HAEMOPHILIA/CONTAMINATED BLOOD: THE CASE FOR PARTNERS/CARERS/WIDOWS AND PROPOSALS FOR RESOLUTION

SUBMISSION TO ANNE MILTON PARLIAMENTARY UNDER SECRETARY OF STATE FOR HEALTH

by

Carol Grayson

Behind each adverse event there is a patient, a doctor, and a doctor-patient relationship. A patient must be told when things have gone wrong. Every effort must be made to minimise the after effects, including financial compensation where necessary. Most patients wish to know in detail what happened and what is being done to reduce the possibility of a recurrence. And members of healthcare teams need mechanism to come to terms with their fallibility. It is hoped that clinical governance will make a difference (BMJ Letters Page 19-16th August 2000)

Behind each HIV/HCV infected haemophilia patient there is a family support network, carers (predominantly women) and often bereaved relatives that mostly go unrecognised (Carol Grayson, 2010)

Introduction and a little background

On 22nd July 2010 haemophiliac Colette Wintle and I (widow of a haemophilic who died as a result of being given HIV/HCV infected NHS treatment) were grateful to meet with Anne Milton Parliamentary Under Secretary of State for Health to discuss the issues for females with bleeding disorders **"infected"** by blood borne viruses and **"affected"** partners of haemophiliacs, the carers and the bereaved. We particularly wanted to highlight the need for "gender justice" as over the years females within the haemophilia community have not been given the same consideration as males in financial terms with regard to their multiple losses.

We wanted to stress that these women exist in their own right and are not an appendage of their husbands. Historically government Trusts have failed to provide adequate funding to respond to the needs of long term carers and widows/bereaved partners. Until recently women had been largely excluded from ongoing negotiations with government in relation to funding trusts such as Macfarlane and Skipton which were predominantly set up by men for men. We wished to break down this patriarchal attitude and draw attention to the army of unpaid carers to haemophiliacs that have saved the government millions and now it is time for the government to care for the carers. We also want to ensure that infected intimates of haemophiliacs are treated equally to the infected haemophiliac and the bereaved compensated in their own right.

The following blog Gender Justice gives a brief overview of our meeting with Anne Milton http://www.ctrlaltshift.co.uk/article/blog-carol-grayson-exclusive-gender-justice Testimonies of infected and affected women can be viewed as part of the evidence submitted to Lord Archer of Sandwell for his privately funded Public Inquiry http://www.archercbbp.com/ There are also 60 recorded stories which include the female perspective as part of the Brighton University Living Stories website http://www.livingstories.org.uk/ which is housed under Haemophilia and HIV Life Project stored at the British Library Sound Archive.

Attached to this submission are the responses to detailed questionnaires that were sent out to members of the haemophilia community as part of my MA dissertation and hopefully will give an indication as to how our community feels on a number of important issues including the Macfarlane Trust and Skipton Fund. These are coded with numbers for anonymity, H indicates haemophiliac, P indicates partner of a haemophiliac.

I write from the position of haemophiliac wife, carer, widow, mother, qualified Registered Mental Nurse, global health activist with an MA in Gender, Culture and Development and awarded ESRC Michael Young Prize 2009 for my research.

I have attached my own personal testimony as a widow living each day with the problems caused by HIV/HCV to the Archer Inquiry which also outlines a little campaign history to share with the Minister as she indicated that we may never know what happened. This might provide a little insight into some of the background. There is also a link here for a short film I made for the Guardian of my own life experience to educate others... http://www.guardian.co.uk/society/video/2009/feb/23/blood-safety I feel it is important for officials in the Department of Health to read these and have some understanding of the issues involved as the previous government in the words of Lord Morris of Manchester "couldn't even cross the road to attend the Archer Public Inquiry." It took courage and time for the haemophilia community to produce witness statements so I think it is not unreasonable to expect that they will be read. There is also some background history to the campaign initiative for "compensation on a parity with Eire/Ireland" which my husband and I began back in 1996. You may find this useful as lawyers Michelmores used my arguement and evidence for the Judicial Review, Andrew March v Secretary of State for Health.

My colleague Colette will cover issues for infected women with bleeding disorders while I focus on partners, widows and carers. There are no "typical" examples of people's histories living with the viruses as everyone's story is different however there are common difficulties faced. Below is a letter which I received today from widow Rita Greenwood which she asked me to pass on to you. It serves as an example of why the haemophilia community is seeking resolution. Some widows of those infected with hepatitis C have still not yet received a penny depending on the date their husband died. This is a great injustice. The following letter was typed with thanks to Nadia, Rita's 11 year old granddaughter.

Letter written by widow of a haemophiliac who died from hepatitis C

"My late husband John was a mild to moderate haemophiliac. He was treated at the Haematology Centre at Manchester Royal Infirmary. I was later told that John could have been given another treatment but the Centre's policy was that all their patients had to receive Factor 8. John contracted Hepatitis C in the late 1970's. He tested negative for HIV. Everything about Hepatitis C was kept very secretive. We were never warned about inter partner/familial cross infection.

In June 1996 John reported to the Centre for treatment and was given a routine blood test. Within two weeks our lives were ruined! We were called in urgently and told that if a liver transplant was not done A.S.A.P that John would be dead by Christmas. Words can't describe the shock and horror of this! Our daughter accompanied us to see the liver surgeon. John's notes were left open and unattended near us. Our daughter told me

later that in the internal memo from the Haematologist to the surgeon he said, "How many more of these poor men are out there?"

John refused a transplant and all offers of medical help saying the medics have done enough damage. He closed the door to all but family and closest friends. John's G.P spoke to me weekly by phone and arranged pain control. I alone nursed him until three weeks before his death. He then agreed we could ask for help from the Haemophiliac Centre. A field nurse was sent. She warned me of cross infection and supplied gloves. She wanted me testing for Hepatitis C but I refused. I was too traumatised by the whole situation. Two years ago I was forced to take the test because I had a health scare, which could have been linked to Hepatitis C. Thankfully I am clear. The trauma still continues!!

The nursing sister prepared me for John's death. She warned me it will be preceded by a massive haemorrhage terrifying to the most experienced of nurses. She was absolutely correct! I was alone-6:00 am and blood was all over me, the bed, carpet, wall etc. John's body was removed at 10:00 am and within the next hour an open-topped lorry appeared on my front drive. Two men in space suites emptied my bedroom and ensuite of everything except sanitary fittings. I asked them what was going on. They said they were from the local hospital and everything had to go in their incinerator. (I have several witnesses to this.) That night my daughter, grandson and I huddled together in a single bed totally traumatised by the day's dreadful events.

Ramifications of John's death are still and always will be felt in our family. Not only did we lose a loved one but were deprived of any financial support, (John was a taxi driver with no death insurance or pension), but more importantly deprived of his emotional support. Our daughter suffers from an anxiety/depressive illness and is unable to work. I believe that her father's death has compounded this problem. Added to which our grandson, three at the time of John's death, has been born with an incomplete immune system. Also the shock of John's prognosis and death hastened my Mother's demise. I am a teacher. I was forced to take early retirement to nurse John and then to nurse my Mother despite my age D.O.B 28.11.1941. Circumstances compelled me to resume teaching five years ago to enable me to keep my home. I currently teach four days weekly.

The shock and after effects on my health and sensibilities re the circumstances of John's death can never be measured. The dramatic reduction in my standard of living and all the resulting financial constraints were totally unplanned for. Thankfully I was able to resume my teaching but for how long? I have hoped and prayed these last fourteen years for justice for John, myself and the other widows.

I think you should know that my grandson who is now seventeen has been so inspired by Mr Cameron that he has joined the Conservative Party and is convinced that Mr. Cameron will bring justice to the Haemophiliac Community."

Thanking you,
Rita Greenwood.

GRO-C

WIDOW'S STATEMENT TO CONTAMINATED BLOOD AND BLOOD PRODUCTS INDEPENDENT PUBLIC INQUIRY

BY

CAROL GRAYSON

Introduction

My name is Carol Grayson. I am 47 years old and a widow. I ask the panel to forgive me if I jump around a little as I am here today wearing three hats, that of the widow of a haemophiliac, that of a campaigner who set up my own campaign group, and that of a person that has written an MA dissertation on contaminated blood.

My husband Peter Longstaff was a severe haemophiliac with less than 1% clotting factor. Pete became infected with HIV, hepatitis B and hepatitis C after receiving contaminated blood products and died age 47 on the 16th April 2005. I find it extremely difficult to write about the suffering of my husband as Pete suffered twice over, once as a result of his infections and secondly through the treatment he received from many professionals for speaking out and campaigning on the issue of contaminated blood. Peter was a great husband and father, he was a kind, caring, and brave man whom I loved very much. Pete inspired others and campaigned tirelessly to change Government policy, even in the final days from his hospice bed.

I have one step-son GRO-A now age 23 who suffered greatly watching his father deteriorate and experienced prejudice whilst still a child because of his father's infections. I am fortunate in that I escaped infection with HIV/HCV. My brother-in-law Stephen, a haemophiliac, died age 20 in 1986, another victim of what I believe to have been a largely avoidable disaster, a tragedy that Lord Winston described as the "worst medical treatment disaster in the history of the NHS."

AIDS- Early Days

I think it is important to remind people of what it was like to be infected in the early days of AIDS as the situation has greatly improved over the years as a result of education to challenge ignorance and prejudice. At the time Stephen was dying in 1986 there was mass hysteria in relation to AIDS and the family experienced one particular incident where the family home was daubed with AIDS slogans, this was covered in a local news article. Pete and his mum Alice recalled that Stephen was terrified of infecting anyone, was afraid to touch others and wouldn't leave the house without wearing gloves even in the middle of summer. Stephen also insisted on using his own personal knives and forks and much to the distress of the family would get very upset if others cleaned up his bodily fluids. When he was in hospital reporters attempted to take pictures of patients with AIDS by peering into windows or gaining access to wards by pretending to be staff.

Stephen was a young man who lived and died in fear. Even after death, he was buried in a special coffin and Stephen's brain and other body parts were taken without the family's knowledge and permission which we discovered 20 years later when we were part of the

Organ Retention "scandal." Stephen's remains were finally returned to me in a white casket in 2005 after an investigation was carried out, and they were cremated alongside my husband. Pete and Stephen's father Arnold was very courageous as he campaigned with local press during the 1980s and agreed to be interviewed for a documentary called "First Tuesday" to raise awareness of HIV. His widow Alice (now deceased) believed that the stress of campaigning, dealing with ongoing prejudice, and seeing his youngest son die and his eldest son becoming ill contributed to his early death age 58.

Pete also experienced fear alongside Stephen because of discrimination. On one particular occasion Pete's house was surrounded by a baying mob who wanted him run out of his home because he had been infected with HIV. Pete barricaded himself in as he feared for his life. He was finally rescued when the police arrived to disperse the crowd and his GP persuaded him it was safe to come out.

Background To Campaigning

In 1994 after finding out that Pete was infected with HCV (which I will go into later) my husband and I set up a campaign group to educate haemophiliacs on how they came to be infected, to empower individuals to fight for their human rights, combat prejudice, and provide support to those families infected and affected. We called our group Haemophilia North. I soon became aware that many haemophiliacs outside the north-east of England were contacting me for information regarding their infections and to share information so we changed our remit. We began to campaign on a global scale for those infected through blood and blood products and became Haemophilia Action UK.

Although I was a full-time carer to my husband who was in receipt of severe disability allowance due to his many medical problems as a result of his infections, I was able to utilise my nursing background and former teaching experience gained whilst a Registered Mental Nurse (RMN). I adopted the research skills I acquired years earlier whilst working in the health section of a university library to research the contamination of the UK haemophilia community. Pete and I ran a "Bad Blood" campaign from home supported by the Newcastle "Journal" which published many articles.

One result of this campaign was the Government's agreement to provide an "internal informal" review into past blood policy which was as a direct response to evidence presented to the Journal to support the need for a full and open independent public inquiry. This extremely flawed Government report was entitled "Self-Sufficiency In Blood Products In England And Wales: A Chronology from 1973 to 1991" which was published in 2006. Even the title is a con, it should be renamed "Successive Governments' Failure To Achieve Self-Sufficiency In Blood Products In England And Wales: A Chronology From 1973 to 1991." In fact self-sufficiency has never been achieved to this day. Despite campaigners offering to assist the current Government by supplying our own collection of documents to help politicians with their collective memory loss regarding certain key evidence, this offer was not taken up by the DOH.

As campaigners/litigants Pete and I were able to access copies of some Government documents several years ago that were held at a solicitor's office in Newcastle named Blackett, Pratt and Hart. We wrote to the solicitors more recently requesting that all these documents be released into the public domain. The firm then wrote to the

Government expressing our wish. When the Government were informed of the existence of these records the legal department rapidly recalled them (as you may be aware "over zealous civil servants" had already "inadvertently destroyed" many of their own copies). They then decided what would be released under the Freedom Of Information Act. Other haemophilia campaigners as well as I were later able to source some of these documents under FOI and those released are now up on the Tainted Blood website timeline. In a letter dated 9th February 2004 Melanie Johnson wrote to Lord Morris that "all the information is in the public domain" and because of this the Government did not think a Public Inquiry was the way forward. This statement is incorrect, we hear that the Government are withholding around 60 documents on the grounds of "commercial interest" I have approached the organisation Liberty to see if they can assist me legally in accessing these documents as too often commercial interests have been prioritised over safety.

MA Dissertation

After my husband died I became a full-time mature student at Sunderland University studying for an MA in Gender, Culture And Development. I wrote my MA dissertation on the contamination of our community which is entitled "Blood Runs Not Just Through Our Veins But Through Our Minds: How Has The Global Politics Of Blood Impacted On The UK Haemophilia Community?" The aim of this study was to provide a critique of the Self-Sufficiency Report (SSR) analysing the documents included in the Government report but perhaps more importantly examining those papers that were excluded which the Government claimed were lost or "inadvertently destroyed." As part of my dissertation I also devised a detailed questionnaire which was sent out to

haemophiliacs and partners respecting their right to confidentiality if requested. The aim of the questionnaire was to identify key themes within the haemophilia community, to look at how being infected with HIV/HCV had affected their personal identity and that of their partners and also to establish how participants viewed the organisations that were supposed to support and treat some of the most vulnerable patients in society. It is important to consider the replies to the questionnaires supplied by haemophiliacs and their partners across the UK. There are reoccurring themes expressed by participants with regard to patterns of behaviour from professionals in relation to informed consent and testing for infectious diseases without permission. This has been a common complaint amongst patients

I am aware that I have very limited time today and I ask that the panel read my dissertation which I have provided alongside a copy of the Self-Sufficiency Report which is included in the appendices. I claim that evidence within the study also changes the timeline of who knew what and when in relation to the risks of HIV and hepatitis C. I believe I have also demonstrated that much of the evidence in relation to alleged incompetence, cost-cutting, and the prioritisation of economy over safety has been withheld from the public domain. Reporters on the BBC 2 programme "Newsnight" refer to a number of my documents in their film on contaminated blood and I ask that the panel consider the content of this film when they are looking at all the evidence.

Testing Without Permission- My husband's Case

My husband was informed in my presence in May 1994 for the first time that he had been infected with hepatitis C. Pete did not give informed consent to test for HCV that time, in fact a note in his medical records from that period states clearly "no to testing." In 1994 we were starting to read about hepatitis C in haemophilia literature but wanted to research this issue and consider the implications of testing first rather than make a spur of the moment decision. We did not know at that stage that Pete had already been tested without his knowledge and consent.

An earlier test result in his medical records revealed that Pete was in fact tested on 24/12/92 without pre or post test counselling and against General Medical Council guidelines. I accompanied him to all hospital appointments as this time as we were preparing all our medical equipment for a long trip abroad in January 1993. I would like to point out that blood given for clotting levels should not be used for testing for infectious diseases without the full consent of the patient. In fact we went abroad for over a year in 1993 unaware that Pete was infected with HCV and because of this we were not insured for hepatitis C and its complications. This could have been disastrous if Pete had fallen ill during this period. Pete did have very expensive insurance to cover him for HIV and related illnesses which ironically we had to pay for ourselves even though he was infected through his NHS treatment.

GMC Investigation

We asked the GMC to investigate the matter of testing without permission along with the cases of several other Newcastle patients that had similar experiences. The GMC concluded that it wasn't that what we said hadn't happened but because the doctors had failed to documents matters like pre and post test counselling and written consent they couldn't reach a conclusion through lack of information in the medical records so doctors had to be given the benefit of the doubt! According to one staff member at the GMC doctors were apparently claiming that the RVI Haemophilia Centre was all one big happy family and therefore they didn't always write such things down. I find it interesting that with regard to our complaints to the GMC the doctors concerned were able to see everything relating to our complaints yet we were not able to see any of the doctors' replies so we had no way of arguing against what they had written. I find this is a grossly unfair system weighted entirely against the patient which allows the medical profession ultimate protection. All the cases were dismissed across the country. It is worth noting that 19 of the 20 participants in my MA haemophilia questionnaire claimed either they or their partners were tested for viruses without their knowledge and permission.

Peter Longstaff – Treatment Background

In the early 1970s when my husband had a bleeding episode he was treated with cryoprecipitate from single or a small number of UK volunteer donors (around 10). Pete found cryoprecipitate to be an effective treatment although it required trips to hospital and in fact he returned to using it during his initial period of treatment strike in the late 1990s/2000 when he refused to be treated with pooled plasma from paid donors. (I will explain this later). Around 1973/74 the UK began licensing pooled factor concentrates

imported from US paid donors. These were virally "high-risk" donors including prisoners and "skid-row" donors and the plasma pools at their largest could contain up to 60,000 donors (see dissertation). As you can imagine the risk of contracting hepatitis went from a low risk in well screened UK volunteer donors providing single or low donor cryoprecipitate to an extremely high hepatitis risk. I question why haemophiliacs were discriminated against in terms of their medical treatment. Other NHS patients requiring blood were given blood from well-screened volunteer UK donors and there was a strict code of practice with regard to the collection of blood in the UK which was seen to be among the safest in the world. How then could the UK Government ignore the importance of their own safety rules when it came to the haemophilia community and source treatment products from large plasma pools from the highest risk donors in the US?

It must be remembered that the US companies also sourced at one time from countries in Central America where the impoverished people of Belize, Nicaragua, etc were exploited for their blood in practices which also put the donors' health at risk (see dissertation). The World Health Organisation (1975) provided good practice guidelines in relation to both donors and recipients and advised at that time that if you had a country with a low incidence of hepatitis such as the UK, Governments should not source from countries with a higher incidence of hepatitis such as the US. I would like to acknowledge that no treatment comes without risk but the question is what is the level of that risk, who decides what is an acceptable risk, and is the risk known and understood by patients and relatives.

Safety Warnings To The UK

As far back as 1975 Dr J Garrott Allen wrote a letter to Dr William Maycock at Blood Products Laboratory (BPL) (see dissertation for full letter) describing one American plasma product Konye as "extraordinarily hazardous" with a 50 to 90% hepatitis risk. As Garrott Allen explained this was because Cutter's source of blood was 100% from skid-row derelicts. He refers to a new strain of hepatitis that is not A or B (Non-A, Non-B, later known as hepatitis C) and states, "it still seems to be more frequently encountered in the lower socio-economic groups of paid and prison donors. It is minimal among volunteer donors." The UK was very clearly warned about the dangers of imported plasma in this letter. In order to write my MA I examined many medical journal articles and documents related to the sourcing of plasma from the 1960s onward. Garrott Allen had studied hepatitis for many years even before this time, hence the warning that pooled plasma was inherently dangerous. He was later quoted as saying that drug companies had known all along that "no medical, economic or social reason could justify ever using pooled plasma and its concentrates. Large pools are highly profitable but medically bankrupt." (Starr, 1998, p. 317).

Unethical Treatment

I ask the panel to consider why such an unethical treatment could have been allowed onto the market by UK licensing authorities BEFORE financial investment was put into developing a way to eliminate hepatitis viruses such as A and B even before the emergence of NANB hepatitis? As doctors and scientists are so keen to remind us history has shown it is not "if" a new virus emerges but "when", this is an inevitable fact. If money had been invested into finding a process to eliminate hepatitis viruses many people would have escaped infection with both hepatitis C and later HIV. What

happened instead is that Governments, pharmaceutical companies and the medical profession reacted only AFTER HIV came along. Viral inactivation was developed quite quickly but by then it was too late for many haemophiliacs. I feel we will look back on this period of medical history as a moment of madness, the madness lays in the fact that so many doctors went along with this new factor concentrate treatment whilst ignoring the dangers. It was marketed as a miracle treatment when trials on humans began in the UK. The medical profession/Government/pharmaceutical companies will tell you that haemophiliacs "demanded" this experimental treatment, but what they won't tell you is that they did not bother to discuss where the treatment was sourced or make sure haemophiliacs knew the risks of this treatment. The Nuremburg Code states:

> The voluntary consent of the human subject is absolutely essential. This means that the person involved should have the legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of consent or coercion and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiments; the methods and means by which it is to be conducted; all inconveniences and hazards reasonable to be expected; and the effects upon his health or person which may possibly come from participation in the experiment.
>
> http://ohsr.od.nih.gov/guidelines/nuremburg.html

I allege that these professionals abused their power adopted a paternalistic attitude and made a decision for their patients that "the benefits of the treatment outweighed the risks." They failed to properly explain the dangers to patients or inform them where the treatment was sourced so that they could be a joint part of the decision making process.

Many haemophiliacs will state that "the risks from pooled factor concentrates outweighed the benefits of the treatment" and their decision to take factor concentrates in the early days was not based on full informed choice. You will no doubt hear the argument from the medical profession that the decision not to tell patients of the risks was part of the culture at the time. Unethical experiments on disabled patients were once part of the culture of Nazi Germany at places like Auswich which I have visited but these practises were grossly unethical, immoral and illegal.

There are many comparisons to be made between what happened to haemophiliacs and the Tuskegee Syphilis experiment which President Clinton apologised for years after the event. This was a research project which tested Black men in the States for syphilis and failed to inform them that they had the disease. Those carrying out the experiment wanted to study the progress of the disease and did not treat these men for their condition. In the same way many haemophiliacs were not informed of their positive hepatitis C test results, sometimes for years, they were infected through their NHS blood products and often no active treatment was offered when it was available. Patients were kept in-house and often not referred over to liver specialists. Treatment only improved when haemophiliacs began finding out about their positive test results and they then had to fight hard for treatment for hepatitis C.

Conflict Of Interest

It has to be remembered that going back to the 1970s/1980 this was an era when a blind eye was turned to financial incentives offered to doctors from plasma companies. This

has been well documented in numerous publications including "Blood: An Epic History Of Medicine And Commerce" by Douglas Starr (1998). I think it is important for the panel to ask any doctor that presents evidence at this Inquiry whether they have ever received financial incentives, money for research, expenses to conferences from plasma companies or acted as consultants to pharmaceutical companies during their careers working with haemophiliacs as "conflict of interest" may have been an issue here. I note for example in 1982 UKHCDO minutes that the post of a haemophilia nurse was funded by plasma companies and the Haemophilia Society also has a history of receiving funding from the plasma companies (see dissertation).

World In Action 1975 Documentary Warning

In 1975 my husband watched a Granada, World In Action "Blood Money" documentary which looked at the collection of US plasma tracing treatment used by Newcastle haemophiliacs back to source. It featured donors that Professor Arie Zuckerman stated "were an offence to human dignity" with donors whom any British physician would have "rejected straightaway" (Starr, 1998, p. 235). After watching this programme in 1975 my husband was so disgusted that he returned his plasma concentrates to his hospital refusing to take them anymore. He recalled for a documentary team that were filming him at one time that one of the treatment bottles bounced off the desk and accidently hit his doctor. He stated that both he and the consultant were angry and a member of staff intervened. Pete was then falsely reassured that this practice had ceased and treatment would no longer be coming from these unsafe sources. However this was incorrect and Dr Peter Jones, Consultant Haematologist at the RVI wrote about his concerns

regarding the sourcing of treatment in medical journals and books just a few years later, this is covered and referenced in the dissertation.

My friend Colette Wintle and I presented a copy of the 1975 World In Action documentary to Lord Hunt at a meeting at the Department of Health, yet there is no reference to this or the Garrott Allen letter in the Self Sufficiency Report. Lord David Owen recognised the dangers of using imported blood and that is why he made a parliamentary commitment to self-sufficiency in the mid-1970s and put funding aside for this to happen. Unfortunately when he accused the Government of "gross maladministration" his records which I understand were supposed to be kept for 30 years were also "inadvertently destroyed".

Post Mortems

The post-mortem examination on my husband which utilised all his volumes of medical records from birth to death stated that:

> One way or another all the significant disease found at the post-mortem examination has either indirectly or directly occurred as a consequence of viral infections apparently transmitted during human factor VIII therapy and/or as a result of the various treatments which Mr Longstaff had undergone for the complication of those infections."

To add insult to injury I also found out at the inquest that Peter had been infected with a hospital acquired infection, C Difficile.

My brother-in-law Stephen's death certificate states "1a) Bronchopnemonia due to b) Malignant Lymphoma due to c) HTL Virus Infection 2) Haemophilia. Both Peter and Stephen were informed of their HIV infection after being tested in 1985 and told by their consultant at the RVI hospital Newcastle that they were infected through the American plasma.

PHLS Warning To Withdraw Treatment Because Of AIDS

I have a letter from Dr N S Galbraith former director of the Public Health Laboratory Service dated 9th May 1983 sent to me with his permission which called for all US plasma manufactured after 1978 to be withdrawn from use because of the risk of AIDS. Dr Galbraith showed great foresight. He laid out his reasons for the withdrawal which included the sourcing of US plasma from donors deemed to be at high-risk of transmitting AIDS and also the fact that haemophiliacs in the US and Spain that had been treated with US factor concentrates were showing symptoms that indicated AIDS. This letter was sent to Dr Ian Field at the DHSS but the treatment was never withdrawn. (This letter is presumed to have been "inadvertently destroyed" by Government as it did not appear in the Self Sufficiency Report either).

Susan Douglas of the Mail On Sunday (1st May 1983) had also written a well researched article on "Killer Blood" coming from the US which was quoted by Dr Galbraith. She had even warned of and located the first two cases of UK haemophiliacs with symptoms of AIDS in UK hospitals and spoken to the families. The reward for her article was a

complaint to the Press Complaints Commission by Dr Peter Jones describing her article as alarmist and upsetting to patients. Yet according to HIV litigation papers, earlier that same year Dr Jones had noticed immmunological abnormalities in his own patients similar to AIDS. Douglas later fought back with an article on the 25th November 1984 entitled "AIDS This Scandalous cover-up." On June 24th 1983 six weeks after the Galbraith letter doctors Rizza and Bloom wrote to all haematologists stating there was insufficient evidence to warrant restriction of the use of imported concentrates on haemophiliacs other than certain restrictions in children and mildly affected patients. Had Dr Galbraith's warnings been heeded I believe many lives could have been saved. However as my dissertation shows Government failure to adequately invest in BPL meant that relying on UK production alone would have been very difficult. A document from D Harris to M Prescott at the Treasury Department dated 31st July 1981 (see dissertation) states:

> In 1979 the Laboratory was inspected by the medicines Inspectorate. The gist of the Inspector's report was that conditions of manufacture at BPL were "unsafe and potentially hazardous to patients" The report concluded that, "If BPL were a commercial operation we would have no hesitation in recommending that manufacture should cease until the facility was upgraded to a minimum acceptable level."

This letter was not included in the Self-Sufficiency Report and is presumed to be another document which was "inadvertently destroyed."

Litigation

As mentioned before, an inquest was held into Pete's death due to the fact that I have a legal case in America against four US pharmaceutical companies that supplied factor concentrates to the UK. No-one at the hospital advised me that there must be an inquest if there is an ongoing legal case and I only found out when I made a chance remark to a clerk when going to register my husband's death. The legal case is in relation to alleged safety violations and dangerous practices including the use of prison plasma from virally "high-risk" donors. I instructed our former solicitor to set up contact with legal firm Leif Cabraser Heimann Bernstein after I heard about their work through haemophilia campaigners in the US. This was for my husband, it was then opened up to other haemophiliacs. The companies involved were originally known as Armour Pharmaceutical Company, Bayer Corporation and its Cutter Biological Division, Baxter Hyland Corporation and its Hyland Pharmaceutical Division and Alpha Therapeutics Corporation.

Arkansas Prison Plasma

I would like to point out that at a meeting with Yvette Cooper in the Department Of Health where I spoke about the use of US prison plasma Ms Cooper clearly stated in front of witnesses that if we could prove that haemophiliacs had been treated with prison plasma the Government would investigate this matter. Given that Yvette Cooper has worked on a past Clinton campaign in Arkansas I would imagine that she is well placed to request the assistance of the former Governor of Arkansas Bill Clinton whose former finance chairman Leonard Dunn of Health Management Associates was awarded the lucrative plasma contracts for the prison (Ruddy and Limbacher, 2001). As Clinton now travels the world preaching on AIDS prevention surely he should be willing to assist with

investigations into a past prison plasmapheresis programme in his own back yard. Perhaps the Inquiry could officially approach him in writing for his help in securing the relevant documentation relating to Cummins Unit.

I would like to quote from a letter written by my friend Arkansas documentary maker Kelly Duda who made an excellent documentary "Factor 8: The Arkansas Prison Scandal." Kelly's letter was submitted as evidence to our former QC Stephen Grimes in relation to Pete's past legal case in the High Court for the right to be given the safer recombinant, synthetic treatment as opposed to human plasma. We wanted to explain why Peter felt so strongly about the use of paid plasma donors as he and many other haemophiliacs throughout the world were victims of this immoral "blood for money" trade after receiving prison plasma from the US in the 1970s and 80s. He states:

> The prison system remained unconstitutional in May 1980, when for three days, Peter Longstaff infused several vials of Koate, the brand name of Cutter's factor concentrate, to stop a bleeding episode. He had no idea when he took his medicine from Lot number NC8196 that it was made with the plasma of 297 inmates from Arkansas and an undetermined number of convicts from Avon Park, Florida. John Andervont, a former Inspector and retired director of Blood Center Licensing for the FDA, remembered catching inmates performing phlebotomies at the Arkansas prison. Bill Douglas, a former Arkansas inmate infected with hepatitis C, who sold plasma regularly at the time Longstaff infused Cutter Lot NC8196, stated: 'They didn't care. If you had to crawl to get there you were able to give blood.'

My friend GRO-A , the sister of a Cummins Unit plasma donor also wrote a letter to Tony Blair dated 22nd March, 2001 which I handed in myself at 10 Downing Street accompanied by a number of MPs and I believe Lord Morris. We have never received a reply. One quote from GRO-A reads:

My brother, GRO-A was a prisoner in the Cummins Unit from 1984 until his death from hepatitis C on March 14th 1999. Neither my brother nor his family was aware of the fact that he had this virus until approximately 1996, but according to John Byus, the current Medical Administrator of the ADC, GRO-A had the virus at the time he was first incarcerated there. During part of the time that my brother was donating plasma, Mr. Byus, a Registered Nurse worked in the Cummins Unit Infirmary, so he is in a position to know this fact. GRO-A was, nonetheless permitted to donate plasma at every collection session from 1984 until the programme was terminated in 1992.

The alleged safety violations in the letters from Kelly and GRO-A make shocking reading and former prisoners have given testimonies to support US haemophiliacs in courts in the US. I would like to state I make no judgement on those who sold their blood but condemn those who set up the prison plasmapheresis programmes and I can supply the panel with a document from 1984 entitled "Plasmapheresis Centers In Correctional Institutions: An Information Bulletin" which gives an idea of the safety issues involved.

Kelly is willing to testify and show his evidence to the Inquiry and I am sure GRO-A would too even if it is by video link.

Treatment Strike

My husband led a treatment strike for 5 years from around 2000 refusing to take human plasma on moral grounds as the UK was still relying on the use of paid US plasma donors for the manufacture of factor concentrates and also an alternative safer treatment was available which the Department of Health and local Trusts refused to prescribe on the grounds of cost. Pete and I strongly opposed this immoral trade where international companies continue even today to exploit sick and impoverished people around the world who sell their blood for a pittance. Plasma is often collected using dangerous

practises which then infects the recipients. I was able to educate myself further regarding this extremely profitable business on my recent visit to China to meet and interview infected haemophiliacs there. Richard Titmuss wrote a book in 1970 very familiar to many haematologists called the Gift Relationship where he directly compared the UK system of blood collection to that of the US. I urge the panel to read this book which I refer to in my dissertation. His words which were then a prediction are now a reality:

> Short of examining humankind itself and the institution of slavery- of men and women as market commodities- blood as a living tissue may now constitute in Western Societies one of the ultimate tests of where the "social" begins and the "economic ends. If blood is considered in theory, in law, and is treated as trading commodity, then ultimately human hearts, kidneys, eyes and other organs of the body may also come to be treated as commodities to be bought and sold in the marketplace.

(Titmuss, 1970, in revised edition, Oakley and Ashton 1997, p. 219).

CJD

In addition to receiving US prison plasma, Peter received UK blood products from the Blood Products Laboratory (BPL). My husband was also more recently exposed to plasma from UK donors infected with v CJD although examination of his brain after death by Professor Ironside of the CJD Surveillance Unit, (with Peter's pre-planned informed consent) showed that he was not incubating vCJD. For a number of years however we were not told of Peter's exposure to v CJD until I was sent leaked letters which originated from the Leeds Executive and BPL which said to withdraw the treatment and included the batch numbers but not to tell haemophiliacs. I sent copies of

these to the Guardian around 2000 and the Government were then pressurised to change their position, do a look-back excercise and ask patients if they wished to know of their exposure. Withholding of such information was of great concern to Peter and I. As a full-time carer not knowing at that time if he was infected and administering his treatment intravenously plus dealing with blood spillages I was potentially put at risk.

It is also important to note that I wrote to the Government and local health authority as far back as 1996 begging them to learn from the mistakes regarding HIV and hepatitis C and err on the side of caution. I requested that patients be treated with recombinant. The Health Authority turned us down on the grounds of cost in the Spring of 1996 and Pete's first exposure to v CJD was in the Autumn of that same year thus was avoidable. Patients including young haemophiliacs that have been exposed to v CJD now live with the added worry of not knowing if they are incubating the disease.

I even had to ask for guidelines on how to deal with a blood spillage with regard to v CJD but was passed from pillar to post with everyone reluctant to put anything in writing. Telephone advice was at best contradictory from "don't worry just wash bloody clothes as normal" to "dispose of soiled clothes in special bio-hazard bags". Many carers have still not been given proper advice on how to deal with blood spillages regarding v CJD. There was one incident where Pete bled onto the carpet and I rang the insurance company who rang a Public Health department. My carpet was removed by men who would not cross my doorstep until they had donned full bio-hazard suits, (I have photographs of this) the waste was then sent from Newcastle to Leeds to be incinerated. A blood-stained sofa was disposed of in a similar way. All this was very distressing to my

husband as he was very angry that no-one at the RVI hospital seemed to care about the safety of the carer.

HIV Litigation/Hepatitis Waiver

My dissertation argues that the dangers of NANB (hepatitis C) were known about much earlier than the Government claims in the Self-Sufficiency report. I also have a Hepatitis C State Of Knowledge document paid for with Legal Aid funding and written for our solicitor by Professor Preston which I can submit to the Inquiry. Preston concludes:

> During the mid-1970s and early 1980s, there was clear evidence that non-A, non-B hepatitis was an important cause of post-transfusion hepatitis. In 1978, we demonstrated through liver biopsy, that there was clear evidence of chronic liver disease in our haemophilia patients and that this was attributable to non-A, non-B hepatitis"

One issue that disturbs many within the haemophilia community is the fact that haemophiliacs were made to sign a hepatitis waiver in the HIV litigation that they would not take further legal action for hepatitis infection. The Government, medical profession, Haemophilia Society and even the solicitors acting for haemophiliacs were all telling haemophiliacs in 1991 that hepatitis C was nothing to worry about. In fact the Haemophilia Society asked two trustees to look into hepatitis and consult with medical experts. Society minutes of 1992 conclude that it is not a problem for haemophiliacs. I asked former Chief Executive Karin Pappenheim to name the medical experts that could have said this in 1992 but she was uncooperative. Although campaigners' relationship with the Society has definitely improved I have many letters showing their past attitude to those infected. The Haemophilia Society were divisive when running their campaign, dividing those with HIV and those with hepatitis C which was very distressing. We also

had to fight very hard to stop the Society from dropping their campaign for a Public Inquiry.

I have a QC legal opinion on the hepatitis state of knowledge issue at the time of the waiver (which again I can submit). I wish to state that according to Matt Kelly QC, GRO-D GRO-D solicitor acting for haemophiliacs "did play-down the significance of hepatitis C" saying that it was "no big deal." Yet the Re-Amended Statement Of Claim under the heading "Hepatitis and/or other viral infections" shows that Hepatitis C was pleaded as one of the consequences of infected blood products. As Matt Kelly QC points out:

> At Paragraph 20 for example it is clearly pleaded that haemophiliacs were at great and particular risk of infection with Hepatitis B and/or NANB viruses and/or other viral infections from blood products used by them which, in the case of Hepatitis B and/or NANB could cause a serious illness of jaundice, liver disease and could sometimes lead to death, and in the case of other viral infections could cause serious illness and could lead to death. The same was pleaded in relation to the risks of commercial concentrates."

Matt Kelly concludes,

> I have the greatest sympathy for Mr Longstaff. His life has, not to put too fine a point on it, been destroyed by the infected blood he was given. He was told by one of the key solicitors in the litigation not to worry about hepatitis C when it was plain that hepatitis C carried with it enormous risks and was a matter of grave concern.

Why did all these professionals play down the dangers of hepatitis C? I suspect it was to save money and avoid further litigation.

Lord Warner Misleads The House

Pete was a registrant of the Macfarlane Trust, I am registered as a partner. Pete was also a recipient of the Skipton Fund. I feel that it is important to mention that the Government not only made serious mistakes in sanctioning the use of products sourced from prison plasma but they also continue to mislead the public with regard to financial schemes in place for haemophiliacs and this needs to be corrected and placed on record. When Lord Warner was asked why the UK Government did not pay out to haemophiliacs and the bereaved on the same level as Canada and Eire he gave the following response in Hansard 5th February 2004.

> My Lords, the awards that were made in Ireland and Canada followed public inquiries or criminal charges which established that wrongful practices were employed. The payment structure of those schemes were therefore based on claims for punitive damages. We do not acknowledge any wrongdoing in England, so it is not fair to make a comparison between those schemes. The Macfarlane Trust will not be involved in this scheme, but there are significant differences.

I would like to say that with regard to our nearest neighbour Eire this statement is totally incorrect and shameful, and despite Lord Warner being in receipt of my evidence he has failed to apologise or raise the level of payments to match Eire (which is around 10 times the level of payment compared to the UK) and include widows and other significant bereaved. Here is my evidence from both Ann McGrane, the Blood Policy Division of the Eire Government and Raymond Bradley Malcolmson Law solicitors that represented haemophiliacs in the Lindsay Tribunal (Public Inquiry) Eire.

Anne McGrane (Assistant Principle Officer) wrote to me on the 26th February 2004 and pointed out that the Hepatitis C and HIV Compensation Tribunal is a no-fault compensation scheme, and she states:

> As you rightly point out, compensation for persons with haemophilia was made on compassionate grounds, without legal liability on the part of the State. He (the Minister acknowledged extraordinary suffering endured by persons with haemophilia who were infected, and by their families."

In a letter to me dated 17th February 2004 solicitor Raymond Bradley wrote:

> A non-statutory Hepatitis C compensation tribunal was established in late 1995, almost one year in advance of the establishment of the Finlay Inquiry into the circumstances of infection of women with Ant-D Immunoglobulin. This compensation tribunal was placed on a statutory footing with the Hepatitis C Compensation Tribunal Act 1997, which was brought into effect by Ministerial Regulation on the 1st November 1997.

How can a haemophiliac's life in Eire be worth around 10 times more than the life of a haemophiliac in the UK. We have two cases which show how ridiculous and grossly unfair this is:

1) There is the case of a haemophiliac in the UK that received blood products from both Eire and the UK and was eligible for both Government pay-outs, one at approximately 10 times the level of the other. Yet the schemes for both were the same in terms of the fact that they were both no fault recompense schemes that came about in advance of a Public Inquiry

2) There is the case of a female haemophiliac where she was given contaminated blood in England/Scotland and her cousins were both given contaminated blood in Eire. Her cousins were recompensed at around ten times the level. To reiterate both schemes were the same in terms of the fact that they were both no fault recompense schemes that came about in advance of a Public Inquiry.

I suggest that the only reason the Government has not paid out at the same level as Eire is that they have infected more than ten times the number of haemophiliacs in the UK through contaminated NHS blood and the simple explanation is they deem it too expensive. The Government now needs to apologise and rectify the situation matching the Eire payments.

Widows

I would like to educate the panel on the situation of the widows whose husbands died of hepatitis C such as my friends here today Maureen Murphy and GRO-A Many widows gave up their careers to care for their husbands and lost pension rights. In addition to the terrible distress of the loss of their loved ones, some then had to give up the family home as they did not receive a penny in recompense. Some are now worrying how to make ends meet on basic state benefits of around £57 a week. This is a disgrace after all they have been though and the Government needs to remedy this situation now that they have had the correct facts about Eire laid in front of them and bring payments in line with those in Eire.

My Situation As The Wife Of A Haemophiliac

I did not have my own children as I was afraid of infecting a child and there was little help and support available in the past to those who wanted to conceive. This remains a difficult issue for me to discuss. In the early days on the one occasion I did become pregnant I was treat with insensitivity and prejudice, asked to sign a sterilization form (which I did not do) and made to wait for hours whilst doctors argued who would remove the foetus of my dead baby after a routine scan showed no movement. The hospital staff discussed in public where this should take place so people around overheard, although I tested negative for HIV/HCV they considered me an infection risk. Procedures were supposed to be in place to treat everyone equally as though they might be infected but I was singled out in public. After the procedure was over I was so angry I showered and took my own blood pressure and temperature with the help of Pete and discharged myself within an hour as their attitude to me was appalling. I felt very hurt, vulnerable, and "dirty"!

The prejudice and Pete and I experienced would fill a book. There was also anger from professionals with regard to campaigning and our stance on treatment. I used to feel very guilty at leaving Pete alone in hospital as he would beg me not to leave him as doctors tried to pressurise him into taking factor concentrates when he had stated many times in writing that he did not want this. I was forced at one point to obtain a private psychiatric report from Dr Tyrie, a Consultant Psychiatrist after an incident when Pete was suffering from severe depression, ascites, and confusion as his liver was failing not long before his death and he was given factor concentrates whilst in this state.

One of my worst memories is of Pete being so unhappy with his treatment in hospital that he discharged himself. I requested an ambulance to take him home as he was too weak to climb the stairs and we were awaiting a stair lift to be installed. The staff told me it would take two days. Pete could not bare to wait and we got a taxi home. It took him 7 hours to crawl up the garden path on his hands and knees and up the stairs as I could not lift him. One of my neighbours wept when she saw him and tried to help us.

Pete's Death

Pete had some faith restored in the medical and nursing profession during his final months at St Oswald's Hospice. I could no longer care for him at home after he fractured his femur. By then his liver could not even take the anaesthetic needed in order to set the fracture. Pete was eventually transferred to a liver unit for further clinical investigations but deteriorated rapidly with C Difficile. On the day he died he was in a lot of pain. We were both told it was near the end and Pete signed "not to resuscitate." We were waiting hours for an ambulance to transfer him back to the hospice where he wished to die. I was terrified to lose him but knew there was no hope and wanted him to die quickly so he could be out of his distress. He died a horrible death in a hospital corridor whilst in transit. He had lost his swallow reflex and he drowned in his own fluid, with fluid shooting up like a fountain into his oxygen mask his arms clawed the air, there was total fear in his eyes. I have nightmares about this. I ripped off his oxygen mask to make his death quicker as it was the last thing I could for him but he thrashed around for a few minutes and died as the ambulance men being wheeled him back to his room. I can still see all the visitors looking at us in horror.

Conclusion

I maintain that blood safety is not just an issue for haemophiliacs but also for the general public. It is an issue for anyone that might ever need a blood transfusion, whether for an operation, during pregnancy, for burns, or car accidents victims, and it is only through learning from past mistakes and unethical conduct inflicted on the haemophilia community that we can improve blood safety. All our white cell plasma now comes from the US because we cannot use our own plasma due to the risk of v CJD. Therefore we need to ensure that these American companies are not continuing to ignore safety regulations by using paid donors from "high-risk" sources. As previously stated it is not a question of if a new virus emerges but when and we must be prepared for that eventuality!

SECOND STATEMENT TO CONTAMINATED BLOOD AND BLOOD PRODUCTS INDEPENDENT INQUIRY

BY

CAROL GRAYSON

Introduction

My name is Carol Grayson, I am the 47 year old widow of Peter Longstaff. Both my husband and brother-in- law were haemophiliacs that died of HIV/HCV as a result of

receiving contaminated factor concentrates, Peter died in 2005, Stephen in 1986. First of all I wish to say thank-you to the Inquiry panel for inviting me to present a second submission today and Vijay for passing on evidence to the panel as and when I find it. Please feel free to interject and ask questions where necessary!

I have campaigned for many years and formally set up my own campaign group Haemophilia Action UK in 1994 running a "bad blood" campaign with the Newcastle Journal www.the-journal.co.uk search Carol Grayson. I also wrote an MA Dissertation entitled "Blood Runs Not Just Through Our Veins But Through Our Minds: How Has The Global Politics Of Blood Impacted On The UK Haemophilia Community?" This provided a critique of the Government Self Sufficiency Report (2006) using documents that the Government claimed to have "inadvertently destroyed". I fought to have these documents released by the Government under the Freedom Of Information Act with help from Newcastle solicitors Blackett, Pratt and Hart. My dissertation also investigated the impact of HIV/HCV infection on haemophiliacs and their families, exploring their attitudes to the national organisations/institutions that were set up to support them. The national Haemophilia Society are kindly supporting the publication of the dissertation and it will go to the Trustees shortly for a formal decision and hopefully should then be available to all those who have requested a copy.

Undisputable Facts/Experimentation On Prisoners And Prisoners As Plasma Donors

This second submission has given me the opportunity to flag up certain issues, tighten up my evidence and challenge some statements brought to the Inquiry by previous

witnesses. The Inquiry is still considering the issue of UK self-sufficiency in blood products which was never achieved by the UK government and why self-sufficiency was so important. I would like to start by reiterating the fact that my dissertation demonstrates using evidence from many different sources that it is an undisputable fact that imported factor concentrates were known to be manufactured from dangerous "high-risk" sources and transmitting hepatitis PRIOR to the licensing of the first imported US products in 1973. So I would ask once again why was such a dangerous and unethical treatment such as pooled factor concentrates licensed not just for import but licensed at in any event **PRIOR** to the manufacturers investing in finding a method of eliminating hepatitis viruses. Who is finally going to take responsibility for this decision?

What more do we know about the prison environment in which plasma was collected? I wish to elaborate on a specific issue briefly mentioned by Kelly Duda in his documentary "Factor 8: The Arkansas Prison Plasma Scandal." I wish to highlight that it is an indisputable fact that from the 1960s through to the 1970s US prisoners were used as guinea- pigs in a variety of unethical experiments which led to severe illness, death, and a number of unmarked graves of inmates that did not survive this experimentation. I would like to draw particular attention to the link between the unethical experimentation on prisoners and the fact that prisoners also became plasma donors, prison plasma was collected through a plasmapheresis programme manufactured into factor concentrates, imported and injected directly into the veins of haemophiliacs in the UK. I would like to draw the panel's attention to a British Medical Journal article by Allen M Hornblum called "They Were Cheap And Available: Prisoners As Research Subject In Twentieth Century America." It is an excellent article but one key point is missing, there is no

mention of the health issues for recipients of prisoners' plasma. The article informs us that "prisons tested everything from tropical diseases and respiratory infections to infectious hepatitis" (BMJ 1997: 315: 1437-1441, 29th November).

It is an undisputable fact that what you had here was a captive group on which to experiment and a population of prisoners that were deliberately exposed to infectious hepatitis amongst other things. From documentary filmmaker Kelly Duda's research for "Factor VIII: The Arkansas Prison Plasma Programme" we are made aware that it is an undisputable fact that prisoners admitted to having unprotected sex with other prisoners, shared needles to inject drugs, sold their blood and sometimes moved between prisons creating a reservoir of hepatitis infection throughout the penal system. This infection could be there as long as the prisoners were there and it is an undisputable fact that prisoners could still transfer hepatitis viruses to others years later long after the viral experiments were stopped on ethical grounds! It is also an undisputable fact that the UK Government and its licensing authorities sanctioned treatment that came from unethical and highly dangerous sources. This was madness and went against all our own UK safety rules.

I submit two quotes regarding the controversial career of Dr Austin Stough who worked on prison plasma programmes. Stough ran a business that quote,

> claimed to have grossed close to $1 million dollars a year, Stough- and the pharmaceutical companies he worked for- profited handsomely, while the inmates he used were made ill and some even died in an extended series of drug tests and blood plasma projects in Oklahoma, Arkansas, and Alabama.

Some of my husband's treatment batch numbers were traced back to Arkansas State Penitentiary. Quote,

> Stough's high volume plasmapheresis programme attracted great commercial interest, but his poorly trained staff and shoddy operations resulted in inmate volunteers receiving the wrong blood type and as many as 30 inmates a month contracting viral hepatitis."

No surprise here then that Dr Garrot Allen aware of the risks associated with prison plasma warned the UK against using imported factor concentrates in 1975 and informed the UK of the "extraordinarily hazardous" non-A, non-B hepatitis risk with a risk level between 50 and 90% infection rate from some products manufactured from prison blood with half of the cases proving fatal. He also noted that non-A, non-B hepatitis was a much more virulent strain of hepatitis more commonly found in prisoners, (see dissertation Appendices A Garrott Allen letter). Just to reinforce Garrott Allen's concerns about the very concept of factor concentrates as an ethical treatment he was quoted as saying, "that drug companies had known all along that "no medical, economic or social reason could justify ever using pooled plasma and its concentrates. Large pools are highly profitable but medically bankrupt" (Starr, 1998, p. 317). I would request that the panel check back to my first Inquiry submission especially the part "safety warnings to the UK."

I draw attention to the following quote from Dr Charles Rizza reflecting on past knowledge of non-A, non-B hepatitis, "we recognised in the mid 70s and early 80s that all of the - concentrates were infected with non-A, non- B hepatitis" (Adams. J. AIDS: The HIV Myth, p.104, 1989) -so why were patients not told this as part of the duty of care to inform patients of risk in order to make an "informed choice" regarding treatment. I would also like to point out that when haematologist Dr Mark Winter gave his evidence on behalf of the UKHCDO he talked about non-A, non-B being discovered in 1975, the article I have here is earlier from the Times, Nov 12th 1974 and states that in the United States up to 90% of transfusion associated illness is caused by this third non-A, non-B agent."

I would like to point out that in the US authorities right up to the Director at the Center For Disease Control were informed just how dangerous prison plasma was as the July 24th 1975 letter in my dissertation Appendices A shows. I point out that this was never meant for publication but it needs to be seen in the UK. Quote,

> Over a 2-week period in February- March 1974, 11 clinical and 8 sub-clinical hepatitis cases were detected among inmates at the Kansas State Penitentiary. The majority were HBsAG –POSITIVE. Investigation revealed that 18 of these 19 cases were in plasma donors at the prison plasmapheresis centre; risk of hepatitis could not be definitely associated with the plasmapheresis operation, since intravenous drug abuse –including the
>
> sharing of needles – was commonly practiced by plasma donors.

I cannot emphasise too strongly that this was the type of dangerous treatment licensed for import by UK authorities, the new "wonder" products that haematologists encouraged their patients adults and children alike to inject without informing them or the parents of the risks associated with these products. Doctors and scientists continually talk about the lower life expectancy off haemophiliacs in the past. Haemophiliacs did have a lower life expectancy before the introduction of cryoprecipitate but it is important to remember that patients survived on cryoprecipitate for years before the concentrates were introduced. Some severe haemophiliacs were already well into their 30s before they ever used factor concentrates. My dissertation expresses the views of many haemophiliacs that in their view as they have since learned of the risks from treatment is that the risks from factor concentrates far outweighed the benefits!

I would like to comment here that presumably the US plasma companies must surely have taken these risks into consideration when choosing prisons as a source of plasma, so I have asked the US lawyers to try to obtain from the plasma companies their documentation on risk assessment regarding plasma collection in prisons. For example, what documents do they hold on the deliberate infection of prisoners with infectious hepatitis (such as in Arkansas) and the deliberate exposure of prisoners to respiratory infections and tropical diseases? What information do they hold on prisoners that were sick or those who didn't survive the Auswich-like experiments, the ones who died and are buried in unmarked graves? What was the US plasma companies risk assessment regarding the dangers of collecting in prisons given that once prisoners were infected these viruses would be there for decades and potentially in the plasma pools for years to come? Could these American companies provide our lawyers with their risk assessment

and can the UK Government explain why they considered such plasma sources to be safe with regard to importing factor concentrates for UK haemophiliacs? Perhaps the Inquiry could take this issue to the Department of Health. I have asked my MP Jim Cousins to raise parliamentary questions on this issue and also to remind Yvette Cooper that when she was working in the DOH and met with a group of haemophiliacs and MPs she promised that if we could prove that UK haemophiliacs had received US prison plasma the UK Government would investigate this matter. We have proven this but are now waiting for the Government to act as promised! I would ask the panel to check out the US Department Of Corrections document (1984) submitted via Vijay which looks at both AIDS and hepatitis risks in prisons and the fact that there was a higher risk in prisons and that this would be an issue for haemophiliacs. Well it would have been a huge issue for haemophiliacs in the UK had they known all the facts! The names of plasma companies contributing to this document and involved in using prison plasma are contained in this document.

Paid Donors- Current Issues

I would like to come right up to date on the issue of paid plasma donors following on from what we have known for years about the dangers associated with paying donors in prisons, on skid-row etc for their blood. We currently import white cell plasma/plasma products from the US. There are some blood products where there is not a synthetic alternative so some patients must still rely on human plasma. I want to draw attention to some current collection practises used by companies which supply the UK and that is the use of paid plasma donors on the US/Mexican border where impoverished people cross over from Mexico to the US to sell their blood. There has long been a safety issue

here regarding remunerated donors and safety concerns/violations along this border were discussed in a documentary which I submitted recently to Vijay for the Inquiry. I have a further article here on this subject, "Crossing The Border To Sell Blood"

http://news.newamericamedia.org/news/view_article.html?article_id=3e985017e737e

I cannot express enough the double standards in the UK by authorities that promote the safety standards of this country such as the use of volunteer, unpaid donors in glossy publications and advertisements yet turn a blind eye to importing plasma products from the US and companies that use paid donors. One of the companies named in this article supplied and I believe is still supplying UK hospitals, certainly my husband stopped taking treatment from this company around 2000 to raise objection to the use of paid donors. How can we go along with a practice that the WHO stated was dangerous and should be stopped as far back as 1975. This is a practice that European directives are supposed to have banned by April 2005. In an article on the Euro-Parliament blood donor ban on Irishhealth.com website, 6/9/2001 it states:

> Voluntary and non-remunerated blood donation was an important means of ensuring safe blood and reduced risks to both donor and patient, the Parliament said. Experience has shown that the type of person who volunteered to give blood was different from the type of person who might feel compelled to give blood for payment. Therefore, MEPs said, blood and blood components should be collected from voluntary and non-remunerated donors only.

http://www.irishhealth.com/?id=2877&level=4

Yet Britain chooses to ignore its own safety regulations not to use paid donors and imports products from remunerated donors!

If we look at the recent example in the press of American toy manufacturer Mattel where they imported toys from China which failed to reach safety standards/laws America, sanctions were placed on the manufacturers and in some cases bans put in place. There should be a clear message to US manufacturers that still use paid donors for products exported to the UK that we will not buy their products unless they meet our own safety regulations and one of those regulations is a ban on the use of paid donors.

http://www.newscientist.com/article/mg13818701.200-bad-blood-in-europe-over-pay

Surely we must ensure that overseas manufacturers reach our high standards of safety regulations if we are to import not fall below our own safety standards.

I would ask the Inquiry panel to recommend to Government to place a ban on products that still use paid donors as this practice remains a cause for safety concern and an example of exploitative and unethical practise. I would also ask that the UK Haemophilia Society review their current policy of accepting lower safety standards for haemophiliacs with imported products and to join me in fighting for the highest possible safety standards and not to compromise on this issue as they have in the past. If they had fought to ban the use of imports that used paid donors years ago many more people might be alive today. Companies have had many years to change their practice and switch over to volunteer donors but as long as haemophilia organisations and the World Federation of Hemophilia promote the use of paid donors there is no incentive for international companies to improve their practice. Why should haemophiliacs in the UK

not expect the same safety standards with blood/blood products as every other citizen in the UK.

I have recently written to the William Clinton AIDS Foundation to request that he both address the past issues of prison blood (particularly the problems associated with the plasmapheresis programme at Arkansas when he was Governor) and the global spread of HIV/HCV, and call for a global ban on remunerated donors in his fight to combat the spread of AIDS. (See Arkansas Times, Aug 16th, 2007, article by Mara Leveritt) where I was interviewed on this subject). There have been very recent global examples of countries using paid donors that have led to many more infections and deaths. Clinton's AIDS Foundation have replied to me and acknowledged my thoughts/insight on the global blood trade but I am still waiting to hear how Bill Clinton will actually address this issue! He will be sent a copy of the dissertation and a response will be requested.

HIV Testing

I read Dr Mark Winter's account of the early days of HIV testing on haemophiliacs and want to raise some questions on matters of concern, perhaps there are other witnesses here to-day that can help provide answers to the issues I raise. I would also like to point out that I too worked in the Health Service during the 1980s when the test was first introduced. I was a nurse caring for some of the first AIDS patients in the UK that came through the psychiatric and addiction services. I felt rather disturbed when I read Dr Winter's account of haematologists' practice at that time and therefore feel I need to present another model of practice that was being carried out during the same period as I

would be horrified that my former colleagues and I be associated with the sort of practise to which he refers. I would like to start with the following quote:

> In September, (1985) the HTLV -3 test as it was then called was widely introduced. It was offered at GUM (Genito-Urinary Medicine) clinics and certain other clinics as arranged and publicised by the District Health Authority. Health Authorities were asked to provide counselling services to people who tested positive, as well as their families and friends.

> Department of Health and Social Services (October 1985). AIDS Booklet 2: Information for Doctors Concerning the Introduction of the HTLV-3 Antibody Test
>
> http://www.avert.org/uk-aids-history.htm

I have here my husband's first positive test result dated 25th March 1985, the specimen of blood was collected on 13th March 1985. I would like to know whether haemophiliacs were used to evaluate these early tests as I believe they were. This raises a number of ethical issues. My husband and his brother Stephen were not blind –tested here. The test forms have their names and details on them. Yet I hardly know of any haemophiliac that was asked if they consented to taking part in evaluating tests. I have here a letter from the recently released Government documents dated March 26th 1985 to a Middlesex hospital talking about the evaluation of anti- HTLV III kits, about the need to evaluate them and the need for a suitable protocol as quote "there is not yet a suitable protocol" this is dated the day after my husband's test result! A DHSS letter of May 31st 1985 reads:

> This is a follow-up to our conversation this morning about the importance that Ministers and the Department attach to completing the evaluation of the AIDS test as rapidly as possible and to have in hand the further steps that are needed when the widespread introduction of tests take place. CMO and I will be reviewing with Ministers on 7th June the position, and I will be grateful if you could let us have flow chart with dates as to when the evaluation studies will be completed and when the Service will be geared up for the countrywide introduction of the test with take-up facilities for confirmatory tests.

A further draft letter states that a report on some kits would be ready by June 1985.

I fully understand the need to evaluate test kits but there are serious ethical implications that should have been addressed first with any study group. The early testing/evaluation of kits should not have compromised patient care but it did. The Department of Health were very clear that counselling should be provided to patients with the introduction of the test as detailed in a circular 3rd May 1985 and that trained counsellors must be put in place in preparation for the introduction of the test. Once again haemophiliacs were treated as guinea pigs and appear to have been used as an early test group to evaluate kits before they were on the general market without a thought as to how these patients and their families would deal with a positive test result:

a) Because their "informed consent" was not sought in the majority of cases

b) They were in many cases being given a positive result without knowing they had been

tested in the first place

c) The doctors delayed for some time or in some case completely failed to put a system in place to provide counselling support and to deal with the terrible fall-out.

As mentioned in my previous submission the importance of "informed consent" and the ethical considerations around this were raised years before in the Nuremburg code following the terrible medical experiments of Auswich and other concentration camps.

In his testimony Dr Mark Winter quotes from Simon Garfield's (The Age Of Innocence p. 55) a book I know well. He refers to doctors at one hospital, one of the major AIDs treatment centres- not specifically working with haemophilia patients and the quote reads:

> We performed a large number of HTLV-3 tests without written consent. Blood was taken from patients with AIDS, patients with Lymphadenopathy……and controls."

He argues that this was a pretty widespread practice, very different to now. Dr Winter stated that the idea that you needed to explain at all times to a patient what blood tests you were doing was not held to be the case. I would agree with Dr Winter on certain points and that is that many doctors were behaving in an unethical way and failing to obtain informed consent. They failed to follow Government guidelines regarding informed consent and also to offer counselling. I would just like to refer to advice from

the Government's chief medical officer Dr Donald Acheson at that time(1985) "he advised against testing for AIDS unless a specific request has been made." Acheson was in the position of Chief Medical Officer from 1983 to 1991, he was actually quick to realise the need for counselling and support to those requiring a test and proving positive. By 1986 the "Don't Die Of Ignorance" campaign followed with health education advertisements on TV and by 1987 a leaflet on the same theme was delivered to every house in the country.

The newspaper article "Tracking The Virus By The Blind Route" by Philip Young describes the ethical debate that was raging at that time of the introduction of the test between human rights activists for the gay community in the form of the Terrence Higgins Trust (formed in 1981) and other AIDS organisations and one north-east haemophilia consultant. THT were warning that "telling unprepared patients they have HIV can have a devastating psychological effect" as Philip Young writes" even totally anonymous testing presents problems. The very nature of AIDS means that random HIV screening could break World Health Organisation guidelines……..and civil rights groups, among others claim it is wrong to test a person's blood without their consent. Viewing the situation through the eyes of a former psychiatric nursing sister I really wish there could be some proper measurable assessment of the psychological damage done to haemophilia patients as a result of unethical practice in a number of areas over the years. To continue if I can quote Jo Dutton spokesman for AIDS North, "I believe that medical investigation should only be taken for the benefit of the patient concerned" Young states "his argument goes to the core of doctors' ethical dilemma." There is further mention of the consequences of testing, psychological, financial if a person is positive and the responsibility to prevent the infection of others. I am not sure why Dr Winter and others weren't aware of this debate. Certainly the gay community were very on the ball and

active on this issue throughout the press from the very early days of AIDS. As a practising nurse this was very much an important issue at that time. Some of my closest friend that were also my work colleagues at that time were gay men so I was fully aware of the issues that the gay community were putting forward to the media.

The consultant in the article mentioned advocated tracking the virus by blind testing. In the north-east where this person practised patients were tested around March 1985 often without their knowledge and informed consent on a named patient basis. Patients often had their blood taken but that is very different to having an HIV test. This so called "AIDS expert" as he was referred to here was the same person that made an official complaint to the Press Complaints Commission in 1983 against journalist Susan Douglas simply for highlighting "killer blood" sourced from "high-risk" donors coming in from America (Mail on Sunday, 1st May 1983) and putting haemophiliacs at risk of AIDS. She identified the first haemophiliac sick with AIDS in the UK. Dr Galbraith actually made reference to this article when he called for all US products manufactured after 1978 to be withdrawn from use in May 1983. The complaint by this haematologist almost wrecked Susan Douglas's career, she had researched her subject well and was telling the truth. I am in contact with her now and she has never received an apology to this day! I find it very disturbing when I see evidence in haemophiliacs records especially those that were mild (in one case with an 87% clotting factor level) that they were given their first imported factor concentrates after that May 1983.

I can tell you more about testing of haemophiliacs in the north-east of England, I have met with a number of patients and their memories are all very similar. Patients were given their results, most not knowing that they had been tested and then some were

subjected to an examination. Those that were told they were positive recall being asked to pull down their underpants and lie down and pull up their knees while their rectal area was examined. Some patients were told nothing others were told that the consultant was looking to see if there was anal dilation! At that time haemophiliacs and gay men were known to be in a high-risk category but the usual procedure in my practice anyway would have been to educate patients as far as possible about AIDS and explain about high-risk groups which could include asking a person if they considered themselves to be in any other high-risk group. I would not have expected any patient to be subjected to a rectal examination unless they themselves had identified a problem, an infection, pain etc. One person examined was 14 years old at that time!

Dr Winter talks about the culture of the time and without doubt in many haemophilia units (though not necessarily on other units) there was a culture of paternalistic, prescriptive care with little thought for the need to involve the patient in the decision making process. My dissertation explores how this extreme power imbalance affected patient treatment. As mentioned I worked as a nurse at the time. My unit had prepared guidelines for pre and post test counselling as advised by Government prior to the test being introduced, we obtained informed consent as part of the patient contact which was also recorded in the medical/nursing notes and we provided the necessary ongoing support to our patients. A patient contact meant that you sat down with the patient, explained the services on offer, discussed their expectations and devised a care plan acceptable to both care provider and patient. The patient then signed the contact that they understood and agreed with their plan of care. This to my mind was just good practice. It is important that the Inquiry is aware that there were alternative treatment models being practiced at that time.

I wish to point out that there is a principle in law called the Bolam principle which is one of the rules used to determine the issue of professional negligence where the defendant has represented him or herself as having more than average skills and abilities

http://en.wikipedia.org/wiki/Bolam_Test One rule is that a doctor, nurse or other health care professional is not negligent if he or she acts in accordance with a practice accepted at the time as proper by a responsible body of medical opinion, even though some other practitioners adopt a different practice. I continually ask myself where does the law stand if the majority of haemophilia doctors dealing with AIDS patients were adopting unethical practice in a number of areas which went against Government guidelines and duty of care to patients. Can there ever be circumstances in medical law where the majority get it wrong and must accept the consequences or is it that just the fact of being in a majority protects certain people no matter how unethically they behave!

Testing without informed consent, withholding of test results continued long after HIV testing right through to hepatitis C testing. I wish to highlight the case of a haemophiliac that came to visit me recently with his medical records to confirm his case. He wishes to remain anonymous but I am sure he would speak to the panel in private if necessary providing his confidentiality was maintained. He recalled how he only found out that he was HVC positive when his wife opened a letter in 1998 which was meant for the GP but went to the family home by mistake. When he confronted his consultant he was told that his parents had been informed in 1993. They insist that this was not the case and even if it was the person concerned was 21 at that time so the consultant had no right to tell his parents and not the infected patient. There was no informed consent to test sought from the patient himself. HCV testing was introduced in 1991 so why did it

take 2 years for this person to be tested when a letter in his notes from 1982 refers to illness due to an attack of non-A, non-B hepatitis so he should have been a priority case for testing. He could also have unknowingly put his partner at risk of infection and his child. I ask myself was this man another of the north-east patients to be originally tested in 1991 but not told until years later alongside my husband and others! What struck me as deepening saddening was that this person had until recently had the utmost faith in his doctors and is now left, confused, bewildered and angry that those he so trusted let him down!

The evidence of people tested without their "informed consent" and permission and results withheld for years brings into question again the hepatitis legal waiver in 1991 particularly when doctors were assisting lawyers with patients' medical records for the HIV litigation and knew that many of their patients would be positive. I also bring to mind a House of Lords ruling in 1984 that tightened up a patient's right to know of medium to high risks associated with their treatment as these risks could impact on their lives. I believe if haemophiliacs had been given the correct information from doctors and lawyers on the dangers of hepatitis C in 1991 and told that they were highly likely to be infected and could become seriously ill or die as was written in the legal pleadings, (or in some cases given their positive tests results which were already in their records) they would never have signed the hepatitis waiver.

A number of patients through-out the country have put in official complaints to the General Medical Council yet despite all the evidence submitted we could get no-where and although the doctors could see every word of our complaints we were not allowed to

see one word of the doctors reply in order to challenge their submissions. This system is heavily weighted against the patient ever obtaining justice when things go wrong. Doctors have admitted in this room that they tested their patients for infectious diseases without informed consent which is against GMC guidelines and can supposedly be brought to a court of law but haemophiliacs can do nothing. I request on behalf of the haemophilia community that a copy of the Archer Inquiry final report whatever the outcome be sent to the GMC so that they can be made aware once again of the issues raised in this Inquiry.

Conflict Of Interest

One thing haemophiliacs would like addressed is the relationship between the plasma companies and the doctors. What funding did doctors receive from plasma companies? Were any haematologists acting as paid advisors to companies or received incentives with regard to research funding or funding for lectures tours abroad etc. Where there financial incentives for doctors asin other countries where doctors received a type of commission the more treatment they prescribed? Where would we be able to obtain this information? I would like to establish more about the buying in of plasma products and why this was not regulated via pharmacy. I happened to be at a local trust meeting only a few years ago to raise the issue of recombinant for patients and noticed an item on the agenda. Basically the pharmacy were annoyed that haemophilia treatment had always by-passed their department and were calling for more control over treatment. I wonder if the UKHCDO can advise where the buying in records are stored? Did plasma go to a central regional depot or was it delivered direct from plasma companies, how were

contacts set up. This is the sort of evidence we need to hear from doctors but is not forthcoming!

Recombinant/v CJD

Haemophiliacs had hoped that lessons had been learnt after the infection of so many haemophiliacs with HIV/HCV. However sadly safety issues were once again ignored in relation to v CJD. My husband first wrote asking for recombinant in 1996 and I have submitted a letter where he was refused this treatment on 3rd April 1996. Once again the letter demonstrates how systems failed haemophiliacs. There was a breakdown in manufacture which led to shortages and despite all that haemophiliacs had been through economy was once again placed over safety as the letter shows. It is worth noting that if doctors had listened to their patients and granted their request for recombinant exposure to v CJD could have been prevented. My husband's first exposure to v CJD was in the Autumn of 1996. I would like to provide the panel with a copy of my husband's legal statement in his fight to access recombinant. He also went on a high-profile treatment strike to raise awareness of the safety issues surrounding human plasma and future risks including v CJD, as the virology experts say it is not if a new virus comes along but when. I am giving you his witness statement in the legal case between The Queen On The Application Of Peter Longstaff and Newcastle N.H.S Primary Care Trust which was heard in the High Court. In a sense these are Peter's words from beyond the grave. He lost his case on the grounds that local trusts can chose how they wish to spend their budget. Recombinant treatment became a post-code lottery and despite all that my husband suffered as a result of his infection with HIV/HCV this was never a consideration for the Trust. Pete was deprived of synthetic treatment for many years even

during his last months at a hospice the local Trust showed no compassion towards him with regard to this issue. Recombinant was phased in and Pete was in the last group to receive recombinant. He was finally eligible on 1st April 2005 and died on the 16th April 2005.

Lessons were not learnt with regard to communicating information in relation to v CJD and haemophiliacs were only given the chance to learn of any exposure after we leaked letters to the press from the Government and a plasma company advising doctors to withdraw treatment because of the v CJD risk but not to tell patients that they had been exposed. I am aware that it will probably not be too long before there is a test for v CJD and after the disasters with HIV and HCV testing I hope all appropriate ethical measures regarding testing and pre and post test counselling are put in place in preparation for any future test.

Education

I would suggest that the past and present case of haemophilia treatment and the ethics surrounding care and treatment decisions is placed on the agenda of medical schools and ethics departments at universities as what better case to explore than ours. Everything that could go wrong did go wrong and the tragic thing is so much could have been prevented. A member of staff at Leeds University has invited me to talk to students on our history of campaigning and "grass-roots" activism on the newly launched MA in Activism and Social Change. I recall one haematologist referring to patients that campaigned as using "low- grade guerrilla tactics". I think that despite everything they

have suffered haemophiliacs and their families although not afraid to be outspoken and challenge the systems that caused them harm have been remarkably dignified and restrained. My fellow campaigners should be proud of their activism and the contribution towards ensuring human rights are upheld and their fight for the best possible standards of ethics and care should be acknowledged. Let's face it there are far more cases of doctors and officials being charged and convicted, jailed in some cases, throughout the world for crimes against haemophiliacs than the other way round!

Parity With Eire/Lord Warner

I wish to clarify the situation with regard to Lord Warner and his misrepresentation in the House of Lords and Hansard regarding the situation in regarding the payments to haemophiliacs in Eire. I first raised the issue immediately after I spotted that Lord Warner had got his facts completely wrong. He claimed that the circumstances in Eire were somehow different to the UK but as my letters from both the Eire Government and Malcolnson Law solicitors proved the Eire Government paid recompense to haemophiliacs and their families at liability levels without accepting legal liability in advance of their Public Inquiry on moral grounds. I gave Lord Warner the benefit of the doubt initially assuming he may have been misinformed by an advisor and provided the necessary paperwork. The haemophilia community did not receive an apology and the mistake was never rectified despite raising the issue with my MP and Lord Morris of Manchester who tried to help also.

I then wrote to the Parliamentary Ombudsperson to make an official complaint and ask that they do something, nothing happened here either. This causes me great concern as I am aware Lord David Owen has his own problems with the Parliamentary Ombudsperson when he asked for the case of gross maladministration by the Government to be investigated. Could I request that should attention be brought to this serious matter of misinformation be flagged up in the final report of the Archer Inquiry that both Lord Warner and the Ombudperson receive a copy of the report. As it is so often the case with the haemophilia community that no matter what evidence we dredge up in support of our claims we are unable to get justice. The decision of the UK Government not to provide recompense for haemophiliacs on a parity with Eire was based on the fact that the situation in Eire was different, this obstacle has now been removed, we can say with confidence that the situation in the Eire is no different to the UK. We have now clarified this with evidence from Irish lawyers and the Eire Government who know their own situation far better than Lord Warner and have backed us in our fight for parity and justice. We also heard a supporting testimony at this Inquiry from Brian O'Mahoney regarding the situation in Eire. The UK Government must now be made to formally address this issue and provide financial parity with Eire.

As we have heard although the Macfarlane Trust and Skipton do their best they do not always deliver and what people want is a reasonable settlement as our friends received in Eire which would give haemophiliacs and their families financial independence as opposed to relying on hand-outs in a system which can often seem humiliating. I would like to give an example of how the system can fail haemophiliacs. One haemophiliac who had been infected with hepatitis C was turned down for the first payment on the grounds that he had cleared the virus but not until years later and after suffering a

debilitating bout of jaundice as a 10 year-old child where he was ill and weak. As the hospital records had "inadvertently been destroyed" by a junior trying to put them on computer a familiar story to many and he was unable to prove his early illness. As it happened I did help him go through some copies of old records very recently he had at home and found a reference to his illness and non-A, non-B infection in 1982. He was finally found to be have allegedly cleared the virus many years later but interestingly when he asked no doctor would either put this in writing or state in writing that he could no longer infect another person. In fact his consultant strongly supported this man in writing that he should receive the 1st payment and not be penalised because of missing records but he was turned down for payment. I was able to establish that two other haemophiliacs that I know that had been infected with hepatitis C, initially been ill and later cleared the virus were paid the first settlement. This shows how unfair this system is and how after everything this man has been through as he also HIV he still cannot claim the payment that he deserves. We will be challenging this but this is an example of why a scheme such as parity with Eire is extremely important as it provides a proper assessment and I understand those assessing actually meet with the infected individuals to discuss their cases so any issues can be ironed out in a humane way.

Dissertation

My dissertation highlighted many of the issues brought into this Inquiry. It was actually written in 2006 and submitted in January 2007 three months before the Inquiry began. As stated I used documents and supporting evidence that weren't at that time in the public domain. While I was writing the dissertation I was also fighting to get many documents released under Freedom Of Information with the help of solicitor Paul Saxon of Blackett,

Pratt and Hart. The Government recalled all these documents and given the Governments appalling record for "inadvertently" destroying evidence I cannot be entirely sure that all the documents are or will be released into the public domain but I believe there is enough now to put the Government to shame. The Government Self-Sufficiency Report 2006 is a fairly worthless document in that it excludes most of the important evidence regarding what happened to our community. This also needs to be formally challenged as this was supposed to appease us and be accepted as an accurate picture of the contamination tragedy. The reason always given in letters for refusing haemophiliacs a public inquiry was that quote "all the information is already in the public domain". We now know this oft repeated statement was untrue. The Government can go some way now to addressing this situation by considering the future report/recommendations of the Archer Inquiry and offering an apology that is long overdue.

RECOMMENDATIONS OF LORD ARCHER AND PROPOSALS FOR RESOLUTION

The haemophilia community wish for the recommendations of Lord Archer of Sandwell to be implemented in full and as a matter of urgency before any more haemophiliac die. Lord Morris of Manchester echoes this in his Contaminated Blood Bill which is an attempt to put these same recommendations into legislation
http://www.publications.parliament.uk/pa/ld200910/ldbills/005/10005.i-i.html

ADDITIONAL INFORMATION TO SUPPORT ARCHERS RECOMMENDATIONS (Submitted by Carol Grayson)

The Need for A Statutory Haemophilia Committee

I believe the podcast below demonstrates the need for patient and carer involvement and representation as part of a statutory body which is very important for a number of reasons. As in

Ireland patient representatives could liaise with the wider haemophilia community to involve more patients in discussions around assessment of their needs in a holistic sense. This could include provision of best possible treatment and appropriate care guidelines (for example in the community, infection control) to be kept informed of economic decisions related to haemophilia care and any ethical issues regarding participation in haemophilia research. Haemophiliacs and their carers have had to become well educated on many health care issues for survival over the past three decades and should be viewed as an additional source of knowledge and information that have a right to be part of the decision making process. Archer lays out ideas for composition of a Committee (this should also include carer representation) its role and duties and states "there should be a statutory requirement to consult the Committee prior to the introduction of legislative or substantial changes in policy" (p 107).

Health Economics and Outcome Assessment: Sustaining Haemophilia Care In A Tightening Economy
(This indicates the importance of including haemophiliacs within a statutory body)

http://www.youtube.com/watch?v=46UOJVCA5mk

Back in 1995 as concerns over v CJD were emerging with regard to blood I was trying to present to the local Primary Care Trust and government the need to weigh up cost/benefits analysis with regard to introducing recombinant treatment to prevent haemophiliacs being exposed to v CJD. My husband and I had no forum other than to take a case to the High Court to fight for recombinant, a safer synthetic clotting factor. Profit was once again prioritised over safety with haemophiliacs being told recombinant was too expensive and it took several years to phase in by age. My husband was so disgusted he protested by going on treatment strike for several years up to his death despite being a severe haemophiliac. (He also did not believe in the "blood for money trade" people being exploited round the world for their life blood and fought for 100% non-remunerated blood donations globally which is now the mantra of the WHO). When I attempted to warn people of the potential risk of v CJD, I was largely ignored at that time. If those with decision making powers and controlling the budgets had listened to me in 1995 many haemophiliacs would not have been exposed to v CJD, my husband was exposed in September 1996. A statutory body would give a forum for such discussions involving treatment and empower the haemophilia community to be involved in meaningful discussions around their treatment in a Committee with statutory powers.

Soon there is also likely to be a test available for v CJD, this will involve a number of ethical issues including who should be tested, pre and post test counselling, who should be told and if someone has been exposed, procedures following a patient's death. Although I was told verbally my husband was not incubating v CJD (though exposed) I am still awaiting a letter of confirmation 5 years on from the CJD Surveillance Unit in Edinburgh. I experienced a similar situation to widow Rita in that men in bio-hazard suits came to remove my carpet and sofa after my husband had a burst vein in his foot, yet ironically I learnt that although there were clear guidelines for hospitals and those disposing of clinical waste there were no guidelines for carers in the community and I believe that may still be the same. These are all issues that could be taken up by a statutory Committee.

There must be a statutory Committee to include patients in these ongoing discussions as this did not happen with HIV/HCV and many patients were subjected to unethical practice and research. **There have been significant shortcomings regarding lack of patient involvement**

in the past and may in some areas still be ongoing. To most haemophiliacs the Haemophilia Alliance is just a name and when patients write requesting to be involved they are not included in meetings or discussions related to ongoing haemophilia care and provision and the Alliance has no statutory powers. The following six replies are just a small sample from questionnaires sent to haemophiliacs as part of my dissertation (submitted 12/1/2007) awarded ESRC Michael Young Prize 2009 http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/about/CI/CP/societynow/issue4/blood_trade.aspx These answers were given in relation to "informed consent" to testing for HIV/HCV and show why it is important to include haemophiliacs as part of a statutory Committee to address issues such as future testing for v CJD.

I was never informed of the risk or consulted when tests were taken to find out about my status (H4)

I was never informed that I had been tested for Hepatitis C until years after the event (H8)

I think we have been test studies for the rest of the general public &doctors have thought they do as they please with us without having to ask our permission (H15)

They tested me for AIDS without telling me they were doing this. No pre test counselling, what it means, same for HCV (+ also infected with HBV) – If they were so honest and transparent why are my medical notes mostly missing (H12)

I felt more of a guinea pig in early years as though I was being used to help contaminated people in the future I was probably going to die sooner rather than later (H21)

They called them in for routine check-ups, took their blood, and they knew long before they told them the outcome, Bastards! (P14)

I recently received this e-mail in response to my request to government for a statutory body...

Our ref: DE00000514166 - haemophilia statutory body/archer report

Dear Ms Grayson,

Thank you for your email of 17 June about the Government's response to the Archer Report. I have been asked to reply.

Proposals for a statutory committee to advise on haemophilia are based on a fundamental misconception about the delivery of health and social care in England. You suggest that the purpose of the Committee will be to advise Government on the management of haemophilia, but responsibility for the treatment and care of haemophilia patients are actually the responsibility of the NHS and social care system.

The proposal for the committee is also premised on the assumption that there are significant shortcomings in the delivery of treatment and care for haemophilia patients. That is not the case. The needs of haemophilia patients are already extremely well provided for through the network of Haemophilia centres and comprehensive care centres. It is worth recalling that

Lord Archer's report made a number of recommendations to "help meet the unmet needs of haemophilia patients and their families", yet identified no shortcomings in treatment or care currently being received by haemophilia patients.

You also suggest that the proposed statutory Committee should have responsibility "for all provisions necessary to address the financial and other needs of haemophilia patients". However, the administration of the current system of ex-gratia payments to haemophilia patients infected with HIV and/or hepatitis C is a matter for the Government.

Finally, the statutory committee that you propose would also simply duplicate existing arrangements, which are working well. The Department has set up a workstream with the Haemophilia Alliance, which is an existing UK wide partnership between patients, haemophilia doctors, and others involved in their care, which gives them a voice in the process of policy making on haemophilia issues. The Alliance will be consulted on any substantial changes to policy on the treatment of haemophilia patients.

Yours sincerely,

Bilal Ghafoor
Customer Service Centre
Department of Health

Health Cards/Specialist Services

Archer stated that :

Those who had been infected should be issued with cards entitling the holder to benefits not freely available under the NHS, including free prescription charges, general practitioner visits, counselling, physiotherapy, home nursing and support services. The card should facilitate access to an NHS hospital bed and specialist services.

Relatives and partners predominantly female often provide care long term care to haemophiliacs and in doing so give up the own careers. The patient should be able to choose his carer and that should not result in a marked reduction of income. If 24 hour nursing care came from an agency it would have to be bought in. One example was presented to Lord Archer that of a woman caring for her haemophiliac for over two decades. A professional health care assessor calculated that this lady had saved the health service around £7.2 million, now consider the number of infected haemophiliacs and multiply that figure. Surely those who have given up careers to become carers should not be penalised financially and could receive an adequate allowance. I recall that by the time my carer's allowance was deducted from my husband's benefit I got about £11 a week, put that next to the hourly rate for an employed carer/nurse, no comparison. Carers and widows are continuously penalised when their husbands are infected as a result of their NHS treatment.

As a qualified nurse myself I provided my husband's care 24 hours a day for many years during the chronic state of his illness and lost out having a career in my own right. The only support I received was towards the end from an excellent local hospice but prior to that I

struggled for years alone becoming depressed and socially isolated as I often it was difficult to leave the home unless another family member took over. Looking after my husband was physically and mentally exhausting, he required a lot of lifting at times and could become quite confused as his liver started to fail. On one occasion my husband was discharged from hospital with no thought as to how I would get him upstairs to our flat. I cry even now thinking of my husband in such pain left on the floor as even with my help it took several hours for him to crawl from the gates through the garden and stairs to bed and though I rang the hospital no-one would come to help me. I was told the ambulance men could only take him down not up. I then had to wait weeks for a lift to be installed.

I lost years of wages, pension rights, career development. Within a short time of my husband dying I was existing on a significantly reduced income, my husband could not get insurance, so there was no payment when he died and I was diagnosed as suffering from Post Traumatic Stress Disorder. I have witnessed that alongside grief, PTSD, depression, anxiety states and phobias are common amongst the widows and it is extremely difficult to re-enter normal life after years of caring. Just prior to my husband dying I was having severe asthma attacks which have continued due to stress caring for my loved one and afterwards experiencing the loss. Therefore the above cards should be extended to carers and the bereaved so that they can receive counselling without long waits and free prescriptions etc if needed for their own health care. **Who looks after the carers!**

There is very little support of any to those women who did not have their own children due to fear of infection...a major loss in itself...I was never offered counselling and no one ever talked to me about this terrible loss in my life.

My stepson suffers psychological problems due to multiple losses. In our family alone we lost the following members,

Stephen through HIV/AIDS

Arnold my father in law had heart attack and died campaigning for justice. His GP told the family it was probably due to the stress of losing one son with another infected.

My husband's first wife (mother of my stepson) took her own life after she couldn't cope living with HIV which broke up the marriage and the stigma, victimisation, house being daubed with anti- AIDS slogans

My mother –in –law developed cancer so I was nursing two dying people, mother and son

Then finally my husband from HIV/AIDS/HCV related complications.

COMPENSATION

Compensation payments should be made to all those victims of blood/blood products infected with HIV/HCV and all those affected partners, carers, bereaved. I am focusing specifically here on carers and bereaved partners/widows the "affected" as Colette and other groups will be looking at the specific needs of the infected.

Archer states "we suggest that payments should be at least the equivalent of those payable under the Scheme which applies at any time in Ireland" a recommendation which my husband and I initiated in1996 and for which we have an archive of dozens of letters on this subject which were recently retrieved from the office of my former MP Jim Cousins. Lord Archer took on board our arguement which he turned into recommendation 6 (h) after reading letters I acquired from the Irish government and lawyers in 2004 to tackle Lord Warner's misinformation (see page 90 of the Archer report). I also approached my campaign colleague Colette Wintel who acquired similar letters to myself.

Parity with Eire/Ireland

I have cut and pasted samples of original letters and e-mails which passed between myself and the Irish and UK governments in **2004** (see below).

Dear Carol

I have passed your further correspondence on to Ann McGrane. Ann is not in the office today but I understand that she is working on a reply to your query and she will be in touch as soon as possible.

Regards

Paula O'Reilly

"Carol Grayson" To: <Paula_O'Reilly@GRO-C>
<GRO-C> cc: <GRO-C>
GRO-C Subject: Re: Hep C -Misinformation Westminster govt.
24/02/2004 21:37
Please respond to "Carol Grayson"

Dear Paula, (Could you pass on to Ann Megane and Mr Martin.).
I haven't as yet heard anything from yourselves with regard to the circumstances surrounding your govt recompense scheme for haemophiliacs infected with hepatitis C. Will you be sending something in writing as requested? I have now got an excellent letter detailing the scheme chronologically from Raymond (Bradley), Malcolmson Law, which supports the fact that Lord Warner got his facts on your govt wrong.
Below are the direct quotes from the recent Hansard doc. I also need to look back through past govt docs because our govt has been feeding the line of the Eire govt carrying out "wrongful practises" for some time in debates and in letters to campaigners and fellow politicians. So thanks to the misinformation from our Dept of Health a lot of politicians over here think your govt is guilty of "wrongful practises" leading to the mass contamination of haemophiliacs. They certainly had me confused for a while. I apologise for thinking your govt was guilty, it's all this Westminster

propaganda, how do we know what to believe. I am still waiting for weapons of mass destruction to come crashing through my front door! I am told by Raymond that the Eire govt never legally accepted liability or admitted responsibility in relation to contamination of haemophiliacs. I have no reason at all to doubt Raymond but in the event you have ever admitted wrongful practices leading to mass contamination, could you list those and send them to me (and of course your own haemophiliacs). If you had any criminal charges/convictions in Eire related specifically to infection of haemophiliacs, not the anti-D cases, could you also list those. Thanks!

From Hansard
Lord Warner, (Parl Under Sec State Health) "It is important to distinguish between the scheme (England) and that in Ireland, where public inquiries and criminal charges affected the basis of the scheme."

Lord Warner, "The awards that were made in Ireland and in Canada followed public inquiries or criminal charges which established that wrongful practises were employed"

BBC Woman's Hour
Melanie Johnson, Health Minister,
Miss Johnson replied that Ireland and Canada "showed wrongful practises" had led to the infections and in the UK "we acted as soon as we could...when a test for hepatitis C was brought in".

What she forgot to add was that in England haemophiliacs were tested for hep
C without their knowledge and permission and positive test results withheld for years!

Speaking of wrongful practise I recently received film footage from Arkansas
containing testimonies from U.S. prisoners and former prison plasma centre workers. I didn't think people were allowed to experiment on prisoners with different strains of hepatitis viruses, and then to set up a plasma programme. Shocking! I thought that kind of thing died out with Mengele!

Cheers
Carol Grayson (Haemophilia Action UK)

13 February 2004

Ms. Carol Grayson

Haemophilia Action UK

GRO-C

GRO-C

Dear Ms Grayson.

I wish to refer to our telephone conversation on 12th February and subsequent e/mails regarding compensation for haemophiliacs who contracted Hepatitis C and / or HIV from the administration of clotting factor products. To summarise, the Hepatitis C & HIV Compensation Tribunal is a no-fault compensation scheme for persons who were infected with either Hepatitis C, or HIV, or both, from the administration within the State of infected blood or blood products, including Anti-D Immunoglobulin and the products used to treat persons with haemophilia or other blood clotting disorders. The legislation provides that awards of the Tribunal are calculated on the same basis as the calculation of damages in High Court civil proceedings. The legislation also provides the right of appeal to the High Court in respect of the Tribunal's decisions. The Tribunal's Annual Report is available on their website (http://www.hepccomptrib.com).

The background to payment of compensation of persons with haemophilia is quite complex but I have endeavoured to set out the facts below. From the quotations which you have e/mailed to me it would certainly seem as if there has been confusion in the U.K. between the circumstances behind the Anti-D infection, and the infection of persons with haemophilia. As you rightly point out, compensation for persons with haemophilia was made on compassionate grounds, without legal liability on the part of the State. In a speech to the Dáil on the Report of the Haemophilia Tribunal the Minister acknowledged the regret of the government at the immense tragedy which befell citizens of the State whilst availing themselves of State health services. He also acknowledged the extraordinary suffering endured by persons with haemophilia who were infected, and by their families.

The background behind the establishment of the Compensation Tribunal is as follows. The Tribunal was established on a non-statutory basis in December 1995 in respect of Hepatitis C infection only, and was put on a statutory footing in November 1997 by means of the Hepatitis C Compensation Tribunal Act. An amending Act was passed in 2002 extending the remit of the Tribunal to include HIV. The original Scheme of Compensation announced by the then Government in June 1995 was confined to women who contracted Hepatitis C through the administration of the Anti-D product, and to any infected partners and children of these women. The purpose of the scheme was to provide compensation on an ex-gratia basis, as legal advice to the Government was that the State itself was not liable. The same legal advice regarding liability would also pertain to the infection of persons with haemophilia.

Further analysis of issues relating to the Anti-D contamination had revealed that some of the women who were infected with Hepatitis C through the administration of

the Anti-D product in 1977/8 went on to become blood donors. As a result, in the years between the contamination of Anti-D in 1977/8 and the introduction of testing for Hepatitis C in 1991, it was recognised that some instances of Hepatitis C acquired through blood transfusions could also be linked back to the Anti-D problem. Factor 9 clotting product for haemophiliacs was also produced from native plasma. Following further consideration and consultation during 1995, it was announced in September of that year that the compensation scheme was to be extended to cover all those who had contracted Hepatitis C from a blood transfusion or blood product administered within the State. The primary reason for this was the perceived difficulty in the public mind in justifying the distinction between different categories of blood product recipient. Also, as the scheme of compensation was a no-fault scheme, there was a perception that any restrictions on access might be interpreted as an implicit admission of liability.

For information on the background to the establishment of the Compensation Tribunal and the contamination of the Anti-D product with Hepatitis C you may wish to refer to the Report of the Tribunal of Inquiry into the Blood Transfusion Service Board (Finlay Report), 1997, which is available on the Department's website (http://www.doh.ie/publications/allpub1997.html).

Following the completion of the Finlay Tribunal, a second Tribunal was held into haemophilia related-issues. The *Report of the Tribunal of Inquiry into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters* (Lindsay Report) was published in 2002 and also is available on the Department's website (http://www.doh.ie/publications/allpub2002.html).

The Lindsay Report is lengthy, and not easily summarised. However, you may wish to note that the Report concluded that the maximum estimated number of infected persons (either HIV, Hepatitis C, or both) in Ireland is 230, of whom 8 were probably infected with HIV by Blood Transfusion Service products. A Blood Transfusion Service Factor IX product was identified as the probable source of infection with hepatitis C of 4 persons with haemophilia B. The remainder of the infections was attributable to products supplied by the international pharmaceutical companies. Having considered the Report carefully, the Government decided to refer it to the Director of Public Prosecutions. To date the DPP has not concluded his examination of the Report's findings.

I hope this answers your queries. If you have any other questions please do not hesitate to get in touch.

Yours sincerely

Ann McGrane

Assistant Principal Officer

Blood Policy Division

Reply from Haemophila Society to my e-mail on (Feb 2004)

Carol,
Thanks for the update. Clearly we had noted that both ministers' statements were extremely unsatisfactory, however, we may have missed some details that you have picked up.

Could you let me have a bit more detail on the precise statements that were misleading and why from the ministers? There might be a possibility to complain to parliamentary ombudsman if it can be shown that MPs were mislead by inaccurate ministerial statements, but you have to be really specific. They will expect chapter and verse. Same applies if we are to encourage any of our parliamentary supporters to make a complaint - generalisations won't suffice.

regards

Karin

Karin Pappenheim
Chief Executive
(Direct line: GRO-C)

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Website: www.haemophilia.org.uk - E-mail: karin@ GRO-C

-----Original Message-----
From: Carol Grayson [mailto: GRO-C
Sent: 21 February 2004 15:29
To: Karin Pappenheim
Subject: Re-Misinformation from Lord Warner and Melanie Johnson (DOH)

Karin,
I am sure the Haemophilia Society can't have failed to notice the completely incorrect information presented by Lord Warner, in the recent House of Lords debate documented in Hansard, and Melanie

Johnson on "Woman's Hour", with regard to the facts surrounding the Eire and Canadian payment schemes. We have now obtained our evidence from legal sources to back this up which I have already presented to my MP and will be sending to other politicians. Haemophilia Action UK and other campaign groups will be calling for a public apology from Lord Warner and Melanie Johnson in writing to haemophiliacs, the general public and politicians supporting haemophiliacs for misleading them. If this is not forthcoming we will be calling for resignations via politicians who support us. There is no excuse now why this country cannot pay out at the same levels of payment as its European neighbour Eire who decided to pay- out similar levels to the amounts that would have been given in civil pay-outs. This was on compassionate and moral grounds in recognition of damage and distress although no liability has ever been admitted. I met with my M.P. this week-end and he agrees on the evidence he has seen that when we take this to Europe it is likely that because of the discrimination which is occurring from the government to our haemophilia population, payments will have to be increased to the levels paid out in Eire.

What has the Society done to tackle the government on the issue of misinformation from the DOH and what it is doing to bring this to the attention of the general public via the media. Our group has already spoken to journalists who will be running this story and contacted programmes such as "Woman's Hour," to inform them of the situation. We have not as yet seen any public condemnation of these politicians and their so called "facts", from the Haemophilia Society either in the press or Society newsletters!

Carol Grayson (Haemophilia Action UK)

The following letter was sent to the Scottish Executive as they were giving the same line as Westminster and this followed on from letters sent to Lord Warner and Lord Morris to get Hansard corrected and an apology issued. I even wrote to the Parliamentary Ombudsperson.

8th May 2004

GRO-C

TEL GRO-C

RE MISINFORMATION ON EIRE HEPATITIS C SETTLEMENT

Dear Mr Chisholm,

I am writing to you once again, as in past letters to me, you stated your interest in viewing any relevant evidence/ information with regard to blood contamination issues, and offered to pay my photocopying costs. I am sending you the following enclosures free of charge as a gesture of goodwill to help educate you on the facts of the Eire settlement.

I was forwarded your letter of 20th March 2004 to Christine Grahame MSP for comment, as we have also previously raised concerns over similar misinformation coming from the Department of Health, England, via our MP Jim Cousins. Your letter addressed issues with regard to the Irish financial assistance scheme for people infected with hepatitis C through infected blood and blood products. Direct quotations from Lord Warner, Melanie Johnson, and yourself have been sent by me directly, both to the Irish government, and Irish solicitors representing haemophiliacs, for their comments. The enclosed letters are the result of my ongoing contact with both, I have also received e-mails and had phone-calls from them to clarify their position. I will begin with the following comment from Ann McGrane, Assistant Principle Officer, Blood Policy Division.

"From the quotations which you have e-mailed me it would certainly seem as if there has been confusion in the U.K. between the circumstances behind the Anti-D infection, and the infection of persons with haemophilia."

Questions have been asked by politicians and haemophiliacs and their families in Scotland and England as to why the proposed HCV payments are less than those made in other countries, in particular the Republic of Ireland. In your letter you state:-

"I think it is entirely appropriate to make the distinction between a scheme that followed hard on the heels of a judicial review that condemned the nation's blood service and a scheme where that is not the case."

The above statement is completely incorrect.

Please refer to the letter from solicitor Raymond Bradley of Malcolmson Law solicitors who in fact negotiated the HCV settlement with the Eire government. With all due respect, I think we can safely assume that after 10 years on the case he knows a little bit more about the terms and circumstances surrounding the Irish "ex-gratia" payment to haemophiliacs than you do. Please note that quote:-

A) "The non-statutory Hepatitis C Compensation Tribunal PRE-DATED any public inquiry investigation".

B) "The statutory Hepatitis C Compensation Tribunal PRE-DATED by almost two years, the establishment of the Lindsay Tribunal to investigate the circumstances of infection of people with Haemophilia with HIV and /or Hepatitis C".

C) "The commitment by the Irish Government to REVERSE the 1991 HIV Compensation Settlement occurred IN ADVANCE of the commencement of evidence before the Lindsay Tribunal Report".

D) "At no juncture has the Irish Government, in relation to any claim by any person with Haemophilia before the Irish Courts, accepted liability, ie. Filed or delivered a Defence admitting responsibility."

Raymond Bradley, quote:-

"In those circumstances, it is patently incorrect for it to be indicated that the Irish compensation schemes arose in circumstances where the Irish Government admitted responsibility, or, alternatively, were as a consequence of any public tribunal of inquiry investigation".

Please note in terms of legal "wrongdoing", the Irish government has never admitted "legal liability".

I have spoken on a number of occasions with the Blood Policy Unit, part of the Irish government offices, and ask you to read the letter written to me from Ann McGrane.

She writes, "The Hepatitis C and HIV Compensation Tribunal is a no-fault compensation scheme for persons who were infected with either Hepatitis C, or HIV, or both, from the administration within the State of infected blood or blood products, including Anti-D Immunoglobulin and the products used to treat persons with haemophilia or other blood clotting disorders".

It is absolutely correct that the awards were calculated on the "same basis" as the calculation of damages in the High Court civil proceedings. Ann explained to me by phone that this was in recognition of "extraordinary suffering", and that payments were, "ex-gratia" payments, paid out on "no-liability", "moral", "compassionate", grounds, see her letter.

Please read Ann McGrane's full letter and note that "to-date the DPP (Director of Public Prosecutions) has not concluded his examination of the Report's findings", so please explain how the hepatitis C payments can be based on criminal charges as stated by Melanie Johnson, (DOH, England), when the law states "innocent until proven guilty" and there has been no conclusion of findings yet! Even if anyone is found guilty in the future, it is irrelevant as far as the financial payments are concerned as the Irish government have already been paid out to haemophiliacs on a "no-liability", "ex-gratia" basis.

I note that you frequently refer to the Finlay Tribunal, which was "an investigation into the circumstances of infections of Anti-D Immunoglobulin, a product administered to a woman post delivery of a first child," but appear to fail to recognise the findings of the Lindsay Tribunal, "the Tribunal Of Inquiry into the infection with HIV and hepatitis C of persons with haemophilia and related matters."

Please note the attached pages from the book, "A Case Of Bad Blood" by Rosemary Daly and Paul Cunningham, both individuals are contacts of mine who have assisted me over the years. This is an entire book about the contamination of haemophiliacs and the resulting Lindsay Tribunal. These pages state that no-one was held accountable for the infection of haemophiliacs and with regard to the Lindsay Tribunal,

"it is not the function of a tribunal of inquiry to decide issues of criminal or civil liability."

Politicians are either genuinely confused or appear to be making it up as they go along with regard to the Irish settlement. We ask that you make a full public apology in writing for the misinformation you have stated. Politicians have no excuse now for not valuing haemophiliacs in the same way as the Irish Government, and haemophiliacs demand parity with Eire with regard to the HCV settlement. Why should a

haemophiliac's life in England, Wales, Scotland, and Northern Ireland, be worth only one tenth that of a haemophiliac living in Eire, our European neighbour.

We have the ridiculous situation where cousins within the same family will receive vastly differing financial payments for their hepatitis C infection because one haemophiliac lives in Dublin and one in Worcester. This cannot be just and fair, especially as both could have been infected with the same American plasma products, even down to the same batch numbers, just administered in different countries!

Please note that according to the letter from the Irish government, of the 230 estimated maximum number of persons infected with HIV, Hepatitis C or both, only 8 haemophiliacs were probably infected with HIV by Blood Transfusion Service products, and only 4 persons with haemophilia B were probably infected with hepatitis C via Transfusion Service Factor IX. "The remainder of the infections was attributable to products supplied by the international pharmaceutical companies."

In case I have not mentioned this before, I am the lady who established the initial contact with U.S. lawyers, including setting up a meeting between Scottish haemophiliacs and Lief Cabraser (LCHB), San Francisco. There are now 1,000 haemophilia cases from Europe going ahead in America on a no-win, no-fee basis. We have the judge we want and so far the plasma companies have failed to have cases thrown out. We are in the discovery phase and looking forward to accessing shipping records detailing which individuals bought the U.S. prison plasma for the UK and where the batches went. You may be approached for records at this end!

It is very important that you acknowledge in public that the Irish settlement was quote, "an ex-gratia, no liability, moral, compassionate, payment, made in recognition of extraordinary suffering" see letter from Irish government. We are told that the proposed UK settlement is an "ex-gratia, no-liability, moral, compassionate, payment," yet this proposed settlement does not appear to recognise the "extraordinary suffering" of haemophiliacs in the same way. We believe haemophiliacs are being discriminated against, and that is why we have now turned to Europe and the Human Rights Act.

We also have the interesting situation and example where a haemophiliac has received blood products in England and also in Eire whilst on holiday, depending on which country he launches his claim, the financial difference could be as much as £200,000, possibly more. This could be the same for any Scottish haemophiliac who has had blood products in both countries. In one country his wife/partner/carer would be recognised and money awarded for example for loss of sexual relations, loss of career if the wife became his carer, loss of the right to found a family because of infection with HIV/HCV, in another country she would not be financially recognised. In Eire the bereaved are recognised in financial terms, in the proposed Skipton Fund settlement they are not. This cannot be right!

The matter of "misinformation" on the Eire settlement has now been referred to the Parliamentary Ombudsman in England via MPs, as so far no apology has been forthcoming from either Lord Warner or Melanie Johnson.

I enclose with permission of those concerned, information on the categories of individuals who are eligible for payments in Eire and suggest that you re-think the UK scheme as soon as possible to include all the other categories of persons who should receive recompense on a parity with Eire, our European neighbour!

Haemophiliacs and their families have taken their case to the European Parliament, part of our case is that we can't trust our own politicians to be honest with regard to blood contamination matters, and the denial of the right to a full and open public inquiry. We are currently being advised and supported by ECAS. A French lawyer is looking at cases. The French are only too familiar with the cover-up over the contamination of haemophiliacs, as one of their health ministers was sent to prison with regard to this issue. I am sure the French would not wish their European neighbour to get away scot-free in this respect.

I would suggest that you admit to your mistakes with regard to information you have released on the Eire settlement and implement a settlement for haemophiliacs in line with that of Eire. We are also concerned that there appears to be discrimination with regard to those who received an HIV ex-gratia payment, and those who will receive the HCV settlement in terms of the level of settlement, and the fact that that the HIV settlement was taken from a contingency fund and not from the NHS budget. We request that the HCV payment comes from a contingency fund where it will not affect NHS spending and payments in line with Eire can be awarded.

I look forward to your prompt response. Please could you copy your reply to members of the Health Committee, Jack McConnell, and specifically Christine Grahame. If I can be of any further assistance in the meantime please do not hesitate to contact me. I understand that I can expect a reply within 20 days from your department within 20 days, and look forward to hearing from you on this matter.

Yours sincerely

Carol Grayson (Haemophilia Action UK)

Jack McConnell

Christine Grahame MSP

Health Committee

Press various

CARERS/COMPENSATION

Archer recommends that direct relief should be provided for those **infected,** and for **carers who should have been prevented from working**. He also states that this should be paid through the Department of work and Pensions, not through a trust and should not be means tested nor taxable. I suggest some form of **retrospective payment should also be made towards those who were carers for many years but whose husbands died.** If this can't happen a substantial lump sum should be paid to all those who were carers and length of time caring should be taken into account. Carers should receive payment (compensation) in their own right as they are not an appendage of their husbands.

Comments On The Macfarlane Trust Taken From My Dissertation Questionnaires:-

Insulting and everyday they exist is having a negative effect on my longevity and feeling of worth (H4)

MFT set up to keep us quiet in 1990. The service has been extremely poor. Staff have been corrupt (referring to embezzlement where a member of staff was sentenced for stealing £420,000) and inconsistent and selective over registrants. Out of touch with our needs at times and unresponsive to our actual real concerns- Payments pay the bills and keep me ticking over- thats all- I survive under national average income with more than average life costs (H12)

Generally good, but they change all of their policies from month to month, and sometimes when you ask for help, you feel like you are begging (H16)

Comments On Skipton Fund Taken From My Dissertation Questionnaires:-

Does not reflect what we have gone through, what we are continuing to go through or the further limits it has put on our lives (H2)

In one word – Laughable. Does the Government really believe that I am willing to place such a low value on my life? The payments indicate exactly what they think an infected haemophiliac's life is worth- next to nothing. The Government in Eire agreed without acceptance of liability to pay my two male cousins six figure sums of compensation for the harm caused to them from receiving exactly the same infected US plasma. Why does my government think my life is worth a fraction of that of an Irish family??(H14)

Why should there have been a cut off point? This is once again the exploitation of the very people that were there to support their partners through the most difficult times of their lives, during which time we were the unforgotten army of carers that were left to cope with the

most devastating things that one could ever encounter within a lifetime, it would appear that successive governments have exploited the love of the partners of the people that received contaminated factor 8(P17)

WIDOWS/PARTNERS/ AND INFECTED INTIMATES: LUMP SUM PAYMENTS

I would suggest that ALL widows/partners and infected intimates receive a substantial lump sum payment, non taxable, non means tested that would not affect any state benefits, not paid through a trust where people have to go cap in hand begging for small amounts to survive. This should be a decent sum to go some way towards covering the multiple losses on the grounds of "extraordinary suffering" as the Minister recognises the "unique situation of the haemophilia community compared to other disasters".

Loss of loved one(s) due to infection.

Loss of having a child/children

Loss of earnings/career often over many years (women were often the main wage earner)

Loss of pension

Loss of insurance as infected partner uninsurable

Loss of health both physical and psychological

Loss of relationship physical intimacy/sex life

Loss of home in some cases due to financial insecurity

Loss of independence and an ordinary life

Loss of time

Any payment made should also take into account suffering due to years of stigma and discrimination related to HIV/HCV. There is also a higher costs of living due to the viruses in reduced financial circumstances, for example heating bills are high when a person is too ill to work, there are costs of supplementary therapies and nursing bills if the partner wish to continue full time work, higher travel and home insurance costs living with an infected "bleeder." An example of inequality is that when the haemophiliac is sick there may be some support towards heating bills but when he dies and his wife/partner is unable to work due to grief/ill health the heating payments stop, this is grossly unfair and immediately puts the bereaved person into financial difficulties as benefits for the family are removed by both the government trust and Benefits Office and replaced by a basic benefit basic benefit. Some bereaved persons whose partners were infected by hepatitis C get nothing at all.

Children

Children of haemophiliacs have also suffered both physically and mentally. Some were infected through transmission via the partners of haemophiliacs and also the many bereaved

children who lost out on a parent, in some cases both parents where the partner was infected. Due to reduced financial circumstances with the bereaved family they also lost out in that respect too and any lump sum should reflect that children had to be provided for over the years and suffered in their own right.

Discrimination by virus

There is serious discrimination in terms of virus. The amount of financial help people receive is determined by which virus they or their partner has. There is now good treatment available to combat illnesses associated with HIV infection, however many haemophiliacs are now dying of hepatitis C as they have long standing infection and were often exposed to different strains and genotypes in multiple exposure through NHS treatment. The deaths of haemophiliacs were historically often not recorded properly with HIV/HCV left off death certificates, few post mortems carried out. The death of my husband was only recorded properly because I stood my ground and was also informed that anyone involved in a legal case over infection must have have an inquest however I was only told this by chance through chatting to an admin assistant about my husband's death whilst at the Coroner's Office. Therefore I do not believe all research data on haemophiliacs is accurate especially not into deaths. What should be asked is how many deaths were the subject of an inquest where a proper post mortem could be carried out. I ask the DOH to reconsider their response below. Compensation should be calculated according to multiple losses and need not by virus.

Below is the DOH response to my concerns over discrimination by virus.

Our ref: DE00000447209

Dear Ms Grayson,

Thank you for your further email of 28 September about contaminated blood. I have been asked to reply.

The difference between the ex-gratia payment schemes for HIV and hepatitis C reflect the different times when they were set up rather than differences between the viruses themselves.

The Macfarlane Trust was established in 1988 to assist people with haemophilia who had contracted HIV infection through NHS treatment of their haemophilia with contaminated blood products. The Eileen Trust was set up in 1993 to assist people, other than those with haemophilia, who contracted HIV through NHS treatment with contaminated blood products. When the Macfarlane and Eileen Trusts were established, there was no effective antiretroviral drug treatment for HIV to prevent progression to AIDS, and life expectancy was short.

The Skipton Fund was set up in 2004 to implement and manage a UK-wide ex-gratia payment scheme for people infected with hepatitis C from NHS treatment with blood, blood products or tissue. When the Skipton Fund was established, there were already NICE -recommended drug treatments for hepatitis C available. These

treatments are effective for many patients in preventing progression to cirrhosis and primary liver cancer. Evidence suggests that most people with chronic hepatitis C infection do not develop serious liver disease in the absence of treatment.

The Government has committed to review the financial relief scheme (the Skipton Fund) for people infected with hepatitis C in 2014.

I hope this clarifies the Government's position.

Yours sincerely,

Lynsey Morton
Customer Service Centre
Department of Health

The Need To Educate Regarding This Tragedy

I believe that doctors and nurses going through basic training should be taught about the "haemophilia holocaust" because so many treatment and ethical issues have been raised over the past 30 years. Haemophilia trainers should be funded through a central training scheme to offer educational sessions to any interested parties. It is also very relevant to anyone wishing to learn about campaigning through the media or advocacy journalism.

(My dissertation is used to show students at Leeds University on the MA in Activism and Social Change how to turn grassroots campaigning into a credible piece of academic research).

Females with bleeding disorders should also be utilised to educate health care staff on specific problems for women as many are still not well educated in this area.

Women Bleed Too is a campaign set up by the national Haemophilia Society for women with bleeding disorders.

http://www.womenbleedtoo.org.uk/index.php?pub_content_id=3

Funny Blog is a blog from a woman with a bleeding disorder

http://rosamundcooper.blogspot.com/

Need For Ongoing Dialogue

The recent meeting with Anne Milton was constructive and there is a need for ongoing dialogue and a follow up meeting in relation to **infected** and **affected women** within the

haemophilia community once the Department of Health has considered all proposals from those who attended recent meetings and come to a conclusion as to how to act in response to this tragedy.

The need for resolution for our haemophilia community is supported by the AVMA (Action for Victims of Medical Accidents) who will be writing to you shortly.

APOLOGIES

General apology

Finally haemophiliacs have waited many years for an apology for the "worst medical treatment disaster in the history of the NHS." The community feels this is a very important aspect of resolution and should come in the form of a public announcement and written statement in the Commons.

Specific Apologies

Colette Wintle and I highlighted the misinformation coming from government with regards to Lord Warner and Ireland as far back as February 2004. I mentioned my husband and Iset up the initiative for parity with Ireland back in 1996. (I am sure Earl Howe will verify that Colette gave him copies of our original letters from 2004 and he has indeed been most supportive over the years). We were however repeatedly ignored by the previous Labour government which led to great frustration and distress. Had our evidence been taken seriously there would have been no need for a Judicial Review which used our evidence anyway. My husband is no longer here to hear the response to the JR (he died in 2005) and Colette and I believe an apology to us for the serious misinformation from Lord Warner and others is 6 years overdue.

I believe apologies are long overdue also in relation to former Health Minister Lord David Owen with regard to failing to carry out his commitment for the UK to become self-sufficient (given in 1974) once he had departed for the Foreign Office and the destruction of his papers from the time he was Health Minister.

An apology should also be given to the family of the late Dr Spence Galbraith (formerly of Public Health Laboratory Service) whose timely warning to remove all US plasma treatment from the shelves due to the serious risk of AIDS was ignored in May 1983. He went to his grave very angry at the huge tragedy that followed and without personal resolution. I spoke at length to Dr Galbraith and also to the person who admitted to his mistake in not following Dr Galbraith's advice. (I have omitted his name here though have given it to the DOH) I have forgiven him due to his apology). He has apologised to me personally in a phone call for his wrongdoing and also admitted that "treatment was no so ethical then" but public apologies are also required from the government.

Author

Carol Grayson (RMN, MA Gender Culture and Development, Distinction, Winner of Economic and Social Research Council Michael Young Prize 2009)

E-mail GRO-C

THANK-YOU FOR TAKING THE TIME TO READ THIS