PRIOR 6 1985 all Haemophiliacs were treated with contaminated blood products. The product known as factor VIII was given as the treatment to control internal bleeding episodes. This treatment replaces the clotting factor missing from their blood, so in turn easier the pain that is suffered while suffering a bleeding episode this pain can be very severe. which I in the past was first relieved by pain killers.

(IBI) II In the late 70's a new treatment was introduced IV was to be the begining of a new life style for all who suffer the Haemophilia, no more bleeding in to joints, muscles which caused severe arthritis in later life for sufferers, less missed days from school and work what wonderful news WRONG This wonderful new treatment resulted in these patients being infected with dreadful diseases with fatal consequences (H.I.V. / Hepatatis of so many strains)

(IBI) II The Haemophiliac is born with this genatic disease as are others who suffer Hereditary disorders (Down's) they have to accept this condition and whatever pain goes with it, they also like to prove that they can be equal with everyone else, so always have to work that little bit harder very often under great strain and pain. After leaving School in 1950 my husband was never out of work even after being made redundant 1988 he was unemployed for 1 week. (His last working day was 5/11/91)

An American widow who lost her husband in Lockerbie air crash claimed for loss of salary, loss of interest, loss of companionship and also loss of services e.g. maintenance of home, garden, household chores etc. She received compensation for all these things.

(181) 11 My Husband would go to work at times in great pain, afraid to stay off for fear of losing his job. Being a Haemophiliac you always try to work hard at your job you never told people of the problem only because employers may not think that they could do that job, he was always trying to prove that he was no different, he knew of course the jobs he could not do. Employers and in general public all think that by being a Haemophiliac that if you say cut your finger you would bleed to death, so employers would not take the risk, the T.V. programme (Medics) did nothing to help matters by their screening of a patient with Haemophilia dying from a nose bleed, my grandson who suffers from the complaint was to start school so after the showing of this programme the School Staff were terrified wondering how they would cope with Christopher. People must be educated that Haemophiliacs are normal people, with a medical problem like lots of others, the sufferers themselves learn their limitations and they get on with life if they are allowed to. My Husbands Uncle lived until well into his 70's

(181) 11 he was the 'Lucky One' he never received Factor VIII

Haemophilia as you know is
an inherited, so in my Husbands
family there were many family
members suffering from Haemophilia
Sadly we have lost family members
through receiving contaminated blood
products, they were infected with
either H.I.V or Hep C, it has been
very hard for all family member
to handle, this loss, but we also
have to the added problem that
the family members who lost their
lives through H.I.V. they have had
recompense by the Government, and
rightly so, but the member who died
from H.C.V. the government will not
recognise. (why?) My Husband died
from Live Cancer as a result of Hep C
Infection, so I receive no recompense
The Government has stated that it only
paid recompense to the Haemophiliacs
with H.I.V. because of the Stigma attached

see over

GRO-C

(FOR IBI)

6d. I feel the government should start looking at the suffering that both H.I.V. and Hep C Haemophiliacs have had to cope with. Very brave men. They are indeed

(See over)

There are many families in the country who are split in this way.

In fact Haemophiliacs throughout the world have been treated very badly, many countries have indeed accepted their role in this very sad way they treated Haemophiliacs but the British Government do not.

JULY 1987: Jaundiced x 2 (ambiguous) but irrelevant (they knew of liver problems). Palpable liver and "slight splenomegaly"

FEB 86 - JULY 89

(FOR IBI)

11 Why did you compensate HIV
(131) Explain the Difference between the 2 Virus that Haemophilia Suffer from.
Both are infectious, both are contacted from Blood product Factor VIII Death is the result from Both. ?

11 Mr Malone stated that there were 'Special Circumstance' regarding HIV. Clinical as well Social. he mentioned the Social side. e.g. Employment, Mortgage, Insurance.
Special Circumstance with Hep C. is also Employment Mort Ins and many Clinical problems
Having witnessed Both Virus in a family of 3 Brothers Mr. Malone has no Idea as to how these Viruses are not only Similar they both kill.

11 Hep C has been refered to as a Sneaky Virus.

6 Dame Sheila Sherlock stated that they had known for a number of years it was serious a Blood spread and at least to was leading to Cirrohhis and liver Cancer. Hep C after many years a to disease was diagnosed.
1989 first test was on the market 18 month later after the rest of Europe & America we started testing.
In Scotland the B/T/S. Traced all their Donors. by doing so, they were able to treat them and the patients who had received their Blood. Record are kept and sample of Blood plasma can be kept for Decades. Scotland BTS,
Dr Jack Gillon was asked was he not making a rod for his own back. Replied. Not to refuse to Identify these people on the grounds that they have a case against us that has to be taken on the chin.

LC 1

No. Date

My Husband was a Haemophiliac who was infected with Hepatatis C from receiving contaminated Blood Products Factor VIII.
He developed Severe Liver damage which led to liver cancer, this resulted in his death Sept '94

My Husband was one of three Haemophiliac Brothers, all three have died as a result of receiving contaminated Blood Two Brothers Sadly died from H.I.V. Two different Lives from this one product, but with the same ending

Another point in this sad case is the difference in the way the Government looks at it The families have received Recompence for the Brothers who died from H.I.V my-self and my family are not Regonised, and the Government say they have no intention of doing so.

(181) 11 All the families are disappointed at the Governments approach, for at the end of the day three Brothers have died, we have three Widows a Mother who has lost her three sons Children who have lost their Father and grandchildren who will never Know their Grandfather.

15/ No.

16/ No.

17 None.

18 ~~—~~

19 NONE

20 NO

21/ No

22/ No

23 —

24/ A Unable to continue his job

B

C. Quality of life v/a

D Unable to take ~~any~~ such interest in normal family life

E. All insurance policies cashed early 1989 for fear of Haemophilia being shown a policy which had not been declared when taking out insurance. Mortgage protection was refused in 1971 due to having an ulcer.

F Digestion of food very difficult

G. Not being able to talk freely about his condition

H. Knowing time was limited.

I. Our marriage was very good which made this illness hard to accept

11(12) J/ Loss of Salary GRO-C

Cashing in of Policies. Due to being made ~~redundant~~ redundant in early 1988 his terms pension was frozen in ~~1989~~ 1990 Pension rules changed so which enabled my husband to ~~cash his p~~ ~~draw~~ release his pension, access to his pension, this was withdrawn for fear of what may be released by the insurance company to make the Pension null. void. this policy was cashed early at a great loss of money.

His last employment was for 4 yrs so his pension when he left in 1992 was very small £21. per month. which now leaves me a pension of £198 per year.

26 Careful monitoring. Symptoms to watch for and report for follow up

28/ Why wife in 1989 HCV was known about we were told in 1992 and 1994 Before we saw a Liver consultant.

My Husband was a Haemophiliac who died from liver cancer, as a result of being infected with the Hepatitis C Virus, from treatment with contaminated blood products factor 8 as part of his N.H.S. treatment

My Husband came from a family who suffered from Haemophilia, our grandson has inherited the disorder.
My Husband and his brothers were all given the same treatment during 1979/1981 from which by 1985 it was discovered that you had either been infected Hepatitis C or H.I.V. ~~All have~~

All have since died as a result of their treatment

In 1990 the Government made a payment to Haemophiliacs who developed H.I.V. but not if you had Hep. C. So here we have a family treated very unfairly. Infected blood products caused all their death but the government will not make a payment to Hep C. victims this is so unjust
Haemophilia is hereredity, there are many families who will loose loved ones, Haemophiliacs throughout the world have suffered greatly due to having been treated with this infected blood, many countries have treated their Haemophiliacs fairly, but not the U.K. I find it all very sad.

(151) 11 My Husband was a lovely, caring and also a very brave man who did not deserve to die in this way I miss him so very much.

(FOR IBI)

Loss of Earnings
Loss of Services
Loss of Companship

Becoming a widow has been the hardest thing I have ever had to cope with.
The loneliness, the fear, the loss of companship is the greatest mountain I ever had to climb.
The loss is intolerable, the daily routine of going to work coming home discussing over dinner meal how's our day has been, simple things like T.V. What a load of rubbish the programme is, would you like a cup of tea, shall we go for a run, bedtime chats, planning decorating & buying new things for the home, planning holidays
Someone caring for you when you feeling ill. Small simple things but they are the biggest loss of all.
One on my own all those simple things in my life are the biggest, all decisions now are my own, (Social life non existent) House maintenance constant worry, security constant worry, money constant worry.
All of above are true of most widows, but life can be a little easier if you know that your finances are not a constant worry.
Would like to be able to drive, buy car out of the question could not afford to do so

(FOR IBI)

What the medical Profession Say about Hep. C.

Hepatologist DR. GEOFFREY DUSHEIKO R.L.H.
One of the diseases to would lease like to have

Pathologist Dr. AMAR DHILLON RFH
Over a decade the liver will be completley distroyed, Liver Cell Cancer is frequent
After cirrhosis clinical complication are such that the patient cannot survive without a transplant

Dame Sheila Sherlock RFH
It is a very sneaky disease
It had been known about for a number of years. It was very serious and was blood spread (NANO) and leading to cirrhosis and liver cell cancer.
After many years this virus was discovered in California and an antibody test became available to be used by many people 1989 John Barbara BTS refused to test because of the risk of losing doners and the cost involved, so this infected blood went into the system.
U.K tested in 1991 18 months after the rest of Europe and America.

Diagnosed Jan '92 as suffering from cirrhosis which would prove fatal within 2yrs. We were told, he had been infected with Hep. C in 1981 - Hep B in 1979. at the time of suffering from the Hepatitis attacks Hep B and C were not known the first attack in 79 was refered to as a Haemophiliac Hepatitis and nothing to worry about, the second attack was more serious, this followed a ulcer operation. This more serious Hepatitis became known as NON A non B Hep. it was 1989 when it became known as Hep C and us to the seriousness of it. Knee operation Dec 1991 symptom started to appear which made the doctors do tests as to why progress was slow, only then did we find out he was suffering from Cirrhosis.

The 10yr period from being infected with Hep C. saw him quite well for a few years. then small things started bothering him then they would settle ~~he had~~ his digestion then started to give him trouble, this he put down to his ulcer problem, at the back of his mind he worried about his liver but as his attended the Hospital on a regular basis as ~~most~~ all Haemophiliacs do, and have regular blood tests that if he had a problem he would have been told. in fact he did ask as to how his liver was prior to his ~~[illegible]~~ knee op, for he would not like to have this op, if he had any problems, we were told so he had no problems and his was well enough for the op. when infact he was well advanced with cirrhosis and died within 2yrs. At the time it would appear that the Haemophiliacs with Hep C were slipping through the net and it was the H.I.V. patients which were thought of as being the most serious they were but so were their [illegible]

Balance by phone 14/1 -

GRO-C

Basic Comp.
Loss of Earnings
Funeral Exp.
Pensions
P.E.P.

GRO-C

Independant.
Loss of Companionship
Loss Services.

No Payment until all Solicitors

GRO-C

A Council
Mortgage
Rate
Rent
Telephone
T/V Licence
Food

To be under the care of a liver specialist as soon after being diagnosed

To be given all the symptoms of the complaint and to be aware of

To be seen by a dietician

To be offered T/B at the first possible opportunity

[illegible] [illegible]

[illegible] Jan 94 cancelled a day before.

When would the liver condition have been noticed if knee op hadn't take place.
BGP noticed on re-checking liver scans at Royal. [illegible]

Special People.
Mortgage Insurance. Job Position.

Insurance Policies
Cashed In.
Mortgage Protection refused because of ulcer.
All Insurance ask the same question about testing

80.

22 S/Court Needle
24 Sleeping
46
22 S/Court
68
24 Pool Party
90

GRO-C

Dear Sir

My I lost my husband who was a haemophiliac and H.I.V. Neg Sept 3 1994. His death was due to Hep C his certificate read 1.D.3.4.

This letter is to ask you for some financial help as my weekly income is widows benefit of £102 plus £19.4 per annum widows benefit from his last employer pension scheme. I have all the ancillary payment to make e.g. mortgage (no mortgage protection policy possible as due to haemophilia) council + Water rates House insurance heating etc. So money is tight my husband last employment was from June 88 to Dec. 99, when he was forced to retire due to his condition for Hep C. As you can imagine his pension was very small. His previous employment was from 1973-1988 when he was made redundant the pension that was due he felt he had to cash in the fear of it not being valid if Haemophilia was shown on his death certificate. His employer was not aware of his health problems So we have lost out considerably by having to cash in all pension rights + Insurance policies.

I would be most grateful for any assistance you may be able to give me.

GRO-C

1978 Nep B.
1981 Nept C
1992 Jan Diagnosed Suffering from Cirrhosis after Knee
Replacement operation

From Dec 1991 through to 1994 his health deteriorated
April 92 (14th) Varices Severe Bleeding (life threatening)
April 92 30th " " " " "
May 92 14th " " " " "

Eating Diet became a problem food which was
normally eaten began causing digestive problem
Milk could not be tolerated, ~~[illegible]~~ cereals had
to taken with Orange juice, tea with milk ~~not~~ no
longer able to be taken most foods left him bloated (he
lived mostly on Salads & Pasta & Fruit Juices)
Dairy Foods could not be tolerated no longer possible eating out was
Symptoms Itchiness, mouth bleeds leg ulcers, rashes
excessive swelling of stomach which made clothes
quite a problem. Hernia's Tiredness was
constant quality of life was nil
July 94 Family wedding unable to attend due to
being unable to dress suitable wearing Such a Shirt
& tie was impossible due to size of Stomach leisure
clothes was his daily dress. diet caused [illegible] for
August 94 Liver failure traveled to Newcastle for transplant
but were to late on being scanned cancer was confirmed
16 days later he died

Finances After the deaths of his brothers my husband decided
that any insurance policies should be cashed, he knew
that he had a problem but no ~~[illegible]~~ one was picking
up on his liver Problem This cost a lot of money
I live now on a pension for my husband of £196 PA £3.75 Week

15/ No.

16/ No

17 None.

18 ~~—~~

19 NONE

20 NO

21/ No

22/ No

23 —

24/ A Unable to continue his job

B —

C Quality of life nil

D Unable to take ~~any~~ much interest in normal family life

E. All insurance policies cashed ~~early~~ 1989 for fear of Haemophilia being shown a policy which had not been declared when taking out insurance. Mortgage protection was refused in 1971 due to having an ulcer

F Digestion of food very difficult

G. Not being able to talk freely about his condition

H. Knowing time was limited

I / 11(iii) Our marriage was very good which made this illness hard to accept

25/ Loss of Salary GRO-C

Cashing in of Policies. Due to being made ~~[illegible]~~ redundant in early 1988 his firms pension was frozen in ~~[illegible]~~ 1990 Pension rules changed so which enabled my husband to ~~[illegible] release [illegible]~~, access to his pension, this was withdrawn for fear of what may ~~[illegible]~~ be revealed by the insurance company to make the pension null-void. this pension was cashed early at a great loss of money.

His last employment was for 4 yrs so his pension when he left in 1992 was very small £21. per month which now leaves me a pension of £198 per year.

26 ~~Careful~~ monitoring symptom to watch for and report for follow up

28/ Why when in 1989 HCV was known about we were told in 1992 and 1994 before we saw a live consultant.

£18.00 Loss of Earning [illegible] GRO-C

GRO-C

Funeral Expenses GRO-C

Pension Rights

Pension Widow GRO-C

Lost, Companship, Independance, Services,

Expenses buying a car and taking driving lessons to be able to gain independance. All Household maintenance

Basic compensation plus widows pensions.
for life from trustfund
Adjustment to be made also to HIV widows.

25% for infection + 60% illness forces early retirement (Cirrhosis) + 15% for widow plus pension for life. Funeral expenses

GRO-C

A large investment by Society would earn more interest than an investment by a single member.
Members to be able to draw from trustfund when needed.

1979/1981 worked until Dec 91.