along the corridors and even outside into the hospital grounds. The medical team weren't too impressed but a combination of fun and fresh air gave GRO-A the best night's sleep he'd had in ages and a great memory to last him for the short time he had left.

GRO-A was so special to GRO-A and we want everyone to know how special he was to us, too. He supported GRO-A and supported us. We thought the world of him.

You never get over the death of a child, especially this sort of death. One thing that has helped a little is writing poems about him. Here is one we would like to share with you all:

Hello my darling, my little son,  
I've been thinking of you today.  
Sometimes I feel so very close,  
Sometimes so far away;  
But I know you're very near us  
For you're kept within our hearts,  
And I know with all the love we feel  
We'll never be apart.  
I remember the fun we used to share

God, how we used to laugh!  
The little secrets we used to have  
We whisper while we're apart.  
I'll give you some flowers today, sweetheart,  
And I'll smile at you and say:  
'I'll see you in my dreams tonight',  
Then I'll look to you and pray.  
I know I'll see you, darling,  
I know you'll hear me pray,  
And with God's help, my little boy,  
We'll meet again someday.  
God Bless You, my baby.  
See you soon.  
Mummy.

GRO-A

Our fourth son, GRO-A,  
was born on GRO-A 1982.

...he died at home with people  
who loved him...

GRO-A

GRO-A	<p>We have lived with a death sentence hanging over us for years.</p> <p>We need this story told and we need dignity and justice.</p> <p>GRO-A - died 2010</p>
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GRO-A	<p>For over 25 years, Governments and international pharmaceutical companies have shamefully treated British Haemophiliacs with utter contempt.</p> <p>GRO-A - victim and campaigner</p>
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GRO-A	<p>Over the past 40 years I have been infected and exposed via NHS blood products to the following :</p> <p>HBV, HCV and HIV. I have also been exposed to vCJD and have just received a liver transplant.</p>
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## GRO-A

**GRO-A** was one of the founding members of TaintedBlood. He was infected with HIV and Hepatitis C through his haemophilia treatment in the early 1980's.

Since the group's inception he occupied the role of Chairman, and continued to do so until his sudden and unexpected death from a massive stroke on 13th December 2010.

**GRO-A** had long and varied experience of campaigning for people affected with contaminated blood, particularly as co-founder of the Birchgrove Group in the 1980s.

For many years he was also a Trustee of the Haemophilia Society. He did a great deal of press work over the years and regularly attended events, lobbies, meetings, etc as part of the campaign. He sat on and chaired a variety of committees.

His influence and knowledge were far-reaching and he will be very much missed by all who knew him.

**Rest in Peace, GRO-A**

GRO-A

*You gave me strength to carry on  
The will to kick some ass.*

*You were one in a million  
My little mate.*

*Take care, God Bless*

GRO-A

GRO-A

I believe that due to the failings of the welfare state and the consequences that followed which led to my infections, what happened to me was wholly avoidable.

GRO-A

I ask "Is the State really accountable to no-one ?"

GRO-A

GRO-A

1956 -

GRO-A

2010

GRO-A

I have already had one liver transplant, but the cancer came back, and under the Milan Criteria I was not entitled to a second chance.



GRO-A

GRO-A campaigned for truth and justice for over half of his life. He joined TaintedBlood at its start in 2006. He was infected with HIV in the 1980s and Hepatitis C in 1990 through haemophilia treatment. Like many other haemophiliacs he was also exposed to vCJD. In 2009 he underwent a liver transplant which seemed for a while to be successful. Sadly this was not to last and in 2010 his liver cancer came back with a vengeance.

GRO-A was jointly responsible for the inception and much of the content of the TaintedBlood Timeline, and was instrumental in processing data accumulated from Freedom of Information and other sources and turning it into useable evidence towards proving our cause.

He had an amazing mind and his political knowledge and understanding was second to none. He fought so hard to live, even trying pioneering drugs in the hope of buying time to spend with his wife GRO-A and his family.

He loved his life and his home and wanted so much to reach an end to the campaign so that he could spend time leading as normal a life as possible. Sadly, this was not to be, and GRO-A died on GRO-A GRO-A 2010. He left behind a void that will never be filled, and will be much missed by everyone who knew him.

Rest in Peace, GRO-A

GRO-A

Is this a dignified way to end one's life ?

GRO-A

GRO-A 1956 - GRO-A 2010

# Alphabet Memories

**A**fraid when we all were told that 2 of our brothers were infected with HIV

**B**rave in their joint outlook and approach to the situation

**C**onfusion that it caused initially

**D**etrimental to family lives and relationships

**E**mootional rollercoaster that became all of our lives but theirs most

**F**urious at the lies and deception that unfolded over the years

**G**rateful for the good times we had

**H**eartbroken at their deaths within 7 months of each other

**I**nnocent children that were also involved

**J**okes shared even through the terrible times

**K**illed by default from a treatment they had no choice but to have

**L**ives affected like ripples in a pond

**M**aking the best of a bad situation

**N**ever forgetting others also affected/ infected

**O**blivious of the impact they had on so many people

Private struggles over many years bravely borne

**Q**uestioning everybody involved and seeking truth for all

**R**esults, results, results.....bloods, scans, liver biopsies; always waiting for results.

**S**earching endlessly for justice but not surviving to see it to fruition

**T**ime ran out for both of them

Utter devastation to our families in 2010

**V**ictory one day for them, and all who have passed away

**W**aiting for a liver transplant, and waiting, and waiting

**X**anthic (meaning yellowish) the colour of my brother's skin when he died and also Xmas will never be the same again

**Y** Why?

**Z**ZZZZzzzzzzzzzz for the sleep I have missed since their deaths; it evades me to this day. **GRO-A** and **GRO-A** are forever not far from my thoughts every day and night of my life.

**GRO-A**

**GRO-A**

**sister**

**I feel the Government would have been happier if we had all died faster.**

Some haemophiliacs have in the past faced criminal proceedings and imprisonment for failing to deal with the situation they unjustly found themselves in and unfortunately infecting others or putting them at risk due to their denial and confusion when faced with such a catastrophe. Why should those who were responsible for this, then neglecting the needs of the victims and knowingly endangering life for financial gain be allowed to walk free and even deny their responsibility for murder?

I was not given any counselling after it was hinted to me following hospitalisation after a car accident that I should be tested for HIV in 1994. My doctor must have been aware of my status already and had asked me seven years earlier if I would like to be told of my status. I declined his offer; I did not want to know.

I had been brought up by a strict health freak father who had avoided the infected blood product issue. He even had difficulty accepting the limitations of my haemophilia, sending me to football and sports despite constant injury. He could not handle physical weakness and this was instilled into me by him which may strangely have helped me to maintain a positive attitude to my health problems or just caused a state of denial in me.

I carried on in my ignorance and denial having a long term partner and daughter both miraculously unaffected (although the relationship with my ex partner broke down due to her reaction to the trauma at the time) before the doctors' hints convinced me to accept my HIV and Hep C status. I was advised to tell no one.

I have been given no counselling or advice on how to cope with life and with the confusion of what actually happened since then. It seems like I was expected to die before becoming a nuisance, or that's what it seems like. The ex-gratia payment did not last long as I had been convinced I would be lucky to last long enough to spend it.

I feel we now deserve separate compensation for the way this has actually been dealt with since it seems like further obvious neglect to me. The original financial gesture seems very short sighted at best and no provision seems to have been made for long term survival and the many issues this brings. I feel the Government would have been happier if we had all died faster.

There are funeral processions in Wootton Bassett for the latest of the soldiers to be killed in our governments name; they at least knew the risks and chose to fight for our security.



We victims of the contaminated blood disaster are also soldiers. The difference though is we have INVOLUNTARILY given our bodies and health to reckless health officials to monitor and experiment on for the last two decades and more.

We also fight to reveal the actual facts of what really happened to prevent such a catastrophe ever being repeated....where were all our processions? Where are our high profile funerals? We deserve recognition and respect but the government's refusal to admit what obviously really happened and take responsibility for it takes away any chance of us getting that respect and acknowledgement.

Still all these years later the corrupt government is making things worse. I have ignored the issues for too long and now I strongly feel I must add my input and do all I can to raise the profile of this issue at this crucial time. I am writing a song about this... check out myspace pcmackey to see my artwork and hear the music I make. It helps me to cope and relieves some frustration ..

GRO-A:

# A Widow's Story

**If I had my way I would have got a big freezer and kept him at home with me but the funeral director told me I couldn't do it.**

I will never ever forget that my husband was taken away from me; murdered, and his murderers are still free to get on with their lives. We have to move on one day; what other choice is there apart from joining our loved ones, something I tried to do.

I'm not religious but I kept thinking and still do, if I take my own life so I can be with my husband, what if I don't end up being with him because I took my own life rather than waiting for it to be taken?

That's worse for me never ever being with him again. At least if I ride out what time I have got left and go when its meant to be, I will be with him again (if there is an afterlife).

That's what keeps me going. I talk to him every day. If I had my way I would have got a big freezer and kept him at home with me but the funeral director told me I couldn't do it.

I think he thought I was a bit mad, but I love him so much it hurts every day that he's not here so no, in my case I still haven't moved on after nearly five years and don't know if I ever will.

You put on a smile and a brave face for the outside world. You have to; people expect it, but inside it's just like day one for me.



## Story

Two days after my dad's death my twin brother was taken into care and made to have blood tests or the home wouldn't take him. My eldest brother was left to fend for himself, my youngest brother was taken back to his mother's native country and the family home sold. The insurance company wouldn't pay the mortgage as dad died of HIV.

[GRO-A] was one of three brothers who were haemophiliacs. He was a mild haemophiliac who never really needed treatment - that was until Factor VIII came onto the market. In 1977 [GRO-A] was infected with Non-A, Non-B and Hep B and from then on his haemophilia got worse which we didn't think possible.

We have been told that as the liver became more damaged his haemophilia would have become worse. His treatment became more regular which exposed him to HTLV111 in 1980. His doctors knew in June 1983 that he had been but [GRO-A] wasn't told until Feb 1985 that he was HIV positive

In July 1984 dad was finally told that he had Non-A, Non-B; this changed our family life. My father had contacted his first wife - my mother - and asked if I could go and live with her and I moved to [GRO-A] in January 1985. I hadn't really known my mother and we didn't get on so in July 1985 she phoned my father to ask if I could go back home.

By this time dad had been told that he was HIV positive and I could not go home because he was dying. I still had no idea of this and my mother placed me into a local care home; I stayed there for 2 years until 1987. While I was in the care home my father would visit me and in [GRO-A] 1985 he came to visit for my birthday. While he was visiting he informed me he was HIV positive; let's just say I didn't take it too well.

I continued to visit my father and four brothers at the family home in [GRO-A] until dad was sectioned under the Mental Health Act in April 1986. In dad's medical notes when he was sectioned they asked him: "Why are you sad?"

He replied: "Because I'm dying of AIDS; tell them that's what makes me so sad." I turned 40 today and have lived longer than he did; I can't imagine what that must have been like for a young man of 37 to know that he was dying and would leave a young wife and five children.

After he was sectioned he came home to stay at weekends now and then, and on the 6th September 1986 he had returned to hospital after a weekend visit. He was then admitted with a piece of tissue stuffed up each nostril because he was bleeding badly.

He was seen at E.N.T. and had each nostril cauterised. He was admitted to a ward and on inspection the doctor wrote: 'Upper abdomen normal, lower abdomen unremarkable, liver 15Cms.' He didn't come home again.

On the [GRO-A] his notes say:

'[GRO-A] has stopped asking about his prognosis'

He died at 10.30 the next day. His sons never saw him; he was zipped into a bag with his head left out for his wife and parents, brothers and sisters to have ten minutes with him, then he was carted away and placed in a lined coffin. The undertaker would not embalm him

I did visit him in April 1986 and had been due to visit him after school on [GRO-A] 1986, but sadly he died that morning. Two days after my dad's death my twin brother was taken into care and made to have blood tests or the home wouldn't take him.

My eldest brother was left to fend for himself, my youngest brother was taken back to his mother's native country and the family home sold. The insurance company wouldn't pay the mortgage as dad died of HIV and didn't tell them - hardly surprising considering how people were treated back then.

My father wasn't the only person infected; he had two brothers also infected. One died in 2002, dual infected, and one is still with us with Hep C only, so it continues to affect us 25 years or so later.

I have written to Health Minister Anne Milton a few times but she thinks ignoring me is best as I want questions answered as to why my dad wasn't told for two years and why a letter that said he was infected in 1980, dated 1983, has been removed from his file.

I have just received a letter from London Whitechapel hospital that they have now lost one of dad's brother's notes even though they wrote to me to say they had located them when we asked them to fill out the Skipton Fund stage one form.



I am making an appointment with my MP Mr Burt tomorrow to bring this to his attention, not that I think I will get any answers, but I will continue to hound them. I want answers and have a right to this. I had the right to a family life; this was taken away from me and my twin brother when my dad died and we were placed into care as a direct result of his death.

All five brothers met up 24 years later for the first time in August 2010. That's what they did to our family; we were all scattered, some into care and others to fend for themselves.

## Story

**Why was my brother not offered a perfect liver? After all, he had been a tax-paying British citizen all his life and he had contracted Hepatitis C through negligence.**

Let me introduce myself. My name is [GRO-A]. I am 39 years old and suffer from Von Willebrands disease, an inherited bleeding disorder. I have a loving partner of 23 years and three wonderful children, aged 11, 16 and 18. My father, my brother and I were infected with Hepatitis C in the early 1980s from contaminated blood products.

My father died in [GRO-A] 2002, three months after being told he had developed liver cancer directly through the Hep C. My brother [GRO-A] was informed last year that he too had liver cancer from the Hep C. He was 42 at the time.

I was told that I had been tested for Hep C on several occasions and that I was a natural clearer, meaning I had possibly infected, but that my body had rid the virus itself and I had nothing to worry about! Then, during November 2006, while I was in hospital looking through my records, I found lots of blood tests for Hep C. Not one of them said negative; what they did say were things like: 'reactive', 'indeterminate' and in three later ones from 1999 and 2002, 'undetectable'. Looking closer, I saw that these had a different hospital number,

and so when I left hospital I brought this up at my haemophilia centre. To try and reassure me the doctors said they would re-test me so, in December 2006 they completed two tests and both results came back positive for Hep C. They also retested my stored blood samples from both 1999 and 2002 and they also came back positive. Not just one, but both! How could that happen after what I had been told? All the haemophilia centre said was that they were very sorry for this MISTAKE!!! They didn't know how this could have happened; they could not rule out a sample or labelling error and would investigate. I still have not received confirmation on this matter.

In January 2007 I was told to start treatment to get rid of the Hep C; a combination of Interferon and Ribavirin (a form of chemotherapy, taken by tablet and intravenously). I commenced this the following month. Boy, did I suffer from side effects! My hair fell out, I lost about three stones, I couldn't get out of bed for days and suffered with severe depression, often contemplating suicide. I was put on a high dose of anti-depressant medication and sleeping tablets. When I got to about week 18 of 24, I was advised by my doctor (a top liver professor at the Royal Free Hospital) to stay on the treatment for a further 24 weeks – something to do with my LFTs not being normal, and the fact that my brother, Angus, had relapsed as 24 weeks treatment was not sufficient. Apparently there was a better chance of the drugs working with a longer prescribed period. So, I agreed to further treatment.

However, due to 'NICE' guidelines, even after an exceptional circumstances appeal by my doctors, they said no, and said that they do not take into account the cause of the Hep C. I had to pay for the final treatment myself; about £7,000 just for the medication. I am still paying this off on credit cards as I was off work sick for 11 months. But I had to take the option and I had to take the chance.

However, despite all this, I unfortunately relapsed. I have now been left with chronic inflammation and moderate fibrosis of the liver. I also suffer from chronic fatigue and depression.

In February 2008 my brother, [GRO-A] was very ill; he was admitted to the Royal Free Hospital. After many tests he was told he had cancer of the liver – again due to the Hep C – and that it was terminal. He wasn't suitable for a liver transplant due to the Milan Criteria which states that to fit the criteria you must have three or fewer tumours; sadly my brother had four. [GRO-A] had to have embolisation to give him some time. On his scan in April it showed that as many as ten tumours had developed – more embolisations. I was with him and his wife the day he had the next procedure, we all knew the future for him and all evolving was bleak. I looked at him and it was like looking at my father at the end of his life.

Then a small miracle happened; His doctor came to his bedside and said:

'Listen, [GRO-A], we have a patient downstairs who's going to get a new liver tomorrow – do you want his old one?'

This patient was a private, Greek, patient. He had an Amyloidosis liver, which means that the liver produces too many toxins and poisons every organ in the body – he was near to death's door.

What choice did my brother have? A liver that was far from perfect, but was not rife with cancer? We are so very grateful to the patient for letting my brother have his liver, but why was my brother not offered a perfect liver? After all, he had been a tax-paying British citizen all his life and he had contracted Hepatitis C through negligence. He was told that he did not have any better chance of obtaining a liver privately so why are other EU residents being given preferential treatment for private transplants?

My brother had the liver transplant the following morning and thank God he's still here and doing all right at present, but when will the Amyloidosis commence with [GRO-A]?

As to me, at the moment, all they can do is so called monitor – i.e. blood tests and scans every couple of months. In late 2004 I was given a letter at the Haemophilia Centre saying that I had been put on the Department of Health's high risk vCJD register for public health reasons, but again there was nothing to worry about. I was advised to tell all medical staff I came into contact with that I may have the disease. I put this into practice in 2007 at Moorfield's Eye Hospital after contracting (and believe me, I am not joking), two cataracts and then two detached retinas, followed by one vitreous haemorrhage, all within eighteen months for no reason – and they don't know why! This has left me nearly blind in my right eye, due to optic nerve damage.

On the times I had to have surgery I was told to fast all night and come in at 07.30 in the morning, but I never had surgery until about 6pm in the evening. I asked the surgeon why and he said this was due to my vCJD status and the cleaning of the theatre and the use of instruments so I had to be last in theatre for public health reasons. Only in the Department of Health's report on high risk vCJD, dated March 2007, by the Health Protection Agency and in the British Medical Journal, it states: '...everyone should show and express national gratitude that they take up such exceptional burdens to protect others from a condition that they may not even have but may be at risk of having...'. So that's gratitude I get?

That's a little look at what's happened to my brother, father and myself so far. The government need to start to acknowledge our fight for justice and own up to the things that went wrong and apologise to the haemophilia community for letting them down time and time again. Let's not forget that it was not just Hep C that was passed on to haemophiliacs through infected blood and blood products but also HIV.

So many have died and so many are dying now, with no support. We also want compensation for us and our loved ones. We cannot obtain any insurance whatsoever – work cover, travel insurance, etc, but more importantly life cover. My brother and I have no insurance; no-one will cover us, and when we die our families will have to fend for themselves after dealing with such a terrible bereavement. No money to pay off mortgages or even to pay for the funeral. What about the families of those that have already died, having to give up homes, etc?

We feel like guinea pigs, but we are humans, just like you.

Thank you for reading my story.

GRO-A



**We have gone from a household income of approx. £35,000 to under £10,000.**

I inherited a severe bleeding disorder, von Willebrand's Disease, which is very similar to haemophilia. As I have <1% of Factor VIII in my blood I have bleeds in just the same way that haemophiliacs do, into muscles, joints, just about anywhere. I have also had two brain haemorrhages.

I am a member of, and contributor to the Tainted Blood website. I am also Hepatitis C positive. It came to my attention recently from a meeting that Health Minister Anne Milton MP had with some of the TaintedBlood (TB) group that she "assumed" that because she had not received many letters on the subject she "thought" that everyone was happy with the outcome of the review earlier this year. Well, I can tell her categorically and most emphatically that I, and many other members, am anything but happy. In fact I am absolutely outraged.

Because I fall into the stage 1 (as it is termed) group I received absolutely nothing from the review apart from free prescriptions. Some windfall. Last year I had to give up my job due to ill health. I had worked in the NHS for over 30 years, in Pathology. It was a job that I loved and it was a huge wrench but I was physically unable to carry on any more.

Apart from the hepatitis C, I have also got chronic arthritis due to the untold number of bleeds into joints and have had cancer twice.

My husband gave up his job to look after me. We have gone from a household income of approx. £35,000 to under £10,000. I have now had to go cap in hand to the Caxton Fund and am awaiting their reply.

In October 2010 I was one of the many haemophiliacs and their families who went to the Commons to listen to the debate unfold. Many MPs rose to tell heart-rending stories of their particular constituent. By the end I was convinced that no one with an ounce of compassion could possibly reject our claims. I was wrong.

I, and many others, was reeling in disbelief. I had struggled with a friend to get down to London that day. I stayed with a friend who lives closer to the capital. It took me over three days to get over the effort in getting there. I was totally physically and mentally exhausted. This is what hepatitis does. It drains you and spits you out. And then it kills you. I have had this virus for over 30 years.

Believe me when I say I am absolutely appalled and disgusted at the cavalier way in which we have been treated.

If the Minister truly thinks we are all "happy" because she has not been deluged with letters it is probably because we are too unwell to be able to do so.

I was recently interviewed for the local BBC radio station. I told them how we had been infected. Your average Joe does not know what has been going on behind closed doors for all these years. It is a national scandal which you are ALL trying to sweep under the carpet permanently.

I have in fact written to the Minister previously at Whitehall, but I think most of the letters end up in the waste paper bin by the civil servants working there.

I have also written to Andrew Lansley and never once got a reply. The only reply I ever received was one via my MP, Mark Lancaster.

I would like to see how many in Parliament could exist on less than £10,000 per year. I am now on ESA and my husband receives a small pension.

As the Government were at fault for this disaster (they cannot argue that they were not as we all know perfectly well that that is the case) then the least they can do for me, and fellow haemophiliacs who have been infected with these viruses, is to ensure that what remains of our lives is not spent in poverty.

GRO-A

GRO-A

'Hey GRO-A you got Aids yet', 'Don't come to GRO-A aid 'cos he's got AIDS'

**Basingstoke September 1986:**

**GRO-A** *do you know how lucky you are to be alive and have free treatment for your Haemophilia?"*

This was said to me by an influential Haematologist at Basingstoke Hospital after being diagnosed a year earlier with HIV at the tender age of 14. Looking for some solace and security in the early stages of teenage life, I tried to discuss this with my Mum and to my disbelief she actually agreed with the doctor! Her words sounded heartless to my innocent and naive ears.

I tried to understand why that was said because when you're a young teen the actions of adults in those formative years seem to last a lifetime. But that was the way then, Parents were the boss, Doctors were 'gods' and children were bought up differently to today but to me it was the wrong kind of approach. Both adults were living with varying degrees of denial, due to the devastating situation caused by contaminated NHS blood. One a parent, one a healthcare 'professional' and both of which were supposed to take care and guide me safely into adulthood.

That said my Mother's reaction I 'sort of' understood. She viewed doctors as life savers and they had indeed saved my life some seven years previously after I fell out of a tree and ended up in a coma for two weeks due to a bleed to my head. So the same viewpoints bound together that Doctor and my Mother. Two very influential people who, in my youth, became polar opposites of what was happening to me. It was very confusing and I became trapped in a 'who cares now?' syndrome.

All I knew was I'd been given a death sentence 'for free' and what, I should be thankful for that? The malice implied by that Doctor's comments came with no shame. She was too arrogant to deliver a fundamental part of the Doctor/patient relationship; trust. From that day forward any trust in my treatment for Haemophilia was inexplicably damaged for me.

To begin to try to explain is a difficult task but in an attempt to define my thoughts on leaving the Hospital that day it dawned on me that I'd become a walking virus, a disease to be ashamed of and I knew I was in trouble. This would define me, and has gone on to do so to this day.

As a family we had to try and deal with what we were told but with very little support how on earth were we going to do that? My mother was in denial - her own son being given HIV through NHS treatment and was meant to have only two years left to live?

"No, no, no they save lives, you are lucky" she'd repeat over & over again amongst many other helpless lines of speech that made no sense to me. I couldn't understand why anyone would agree with such a comment especially in regards to where my young life had ended up. It was very much: "If the Doctor said it, then it's true...doctors don't lie" and anyway, she said, what would I know, I was 'just a kid'.

In fairness, Mum's reactions do make some sense now. What kind of advice can a Mother give when the fear of the unknown is taking precedence over everything else? The senseless situation was just that; senseless, but the gravity of it was immense, as life was unraveling itself from everything we knew and there was no-one to put it back into some sort of order.

It's the natural thread in all good parents, that protecting your kids is a given, out living your children is a must and these emotions are heightened when you're the parent of a child with a chronic illness. Dying from haemophilia was always a risk, yes, but dying because of the very treatment given for it and given by the very people whose job it was to do so, the 'lifesavers', was near impossible for her to quantify. It was only by the tears that I'd hear her cry some nights that I truly understood how hurt she was, even though she couldn't and still can't show it.

It was a catch 22 situation for all of us, and Russian Roulette for me as I was bright enough to realise that the Factor was bound to be infected with other viruses and HIV would just be the start. It was and still is down to the impossible position we've been placed in through NHS supplied contaminated blood.

My Dad on the other hand was the complete opposite. He simply never trusted Factor VIII; not once. I have so many vivid memories of him saying to Doctors on the kids ward: 'Is that stuff safe?' and questioning nearly every needle I was given and the reason for that needle. I was often in hospital as a child and he'd spend every waking hour with me when he wasn't working and when he was at work Mum would do the same. He never allowed them to take liberties with my health or let anything to get in the way of his strong and now clearly correct instincts. The only reason he'd have to retreat was when he was told that Factor VIII was the: "...only treatment available, Bernard."

So against his better judgment he had no choice but to allow Doctors to continue with concentrate therapy but so often he felt defeated and was never reassured when the haematologists came back with: '...of course it's safe!' over and over again. It turned out that he was correct with his fears for my future but this often drove a wedge between Mum and Dad because of their opposing views of what was best for their son.



So, who was to blame for maiming my innocence when I was that 15 year old boy back in 1986? It couldn't be Mum and Dad for the reasons given above, even though being infected caused irreparable damage. It wasn't even my Haemophilia Doctor or nurses at Treloars, a specialist school for young people with physical disabilities where there were many haemophiliacs who subsequently died from their infections.

We were well cared for there and the Doctor had the un-imaginable task of telling us one by one our fate when we were given roughly two years each to live. No in my eyes at that time it was that 'expert' haematologist in Basingstoke because she was unable to say that the NHS had screwed up and screwed up big time. She also genuinely refused to answer any questions I had and the irony was that I and others were referred to her to ask any questions we may have regarding our conditions and prognosis.

It was clear from the offset that afternoon that haemophiliacs were in the way. We were always difficult to treat but now we'd become the untreatable, a death sentence in her consultation room that served as a constant reminder that conflicts with the ethics of being a Doctor, saving lives and not maiming them. And above all I was hurt, really hurt by the prospect of dying by just 17 as I hadn't lived yet. I hadn't had time to notice the broken bottles on the beach but suddenly I was becoming just that...broken!

One of many vivid memories from 1986 was that Mum had an old fashioned carriage clock on the fireplace surround. With every revolution of that clock, with every tick, it felt like I was one second closer to the end. Of course all teenagers question their own mortality, it's the first time in life when we become aware that death is inevitable and is a key factor in our striving for individualism in whatever lies ahead.

But stop! Wait! What, me, dead by 17? No, no way! Is that it? Why? Why me?! All the usual questions, but magnified a hundred times. My desire to stop time by smashing that clock was overwhelming and I still don't know how I restrained myself.

On top of this, because of HIV being given such a high profile by the time media reports of the 'plague', my family thought it best to try to keep me at home as often as they could for my own protection. Little did I know the parents of other kids in our local community had requested that I not visit their homes just in case I infected them.

The risk of other kids taunting me was high and indeed it happened often. Some taunts I vividly remember were:

'Hey **GRO-A** you got Aids yet', 'Don't come to **GRO-A** aid 'cos he's got AIDS', 'Gay...got Aids yet?' and 'Live Aids coming' (after the famous 80's charity concert) amongst many others.

Time was short and it was a terrible time.

So this in turn created further conflict because I couldn't get to grips with any of this. I'd often think: 'Why are they holding me back? Are they that ashamed of me?' I can see now it wasn't shame, it was fear, as every night, in every single U.K home the now infamous Government-funded HIV/Aids prevention campaign advert was running over and over again.

The grim reaper bowling at potential victims as his pins and the falling headstones were constantly telling us not to die of ignorance. Ignorance; excuse me? We were living it straight on and even though the campaign may have saved many lives, it was marking my grave already and my cell count hadn't even gone into decline yet!

The adverts reinforced my constant fear that I was doomed, with not long left to live. Teenage angst had set in; confusion reigned at the centre of life but the level of thinking done by a simple teenage boy was deeper than some adults I knew and some of those in my friendship groups. I was often paralyzed by fear, stranded; apparently miles away and in just a few months had changed profoundly. People would ask: "What have you done with the other **GRO-A**?" in a bid to try to lighten the load of a desperate situation. What they were unaware of, though, was that I so desperately wanted to be the lad I once was but I'd become more subdued and alone in myself.

My school work suffered profoundly even though I was a bright student prior to all that was going on. I became difficult to live with because I was so scared of dying and worried how my other friends with Haemophilia from my centre might die as we were a close knit bunch. I still can't believe that I've lost so many friends due to Aids and Hep C and not a day goes by where I don't think of them.

It shames me to say I'd often contemplate suicide, just to beat the virus because I didn't want to die like that - who would? - but also in this period, and to much delight, my nephew was born, which was a happy experience until (and to my surprise) some family members didn't allow me to get too close to him just in case he caught anything from me. This obviously created further problems. I loved my family but it was starting to feel as if they didn't love me, because the distance between us was becoming really difficult. Being infected had thrown literally everything in turmoil.

I had been a fairly extrovert child, often loud with a zest for life, and could have family and friends in stitches with my fun filled antics without even knowing why. Even though having severe Haemophilia was/is a painful condition, life was pretty much full of all the normal kids stuff. Toys, bikes, face painting, friends, ice cream, school, being good, being naughty and everything in-between. But when the rot of my prognosis set in everything took on a different meaning.

I felt like a disease because I was diseased and all we could hear and see was AIDS. My haemophiliac friends were becoming sick and dying young and so horribly, and we were all constantly living in the shadow of it. On top of all this we were finding out that we were also testing positive for Hepatitis B & C, both of which I contracted, so I just didn't know who or where to turn to. I couldn't turn to my parents because of the usual teenage conflicts and the added pressure of my circumstances.

I used to have a deep awareness of God in life but how could God do this? I couldn't confide in Doctors because they'd become the centre of my fear, highlighted by every syringe of Factor VIII (sometimes nine a week). I couldn't confide in my friends because what I had would only get in the way of their own teenage dreams; the dreams that I thought I wouldn't be a part of because I'd be gone.

I was making memories for other people and probably would not live long enough to have my own, so detachment was inevitable really. There isn't a day that goes by where I don't feel that detachment, even now. For example, I find it really difficult talking on the phone or going out sometimes just in case I die next week. I want to stay a happy memory and for people not to see me when I'm ravaged by one of the many illnesses I've contracted. I guess when my time comes I'll become more agoraphobic. This situation is wrong; so very wrong.

In the time since being 'that kid' I've strived to stay alive and against the odds I still am. I don't know how because I've had some close calls, some breakdowns (both health wise and psychologically) and the paths have really not been easy, in fact sometimes impossible as I was diagnosed with Post Traumatic Stress Disorder last year. That said, I've been able to find good solid friends, even though early on I wouldn't tell anyone that was even a Haemophiliac let alone infected.

But in time and mainly due to the Archer inquiry in London I was able to be more free with my conversations and found that our plight had so much support. It was truly liberating that a unity had been bound by such an avoidable tragedy and we may, at last, have had a hope for justice and have questions answered regarding the appalling ways we've been ignored by every Government since this travesty began. To our disbelief we are still blatantly ignored, along with Lord Archer's recommendations. We're shamefully disregarded as his extensive and detailed report was filed under 'denial'.

I wouldn't be writing this if it wasn't for the very people who've reminded me in recent years who I am, what I mean to them and put simply what it is to be alive. In some of the darkest moments the timing of their support has been and still is a contributing factor towards my longevity.



I also have a partner who is a rock but who's also been through a multitude of highs and lows because of the circumstances we find ourselves in. Living with the fear that one day one of the viruses will eventually get me has been a lifelong education for me but not for him so it's hard on us both. Unfortunately I only have sporadic communication with my family now as the damage was too much for us all. We simply couldn't maintain any kind of 'normal' life after the curse of being infected took prominence and created so many divisions that we eventually splintered apart.

Until now I haven't mentioned that I also have two other Haemophilic brothers who were infected with the same viruses as I was but who didn't grow up with us. One is so broken that he barely communicates with anyone and virtually lives a life of isolation in Kent. I can't reach him in many ways even though I've tried many times. He hangs onto the last remaining memories of his childhood with a simple wish to change the past and pines for our other brother who died from Aids in 1997.

We miss him very much and in many ways he's also where I get my strength from as we were so similar people in that respect. He was 'made of steel' with the guts and determination that you only hear about in worn torn situations.

His hospice nurse once said of him

"In all the years of nursing, I've never met a guy like it or anyone with such raw determination whilst being so seriously ill, that boy's got some guts".

But this was our war and eventually he was killed by his treatment. I was with him right to the end and I'll never forget having to tell him that he only had days left to live, even though he knew it.

Being told that by your own brother is something else and I'll never forget the fear that washed over his face and his massive blue eyes going wide with panic. It's one of the hardest things I've ever had to do in my life and hope I never have to again.

As I touched on earlier, since being 'that kid' I've personally lost over 50 Haemophilic friends and acquaintances from ages raging from 14 to 60 years old and all mostly due to their infections and not Haemophilia.

We've all witnessed such unfathomable pain and heartbreak and we've been living and dying through it for more than 25 years all because of the infections provided courtesy of the NHS and all wrapped up in the name of treatment.



It has been and still is abhorrent and with all honesty it's been quite difficult to write this 'me' story because it's an 'us' story, Every victim is a soul; a deep and painful reminder that every one of us is or was someone's family member - a son, daughter brother, sister, husband, wife, friend and always someone's child. Every death we hear of creates a 'last man in the lifeboat syndrome' and with that comes a level guilt that I'm still alive when over 2000 others aren't but really should be.

This is a simplified version of 'my story'. There's much more I could say but little time to say it so I'll end on this. When we were those innocent children with haemophilia there was the most amazing nurse named Annie whose dedication to our care was lifelong and went onto last for over 30 years.

No matter how much pain we were in we always knew that she'd get us better because she had the 'magic juice'. Annie would never miss a vein when giving any treatments and with every internal bleed, of which there were thousands between us all, she had a way of taking the pain away just by her kind and calm approach. She was every inch what you'd imagine a great nurse to be and a true heroine to me and many other patients at our local Haemophilia centre. [GRO-A] [GRO-A] she had to retire early and in doing so left a legacy of superb care behind her.

In the mid 1990's and very much by coincidence I met a lovely lady named Mary who knew of my condition and knew Annie well after they met at a local church. I was surprised but equally elated as it would of course be lovely to see Annie again but when I asked after her Mary welled up. She went onto explain that she was now a virtual recluse [GRO-A] [GRO-A] because she felt personally responsible for infecting maybe hundreds of patients in her care. I made sure that Mary took my contact details and got a message to Annie that I would love to see her again if she'd like and of course to try to put her mind at rest.

This came to fruition and just a few days later there I was in a small flat with the very lady who made having Haemophilia, well, safe, to honest. In holding her gently on our greeting she began to cry saying "I'm so sorry; you boys know that don't you?"

I kept on reassuring her but there were so many apologies falling from her lips that the guilt this beautiful lady had been living and feeling with was incomprehensible. She truly believed that she was personally responsible for the pain and suffering caused by contaminated blood and it had eaten away at her for all that time and in her words 'through the treatment she'd given us'.

She also repeated several times that she really didn't know and I knew in my heart she really didn't but nor did I ever think she did. Our lovely Annie was just doing her job and really quite brilliantly. I made sure she knew how fantastic all 'her boys' thought she was and still did.

I spent the whole afternoon with her going through an array of mixed emotions over what happened and we got to a point where we were thankfully laughing about old times.

On leaving her flat that day I hoped in some way I'd been able to put her mind at rest and I went on to see Annie fairly often after that. I made sure she got out on her mobility scooter and helped her feel more at ease with what happened to 'her boys' but some six weeks later Annie passed away.

I wasn't the only one who visited her of course as many of her colleagues were in constant contact but in looking back I seemed to be a missing link in a chain of events and I hoped she'd passed healed in some way because one her boys had visited her. Mary confirmed that she'd been able to turn her feelings of guilt around and thankfully died at peace, if only I'd have got there sooner but at least I got there.

So, Basingstoke September 1986 "Do you know how lucky you are to be alive and have free treatment for your Haemophilia?" and would that consultant ask me the very same question again today?.

I wish she would because this time I'd have more answers because back then I was voiceless. Yes I really know how lucky I am to be alive but in regards to the 'free treatment', you get what you pay for. Shame on you NHS, shame on you.

This one's for you, Annie!

GRO-A

GRO-A

# About us

TaintedBlood exists solely to support and to achieve justice for those infected and affected by contaminated blood and blood products in the United Kingdom.

The TaintedBlood committee consists of people who all are either directly affected by contaminated blood or are bereaved from someone affected.

They all act in a purely voluntary capacity and are dedicated to achieving the aims of the group.

All members of the committee act in a voluntary capacity. Taintedblood has no paid members of staff, and any funds raised are used solely towards fulfilling the aims of the group.

On the website **[www.taintedblood.info](http://www.taintedblood.info)** you can find a contact sheet enabling you to email us and a lot more information about the campaign and the people involved.

You can write to us at:

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