MA GENDER, CULTURE AND DEVELOPMENT

APPENDICES B- QUESTIONNAIRE RESPONSES

BLOOD FLOWS NOT JUST THROUGH OUR VEINS BUT THROUGH OUR MINDS. HOW HAS THE GLOBAL POLITICS OF BLOOD IMPACTED ON THE UK HAEMOPHILIA COMMUNITY?

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APPENDICES B

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HAEMOPHILIA DISSERTATION- REQUEST FOR HELP

Dear Friend,

I am once again writing to you to ask for your assistance. As you will be aware my beloved husband Peter died on 16th April 2005 due to his contamination with HIV and hepatitis C through NHS plasma products. His brother Stephen, a haemophiliac, also died in the 1980s as a result of receiving contaminated blood. Following Peter's death I have become a mature student at Sunderland University studying for an MA in Gender, Culture and Development.

Those of you who know me well will not be surprised to learn that I have decided to write my 15,000 word dissertation for my course on the UK haemophilia community. I felt that it was important that something positive emerge from the tragedy that has devastated our close community and I hope that you will help me in achieving this aim.

Firstly let me explain a little about my dissertation. The title is *Blood Flows Not Just Through Our Veins But Through Our Minds. How Has The Global Politics Of Blood Impacted On The UK Haemophilia Community?* As you may have guessed already I wish to examine the infection of haemophiliacs with HIV/HCV and the effect on the UK haemophilia population. I am particularly interested in how haemophiliacs and their families view themselves and their situation and **your opinions** on the organisations/institutions you have come into contact with over the years such as the medical profession, the government, the national Haemophilia Society, Macfarlane Trust, the legal profession, plasma companies, media etc.

I have devised two questionnaires, (enclosed) one specifically for haemophiliacs and a second for those of you who are wives and partners of haemophiliacs and widows and bereaved partners. I will of course fully respect your right to confidentiality so those of you who decide to help me in filling out these questionnaires will be completely anonymous as I know how important confidentiality is for our community. You will be referred to simply by a letter and number which will bear no relation to your name or age. What is also important is that you get an opportunity to express your feelings and opinions and hopefully I will get an opportunity to feed this information back to the government and other organisations so please don't hold back. **HAVE YOUR SAY!**

I have kept the questions as open as possible and if you feel that I have not given you enough space please feel free to write the question number and continue on a separate sheet if necessary. I apologise for the fact that the questionnaire may seem a little long but I know many of you have become prolific writers over the years on the subject of haemophilia and blood borne viruses and it can sometimes be quite cathartic to put your thoughts on paper when so many people have tried to suppress the viewpoint of haemophiliacs and their families.

I have done my best to be sensitive when devising my questions but admit that there is no completely sensitive way to ask certain questions regarding HIV/HCV infection. All I can honestly say is that I know how difficult it can be at times to face challenging questions and the emotions that can raise. I therefore will not be offended in any way if some of you do not wish to participate in this study and are unable to complete the questionnaires.

For those of you that do wish to take part I have included an "informed consent" sheet for you to sign giving your permission for me to use your answers to my questions anonymously and stating that you have read this letter explaining my study. I have also enclosed details of my dissertation supervisor Alka Kurian on a separate sheet. I have included a S.A.E for return of questionnaires and consent forms. The consent forms will only be seen by me. I have tried to contact as many of you as I can by phone to explain the questionnaire, if I missed you I will keep trying. If you need to discuss the questionnaire or your feelings on the subject matter please feel free to ring or e-mail me. You have the right to withdraw from participating in the study at any time and you do not have to give a reason. I would be extremely grateful if you could return the completed questionnaires and consent forms as soon as possible, by **Friday 11th August 2006** at the latest to give me time to write up my study.

I hope my dissertation will give an alternative viewpoint to the standard viewpoint often expressed by the government and other "official" bodies on the contamination of haemophiliacs. I see this study as a way of empowering haemophiliacs and their families. I will also be challenging the *Self-Sufficiency in Blood Products Report* that the government released this year in direct response to questions raised by my campaign group **Haemophilia Action UK** in conjunction with the Newcastle **Journal**. My dissertation will include documents which the government claims were in the public domain but were "inadvertently" destroyed by an "overzealous" civil servant, possibly the same person responsible for destroying Lord Owen's health files. Fortunately copies of some of these documents were held elsewhere so I have utilised the Freedom of Information Act to access these papers and to remind the government of past policies and practice in relation to the care and treatment of haemophiliacs. My dissertation once completed will be available for others to use and will be housed at Sunderland University Library. I hope to put an additional copy in the British Library alongside the haemophilia "*life story*" project from the Haemophilia Society and Brighton University. My dissertation will be subject to copyright however I have no problem with others using my work once completed as long as proper reference is made to myself as the author.

Thank-you for your time and take good care of yourselves.

Best Wishes

Carol (Grayson)

DISSERTATION SUPERVISOR

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(July 2006)

UNIVERSITY of SUNDERLAND

ETHICS COMMITTEE

PARTICIPANT CONSENT FORM

Study Title: **Blood Flows Not Just Through Our Veins But Through Our Minds: How Has The Global Politics Of Blood Impacted On The UK Haemophilia Community?**

Name...

Address...

....

I give consent for myself to be a participant in this study and agree to complete the questionnaire sent to me. I have received an information letter about this study and understand that I have been given the opportunity to ask any questions regarding the study by contacting Carol Grayson on Tel **0191-2815110** if I have any queries or concerns. I understand that I can withdraw from this study at any time.

Date

Signed...
Participant

This study is approved by the University of Sunderland Ethics Committee

B3

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state..65.....

2) What is your ethnic origin? (White British, Scottish Pakistani etc)
Please specify...WHITE BRITISH...................

3) What type of haemophilia do you have A, B, etc? Please specify.....A.......

4) What does the word "blood" mean to you?

DEATH

5) What does the word "haemophiliac" mean to you?

DISABLEMENT, PAIN

6) What do you think the word "haemophiliac" means to the general public?

THOSE THAT KNOW ANYTHING ABOUT HAEMOPHILIA THINK IF WE GET CUT WE WILL BLEED TO DEATH. THE REST HAVE NOT GOT A CLUE

7) Are you HIV positive? Please circle [✓ YES] or NO.

8) Is/Was your wife/partner HIV positive? Please circle YES or [✓ NO]

9) What do the words "HIV positive" mean to you? Please explain.

STIGMA, EXCLUSION AND LIVING UNDER
A DEATH SENTENCE.

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

A PAINFUL DEATH, NO CHANCE OF A LIVER TRANSPLANT
STIGMA, EXCLUSION AND LIVING UNDER A
DEATH SENTENCE.

13) Have you ever been exposed to variant CJD through blood products? Please circle YES or NO or [✓ DON'T KNOW]

14) What do the words "exposed to variant CJD" mean to you? Please explain.

TREPIDATION. AFTER BEING EXPOSED TO HIV/HCV THE POSSIBILITY OF BEING EXPOSED TO A THIRD VIRUS WOULD BE VERY DIFFICULT TO COPE WITH

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain.

BEING INCAPABLE OF DOING PHYSICAL TASKS. DIFFICULT TO FIND EMPLOYMENT IN MY YOUNGER DAYS.

18) Have you ever been a carer? Please circle YES or [✓ NO]

A1

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

[✓ YES] or NO.

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle [✓ YES] or NO.

22) What does the word "carer" mean to you?

SOMEONE WHO CARES AND LOOKS AFTER YOU AND TAKES CARE OF ALL YOUR NEEDS. ON CALL 24 HOURS A DAY.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

VERY POOR

WHEN I WAS TOLD BY MY CONSULTANT AT THE NEWCASTLE RVI TRUST I WAS HIV POSITIVE AT THE SAME TIME HE TOLD ME I WOULD HAVE TO USE UP ALL UNHEATED PRODUCTS IN THE FRIDGES BEFORE GOING ONTO THE NEW, SUPPOSEDLY VIRUS FREE HEAT TREATED PRODUCTS. ON ASKING IF I WOULD BE REINFECTED BY USING UP THIS UNHEATED TREATMENT MY CONSULTANT SAID THAT HE DID NOT KNOW. I FEEL WE HAVE JUST BEEN USED EVEN UP TILL THE PRESENT TIME AS A LONG TERM STUDY. LIVER TRANSPLANTS ARE NON EXISTANT, YOU ARE NEVER REFERRED AT THE RIGHT TIME. IT IS ALWAYS TOO LATE FOR A TRANSPLANT. YOU ARE PUT ON A WARD FOR ONE PURPOSE ONLY AND THAT IS TO DIE.

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

AFTER ACCESSING MY RECORDS I FOUND THAT TESTS HAD BEEN CARRIED OUT WITHOUT MY CONSENT. MY CONSULTANT TOLD ME TO COME AND BE TESTED FOR HIV BUT THEN ADDED THAT HE KNEW I WOULD BE POSITIVE AS MOST OTHER HAEMOPHILIACS WERE.

AS FOR HCV I HAVE A LETTER SAYING I WAS POSITIVE IN 1990 WHEN SUPPOSEDLY THERE WAS NOT AN ACCURATE TEST UNTIL 1994. I WAS NEVER ASKED TO BE TESTED FOR HCV I WAS ONLY TOLD OF THE POSITIVE RESULT.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

WITH CLOSED EYES. NO PUBLIC INQUIRY EVEN THOUGH OVER 1000
H EMOPHILIACS HAVE DIED, RECOMBINANT TREATMENT WAS PHASED IN IN ENGLAND WHEN WALES
AND SCOTLAND GOT IT VIRTUALLY STRAIGHT AWAY + IT WAS PHASED IN BY AGE IN ENGLAND. THE
VERNMENT WILL FUND RECOMBINANT THIS YEAR WHICH LEAVES US WONDERING IF
H WILL FUND FUTURE YEARS. WIVES AND PARTNERS ONLY RECEIVE THE BASIC CARERS
ALLOWANCE EVEN THOUGH THEY ARE IN A HIGH RISK SITUATION Re:- GIVING INTRAVENOUS
EATMENT, MOPPING UP BLOOD SPILLAGES, WASHING SOILED BED LINEN, WIDOWS ARE
ALLY FORGOTTEN. THIS N.H.S. TREATMENT WAS TAKEN IN GOOD FAITH SO MORE SHOULD BE
DONE FOR ALL OF THIS COMMUNITY. EX GRACIA PAYMENT WAS A PITTANCE AND A LOT OF
H EMOPHILIACS SPENT IT ALMOST STRAIGHT AWAY AS LIFE EXPECTANCY WAS LESS THAN 5 YEARS
TO DATE THE GOVERNMENT HAS NOT HAD THE DECENCY TO APOLOGIZE FOR THIS
TRAGEDY THE WORST IN THE HISTORY OF THE N.H.S.

H1

27) Are you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

CONSIDERING THE SITUATION THE REGISTRANTS ARE NOW IN, THE PAYMENTS ARE VERY POOR. A LOT OF PEOPLE ARE NOW HAVING TO USE THIS MONEY TO SUPPLEMENT THEIR INCOME. ONE OFF GRANTS ARE MORE DIFFICULT TO GET, ONLY HALF THE COST OF AN ITEM IS SOMETIMES GIVEN. WITH THE DETERIORATION OF OUR HEALTH THROUGH HIV WE REALLY NEED MORE HELP NOT LESS.

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO.]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund?

VERY LOW AND VERY INSULTING

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

WHY THE GOVERNMENT HAS MISSED THESE PEOPLE OUT FOR THE SAME PAYMENT IS BEYOND BELIEF. THESE WIVES AND PARTNERS HAVE SAVED THE GOVERNMENT THOUSANDS OF POUNDS CAREING FOR THEIR LOVED ONES. THEY DESERVE TO BE PAID THE SAME MONIES THEIR LOVED ONES WOULD HAVE GOT HAD THEY LIVED.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

EXTREME ANGER. HOW THESE PLASMA COMPANIES HAVE NOT BEEN HELD ACCOUNTABLE FOR THEIR ACTIONS AGAINST THE HAEMOPHILIAC COMMUNITY IS BEYOND BELIEF. THESE COMPANIES MUST HAVE REALIZED THE PLACES THEY WERE SOURCING BLOOD FROM WERE VERY HIGH RISK AREAS. ie:- PRISONS, DRUG USERS.

AS ALWAYS MONEY IS THEIR GOD REGARDLESS OF THE COST TO HUMAN LIFE. I CANNOT UNDERSTAND WHY THE BRITISH AND AMERICAN GOVERNMENTS HAVE NOT TAKEN ANY ACTION AGAINST THE PLASMA COMPANIES AND FORCE THEM INTO PAYING COMPENSATION TO EVERYONE INFECTED AND AFFECTED.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

HAD TO BE FORCED INTO DOING SOMETHING BY THE MEMBERSHIP. A TOTAL WASTE OF SPACE.

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

I FEEL THE FIRST TIME WE TRIED TO BRING A CASE AGAINST THE BRITISH GOVERNMENT THOSE SOLICITORS SOLD US DOWN THE RIVER BY ACCEPTING THE FIRST OFFER.
THE AMERICAN LAWYERS WE HAVE NOW ARE TRYING BUT AMERICAN LAW IS VERY SLOW.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

FOR THE NUMBER OF YEARS THAT WE HAVE BEEN ASKING THE PRESS TO GIVE US PUBLICITY I WOULD SAY THAT THEIR RESPONSE HAS BEEN REASONABLY GOOD. AT THE VERY BEGINING THE NORTHERN ECHO WAS VERY GOOD AT FIGHTING OUR CORNER. THE NEWCASTLE JOURNAL ALSO GAVE US GOOD COVERAGE. THE NATIONAL MEDIA HAVE DONE ARTICLES FROM TIME TO TIME, EVEN THOUGH I FEEL THAT THEIR HANDS WERE TIED AT TIMES.

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

EMPOWERED

BEING ABLE TO ACCESS MY MEDICAL RECORDS

BEING ABLE TO TALK TO DOCTORS ON THEIR LEVEL AND QUESTION THEM.

PUTTING POSTERS UP AT MY LOCAL HAEMOPHILIA HOSPITAL (RVI) TO INFORM PEOPLE JUST WHAT HAD HAPPENED TO US THROUGH CONTAMINATED TREATMENT AND HOW THE TRUST AND GOVERNMENT WERE ACTUALLY PLAYING IT DOWN. THEY KNEW THAT HCV WAS NOT ONLY INFECTING US BUT ALSO THE GENERAL PUBLIC. I BELIEVE IT CAUSED THE GOVERNMENT INTO CREATING THE SKIPTON FUND.

LEAVING THE HAEMOPHILIA CENTRE TO GET TREATMENT FOR MY HIV/HCV AT NEWCASTLE GENERAL HOSPITAL. THIS TREATMENT SHOULD HAVE BEEN AVAILABLE AT THE RVI.

DISEMPOWERED

NOT KNOWING THAT THEY HAD BEEN TESTING ME WITHOUT MY PERMISSION.

NOT SEEING TEST RESULTS OR BEING TOLD RESULTS.

NOT KNOWING I WAS DIABETIC AND HAD BEEN FOR SEVERAL YEARS, WHICH I WAS TOLD ABOUT ON ATTENDING NEWCASTLE GENERAL. THIS CAUSED ME MORE STRESS HAVING TO COPE WITH ANOTHER DISEASE AND KNOWING I COULD HAVE BEEN TREATED YEARS BEFORE.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

INJECTING FACTOR 8 TREATMENT INCASE THERE ARE ANY MORE VIRUSES TO COME THROUGH.

41) What if anything has helped you to maintain a positive outlook on life?

MY WIFE AND FAMILY. NOW MY GRANDCHILDREN

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTION 39

H1

FOR A LONG TIME HAEMOPHILIACS WHO KNEW EACH OTHER WERE GIVEN APPOINTMENTS APART OR ON DIFFERENT DAYS SO THAT WE COULD NOT DISCUSS OUR CONDITION AND TREATMENTS, WHERE IN THE PAST WE WOULD SEE EACH OTHER EVERY FEW MONTHS. AT ONE POINT WE HAD TO REGISTER WITH A CLERK IN THE HAEMATOLOGY DEPARTMENT AND WAIT UNTIL WE WERE CALLED, THE REASON GIVEN WAS THAT WE WERE FRIGHTENING OTHER PATIENTS THAT ATTENDED THE DEPARTMENT WITH OUR APPEARANCE ie:- LOSS OF WEIGHT, SALLOW COMPLECTION.

KNOWING THAT WE HAD TO USE ALL THE UNHEATED TREATMENT IN THE FRIDGES BECAUSE WE WOULD NOT GET ANY OTHER PRODUCT UNTIL IT WAS USED.

I STILL WONDER TO THIS DAY WHY THERE WAS NEVER A RECALL ON THE UNHEATED TREATMENT PRODUCT.

H2

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state..56.......

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify....WHITE BRITISH....................................

3) What type of haemophilia do you have A, B, etc? Please specify....A.........

4) What does the word "blood" mean to you?

DISEASE

5) What does the word "haemophiliac" mean to you?

A Hard, lonely a painful life.

6) What do you think the word "haemophiliac" means to the general public?

Bleeder

7) **Are you HIV positive? Please circle [✓ YES] or NO.**

8) **Is/Was your wife/partner HIV positive? Please circle YES or NO.** None

9) **What do the words "HIV positive" mean to you? Please explain.**

ISOLATION. Fear

It means I can not talk to anyone or have relation with them. Silence is safety. Anyone knowing would mean greater isolation

10) **Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.**

11) **Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or NO.** None.

12) **What do the words "HCV (hepatitis C) positive" mean to you? Please explain.**

The same as 9. but more deadly.

The treatment for HIV allows HCV to progress in my system by stressing my liver.

H

13) Have you ever been exposed to variant CJD through blood products? Please circle YES or NO or [✓ DON'T KNOW.]

14) What do the words "exposed to variant CJD" mean to you? Please explain.

Even more exposure to dirty product.

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle YES or NO. none

17) What does the word "disabled" mean to you? Please explain.

Less than. Can't do everything I want to. Have to pay others to do things I could do better.

18) Have you ever been a carer? Please circle YES or [✓ NO.]

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

[✓ YES] or NO.

21) If your answer to question 20 was YES please answer the following question. Is

/Was your wife/partner your carer? Please circle YES or [✓ NO.]

22) What does the word "carer" mean to you?

Someone for a start then helped me live. without whom I would have found life extremely hard.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

. With a total lack of care or concern.

Too bad. Don't bother us.

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

They never asked to test. never told us the results until they had to. never informed us at any time of the risks.

They did NOT ask because they did NOT want us to know What they already new.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

Pay them a little money and they will go away. Dash every hope they may have of finding out Why they were infected

27) Are you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or NO. none

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

Very Poor. Put a poor case from the start. Treat applicants poorly. Had CEO, on last grant application, change the rules twice to ensure I did not qualify.

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or NO. none

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund? Nominal. Does not reflect what we have gone through, what we are continuing to suffer or the further limits it has put on our live

H

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

How bad is it that the government cheats the family of a dead man.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

They will cheat, lie, deceive and deny the Truth to save money. I don't know how they can look in the mirror.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

They are a joke. If anything they helped the government give us such a poor deal.

In the pockets of the drug companies.

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

In this country. They sold us down the river.
I know this because we now know how strong
the information was that they held.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

Disinterest. Almost as if they had an agreement
to play it down.

HC

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

Disempowered – Haemophilia Society.

Empowered. – Those of us who know what has really happened. Make them pay and not in monetary terms.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

Very poor treatment from the hospitals.

H'C

41) What if anything has helped you to maintain a positive outlook on life?

A will not to give in. A need to make Jones Hamilton and Jeavons Pay.

But most of all being there for my son.

<u>THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE</u>

<u>Carol Grayson 25/7/2006</u>

H4

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state.49....

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify...WELSH..............................

3) What type of haemophilia do you have A, B, etc? Please specify.....A.......

4) What does the word "blood" mean to you?

A fluid which carries vital componants around the body to sustain life.

5) What does the word "haemophiliac" mean to you?

A person who has a genetic condition which lacks a clotting protien in blood.

6) What do you think the word "haemophiliac" means to the general public?

A person who will bleed to death if he cuts themselves

H4

7) Are you HIV positive? Please circle [✓ YES] or NO.

8) Is/Was your wife/partner HIV positive? Please circle [✓ YES] or NO.

9) What do the words "HIV positive" mean to you? Please explain.

A viral infection which could progress to AIDS and death

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO].

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

A viral infection which could progress to liver failure and death

H4

13) Have you ever been exposed to variant CJD through blood products? Please circle [✓ YES] or NO or DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you? Please explain.

That I may have the condition and it may cause my death in the future.

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle [✓ YES] or NO.

17) What does the word "disabled" mean to you? Please explain.

A person who has a limited capacity to perform and live a life witho
taking into consideration the consequences.

18) Have you ever been a carer? Please circle [✓ YES] or NO.

H4

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

I was never informed of the risks or consulted when test were taken to find out about my status.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

Poorly and only concerned with reducing their liability rather then being honest by admitting their lack of funding caused this Tragedy to occur in the first place

H4

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle [✓ YES] or NO.

20) Have you ever required a carer to assist with your daily living? Please circle [✓ YES] or NO.

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle [✓ YES] or NO.

22) What does the word "carer" mean to you?

Someone who helps others in need.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

By staying silent in case they are deemed responcible
I feel totally let down by them and the DoH

27) Are you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust? Insulting and every day they exist is having a negitive effect on my longevity and feeling of worth.

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO.]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund? Insulting and based on economics not what the condition deserves in respect to the infection and how it effects the persons ability to have a normal life.

H4

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund I think Government should be ashamed.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

They should accept their part in our infections and make a public apology and pay compansation to all who received infections from their products.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

~~Little little~~

They are and still restricked by their own actions and have not presured and of the parties involved to settle who is responsible. becouse they are to concerned with their own actions and the loss of funding which they need to exist.

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

The legal profession were more interested in making sure they got paid expenses then seeing justice acheved and proper compensation paid to plantiffs involved.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

Unable to be effective due to the Medical proffession and the DoH reluctence to be open and honest about What was Known and by whom?

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

The Haemophilia Society has disempowered us and the Medical proffession including the DoH by the ethos of divide and rule policy

The simple fact that this injustice has never been resolved after 25 years in a court of law empowers me to Keep living life and never excepting that justice will prevail someday soon in the future.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

The stigma which the public assume that all haemophiliacs are also infected with HIV + HCV.

H4

41) What if anything has helped you to maintain a positive outlook on life?

The love of my family, friends, and living life to the full at all times.

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state...57...

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify....WHITE BRITISH................

3) What type of haemophilia do you have A, B, etc? Please specify.....B........

4) What does the word "blood" mean to you?

IT NOW SCARES ME, SINCE BEING INFECTED. I AM AWARE OF PASSING ON INFECTIONS.
I DID THINK OF IT AS A NECESSARY LIFE GIVING RED LIQUID. I NOW UNDERSTAND, TO SOME PEOPLE, IT IS A COMMODITY TO MAKE MONEY. THAT WORRIES ME.

5) What does the word "haemophiliac" mean to you?

AN INDIVIDUAL WHO HAS A BLOOD DISORDER.
I.E. REQUIRES SPECIAL ATTENTION TO BLOOD RELATED PROBLEM.

6) What do you think the word "haemophiliac" means to the general public?

MOST PEOPLE WHO HAVE HEARD THE TERM ASSUME A HAEMOPHILIAC CAN'T WORK AT A NORMAL JOB. THE BELIEVE THEY BLEED MORE I.E. IN TORRANTS, NOT JUST LONGER.
MAJORITY HAVE NOT HEARD THE TERM.

HS

7) Are you HIV positive? Please circle YES or [✓ NO.]

8) Is/Was your wife/partner HIV positive? Please circle YES or [✓ NO.]

9) What do the words "HIV positive" mean to you? Please explain.

HIV Positive, Means Having A Virus Which Can Lead To Aids. Special Care Must Be Taken In Every Day Life So Not To Infect Others Via Blood Contamination & Sex.. Other Problems Involved In Health Will Occur.

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

Being Aware Of Having A Virus Which Causes Many Health Problems, Also Mental Problems [This Is Similar To HIV]. It Can Be Difficult To Know When Problems Are Connected To Virus. Most Doctors Do Not Understand.

I Also Have To Be Careful With Alcohol.

HS

13) Have you ever been exposed to variant CJD through blood products? Please circle YES or NO or [✓ DON'T KNOW.]

14) What do the words "exposed to variant CJD" mean to you? Please explain.

ANOTHER BLOOD BORNE VIRUS, WHICH HAS POTENTIAL TO KILL IN A VERY NASTY MANNER. A FURTHER REASON TO NOT ACCEPT BLOOD FROM DONORS.

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain.

NOT ABLE TO CARRY OUT ALL FUNCTIONS THAT WOULD BE POSSIBLE, IF NO PROBLEM EXISTS.

WHILE ABLE TO WALK, TALK & MANIPULATE WITH NO ASSISTANCE REQUIRED, I CAN NO LONGER DO A PROFESSIONAL JOB DUE TO TIREDNESS.

18) Have you ever been a carer? Please circle [✓ YES] or NO.

HS

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or [✓ NO.]

20) Have you ever required a carer to assist with your daily living? Please circle

YES or [✓ NO.]

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

IN MY CASE I HELPED MY MOTHER IN LATER LIFE. DOING HER MEALS, CLEANING & TAKING HER OUT DURING THE DAY. ALSO TO HOSPITAL AND SOMETIMES ASSISTING HER WHEN SHE FELL. I ALSO DID HER DECORATING ETC SHE DIED TWO YEARS AGO.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

VERY SLOWLY TO RESPOND INITIALLY. NOW THEY DO APPEAR TO BE MORE UNDERSTANDING IN THE HAEMOPHILIA FIELD.

MY INITIAL CONCERN WAS BEING TREATED BY A HAEMOTOLOGIST FOR A LIVER PROBLEM. NOW SPECIALISTS ARE INVOLVED.

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following [✓ YES], NO, DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

THE GOVERNMENTS INITIAL REPONSE WAS VERY POOR. IT HAS GOTTEN WORSE, THEY HAVE TRIED TO BRUSH THE PROBLEM UNDER THE CARPET.

HS

27) Are you a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO.]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund? TOTALLY INADAQUATE. IT IS AN INSULT BASED ON NOTHING IN A HOPE THAT WE WILL GO AWAY.

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

THIS ADDS TO THE VIEW THAT THE GOVERNMENT ARE CALLOUS AND DO NOT ATTEMPT TO UNDERSTAND THE PROBLEM.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

THESE COMANIES HAVE HAD AND STILL HAVE ONE CRITERIA. MAKING MONEY. THEY CONTANTLY COVER UP ALL PROBLEMS NOT INVESTIGATING OR CORRECTING

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

VERY SLOWLY AND WITH MORE CONCERN FOR THEIR & RELATIONSHIP ~~WA~~ WITH PHARMACUETICAL INDUSTRY THAN THEIR OWN MEMBERS

HS

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle YES or [✓ NO.]

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

ERRATIC AT BEST. NO CAMPAIGN HAS BEEN LAUNCHED OR FOLLOWED THROUGH. DOES NOT SEEL ENOUGH.

HS

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

~~I Was Empowered By~~

The Main Problem Has Been The Haemophilia Society Not Taking A Pro-Active Role. I Am Still Concerned That They Are Not ~~Campaign~~ Campaigning Enough.

Groups Such As Haemophilia Action UK And The Manor House Group Help. But Are Not National, Many People Feel Isolated Due To This.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

The Virus And All Complications.
No National Organisation To Rely On.

HS

41) What if anything has helped you to maintain a positive outlook on life?

I WAS GREATLY HELPED WHEN FIRST CONTACTING ~~CAROL~~ HAEMOPHILIA ACTION UK. AND LATER BY MEETING MY PRESENT PARTNER.

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

H8

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state...43...

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify....WHITE BRITISH.............

3) What type of haemophilia do you have A, B, etc? Please specify....A.........

4) What does the word "blood" mean to you? blood is the body's transport system for carrying oxygen, nutrients and other elements essential for the body's survival.

As a haemophiliac of course it is a word and substance that has decided the direction of my life in terms of what I can and cannot do.

5) What does the word "haemophiliac" mean to you? Literally means watery blood. As a haemophiliac it means a lifetime of internal bleeding into joints and muscles causing severe physical pain and disablement, together with resulting psychological stress and social isolation.

6) What do you think the word "haemophiliac" means to the general public? Still generally means someone who bleeds to death if they cut themselves. People lack the understanding that the major problem is internal bleeding rather than external. eg - "don't knock him he might get a bruise"

H8

7) Are you HIV positive? Please circle [✓ YES] or NO. YES

8) Is/Was your wife/partner HIV positive? Please circle YES or NO. NOT APPLICABLE

9) What do the words "HIV positive" mean to you? Please explain. Initially meant a death sentence when diagnosed 20 years ago.
To me they mean being infected with a dirty virus through ~~not~~ no fault of my own

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO. YES

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO] N/A

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.
They mean been infected with a virus commonly associated with people who have become ill through the consumption of too much alcohol.

13) Have you ever been exposed to variant CJD through blood products? Please circle YES or NO or [✓ DON'T KNOW.]

14) What do the words "exposed to variant CJD" mean to you? Please explain.

They mean been exposed to the uncertainty of ~~becoming~~ possibly becoming ill with a human form of a brain disease that normally affects cattle.

15) Would you describe yourself as "disabled"? Please circle [✓ YES] ~~or NO~~.

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO] NOT APPLICABLE

17) What does the word "disabled" mean to you? Please explain. Generally regard it as meaning that my body is badly damaged causing pain and discomfort in everyday life and restricting my ability to do the things I want to do with my life.

18) Have you ever been a carer? Please circle ~~YES or~~ [✓ NO.]

H8

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

YES or NO.

21) If your answer to question 20 was YES please answer the following question. Is

/Was your wife/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

Carer is basically someone who has whole or assisted responsibility for meeting the day to day social needs of a dependant person

23) How do you think the medical profession has responded to the contamination of

haemophiliacs/wives/partners with blood borne viruses?

Initially with confusion - some patients told that these viruses would have little or no effect, others telling patients they only had a few years to live

They do not appear to have accepted any responsibility for ignoring the many warnings given regarding the safety of the treatment they prescribed

HO

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/~~your wife/partner~~.

I was never informed that I had been tested for Hepatitis C untill years after the event.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

It has consistently resisted calls for an inquiry into the contamination scandal.
Presumeably this is to avoid embarrassing politicians past and present for failing to invest in self sufficeery at an earlier stage as promised and to avoid

admitting 'fault' which could be used against them in court against allegations of negligence. They have been very reluctant to give any financial assistance to affected haemophiliacs, preferring to call the sums given as "ex gratia" payments - without admitting fault.

H8

27) Are you a registrant of the Macfarlane Trust? Please circle [✓ YES] ~~or NO~~.

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle

~~YES or NO~~. NOT APPLICABLE

29) If the answer to question 27 or 28 was YES please answer the following question.

What do you feel about the service and level of payment provided by the

Macfarlane Trust? The level of service given by office staff is variable depending on experience and/or training received. Decisions regarding single item grants tend to be arbitary.
The ~~monthly~~ regular monthly payment has decreased in real terms over the fifteen years or so the MT, has been operating

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or NO.
NOT APPLICABLE

32) If your answer to question 30 or 31 was YES please answer the following

question. What do you feel about the level of payment(s) provided by the Skipton

Fund? The level of payment does not match even that given in regard to the payment given for HIV infection.
It does not reflect the seriousness of the condition and, given that there is no monthly payment scheme is

woefully inadequate for those
who have to live with its effects.

H8

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund Disgusted - the scheme should have operated under the same guidelines as the two HIV payments ie payment should be made to the estate of those deceased

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs? - unprintable

NEGLIGENT -

Disgusted that they have in no way compensated those they have injured.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

Although involved in the earlier part of campaigning for compensation they have not been very vocal in calling for a public enquiry into the whole contamination.

They have been restricted in part by having close funding ties withe the companies who supplied the contaminated Factor 8.

In recent years they have distanced themselves from actively campaigning in their own name and have reported on individual campaigns without giving proper reference or credit to the persons concerned

The priority now appears to be helping the next generation of haemophiliacs having decided that the contamination tragedy is a past issue.

H8

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

~~Once~~ The legal profession has consistently failed the Haemophilia community. They supported a government waiver preventing HIV infected haemophiliacs from pursuing compensation for hepatitis viruses and did so knowing many were infected with hepatitis C.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

The media response to the tragedy was to sensationalise and misrepresent the risk of infection. Terms such as "ticking timebombs" were used to describe infected haemophiliacs.

They now regard the tragedy as old news and not worth resourcing it.

HD

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.) Haemophiliacs have been empowered by their families and friends supporting them. They have been disempowered by negative or inadequate media coverage. The governments formed since the tragedy have deliberately disempowered them by refusing to review their own conduct or that of the ~~dry~~ drug companies involved

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

The biggest problem I have faced is various disabilites caused to joints by bleeding throughout my life. I have undergone two knee joint replacemet and elbow surgery.

I have also had to cope with co-ordination difficultes caused by a brain bleed at a very early age

41) What if anything has helped you to maintain a positive outlook on life?

Other than the tremendous support given by my parents I have simply had to stay as focused and positive as possible

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state.......... 42

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify....... WHITE BRITISH

3) What type of haemophilia do you have A, B, etc? Please specify..... A ..... less 1%

4) What does the word "blood" mean to you?

lifeblood – the fluid that runs through my veins oxygenating my body keeping me alive.
bloodlines – family links - bonds
Red sticky and essential

5) What does the word "haemophiliac" mean to you?

A person who lives with haemophilia
A genetic disorder, sometimes starting as a mutation, which leaves the person with an inability for blood to clot properly.

6) What do you think the word "haemophiliac" means to the general public?

A bleeder - if you cut yourself you will bleed to death.

HIL

7) Are you HIV positive? Please circle [✓ YES] or NO.

8) Is/Was your wife/partner HIV positive? Please circle YES or [✓ NO.]

9) What do the words "HIV positive" mean to you? Please explain.

Living with the virus that causes AIDS
Being HIV positive means that life can never be the same. A life of concern ill health and constant battles, mediaction, hospital intervention and restricted prospects. HIV Positive also conjurs up Stigma + Sadness.

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

Living with a virus that is able to cause my liver to scar and eventually become inflamed and cancerous. HCV+ means stigma, fear, worry, ill health, tiredness, nauseaus and more contagious than HIV.
Being HCV+ could be fatal to me.
It defindtely impacts on my daily wellbeing

13) Have you ever been exposed to variant CJD through blood products? Please circle YES or NO [✓ or DON'T KNOW.]

14) What do the words "exposed to variant CJD" mean to you? Please explain.

A prion that is able to eat through the brain leaving it like a sponge in appearance and the patient having an agonising and traumatic death as a result. Exposed to this prion means that I ~~I~~ may have been given blood products that contain this prion.

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain.

It means that I am not "able" to do things other people take for granted as normal range of activities. I am dis-abled from normal healthy tasks and activities.

For instance I walk with a heavy limp, am in constant daily pain, struggle with stairs, can only drive an automatic car, have lower than normal energy levels + survive on daily medication which causes unpleasant side effects.

18) Have you ever been a carer? Please circle [✓ YES] or NO.

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or [✓ NO].

To my mother who died of cancer after a five year illness.

20) Have you ever required a carer to assist with your daily living? Please circle [✓ YES] or NO.

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle [✓ YES] or NO. *

* AS A CHILD IT WAS MY MOTHER - AS AN ADULT BOTH MOTHER + PARTNER + NOW PARTNER.

22) What does the word "carer" mean to you?

SOMEONE WHO UNDERSTANDS MY SITUATION WHEN I AM ILL AND IS ABLE TO DO THE THINGS I CANNOT. TASKS CAN RANGE FROM JUST BEING THERE TO TALK TO AND DISCUSS MY CONCERNS TO EMPTYING BOTTLES OF URINE, CHANGING SHEETS, ADMINISTERING MEDICATION, FEEDING ME WHEN I AM BED BOUND,

IT IS EMOTIONAL SUPPORT AS WELL AS PRACTICLE HELP.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

WITH CONTEMPT - WITH MALICE

THE DOCTORS IN 80'S NEVER TOLD THE TRUTH ABOUT RISKS - NEVER TOLD PATIENTS ABOUT TESTS BEING CARRIED OUT ON THEM OR WHERE TREATMENT WAS SOURCED.

CURRENT MEDICS IN 2006 STILL DENY WRONGDOING AND THERE IS NO SUPPORT TO PATIENTS FROM THE UKHCDO.

THE ACTUAL BODY OF HAEMATOLOGISTS SEEM TO MAKE LIFE AS DIFFICULT FOR PATIENTS AS IT CAN.

I REALLY THINK THAT THEY ALL JUST WISHED WE HAD DIED A LONG TIME AGO SO THEY CAN ALL FORGET ABOUT US.

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO], DON'T KNOW

I KNOW THEY HAVN'T. I DID NOT KNOW I WAS BEING TESTED FOR HIV. I DID NOT KNOW ABOUT ALL THE HEPATITIS TESTS. I DO NOT TRUST THEM AT ALL.

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

AS ABOVE - 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 + TRANSPARENT WHY ARE MY MEDICAL NOTES MOSTLY MISSING?

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

WITH CONTEMPT AND MALICE.

I THINK THE GOVERNMENT HAS GONE TO EXTREME LENGTHS TO COVER UP THIS CONTAMINATION. THEY KNOW THEY HAVE BEEN IN THE WRONG BUT LIE AND CONCEAL AS MUCH INFORMATION AS POSSIBLE.

AGAIN I THINK THEY WISHED WE HAD ALL DROPPED DEAD + SHUT UP A LONG TIME AGO -
UK RELATIONSHIP WITH USA MORE IMPORTANT THAN UK PATIENTS LIVES

27) Are you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO].

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

MFT set up to keep us quiet in 1990. The service has been extremely poor. Staff have been corrupt 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 - that's all - I survive under national average income with more than average life costs

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO].

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund?

A JOKE - Kept some people quiet - (mostly those with no liver problems yet) Again corrupt organisation exempt from public scrutiny. Not reflective of virus damage.

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

Political – They would have had to advertise this more widely to search back. This would have re-ignited many peoples anger + political willpower. I think many widows still do not know about it.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

Hatred – The worst thing is that I still have to use their products, would someone who has been violated be expected to see their perpetrator on a regular basis and be expected to accept it as normal. It screws me up. Their shareholders are still pocketing on the back of my illness. They knew what they were doing but they wanted the dollars not us alive.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

They have been part of it. I feel at the 3 (Govt/pharmas/Soc) the society have at least turned the corner and are now pursuing campaign aims and truth for its patients. In the early days they were part of the contamination system, backing up doctors rather than patients –

Information given to patients in 80's probably led to many of their deaths. Again lack of accountability and responsibility.

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

Poorly - Again $£ led and not really interested in my justice or my feelings. They have raised my hopes at times and let me down. In 1990 they refused to support me on no-win no-fee. As a student at the time I could not afford legal action. I feel that I was poorly informed of choices.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

Sensationalist in 1980's that scared me. In 1990's onwards it has been more informed (Newcastle Journal/Observer)

I believe that political pressure on Media awareness of our situation is immense - stories + programmes pulled overnight

Disempowered -

The lack of support from govt, Medics, media, MFT. Haemo Soc, social workers, other people with HIV sometimes, the infighting between people who share so much in common, the anger and the depression.

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

The most important thing for me has been meeting and getting to know other people in similar position. To know that I am not alone in my feelings. To know that I am not paranoid but actually "switched on" to what has happened. Birchgrove, MFT website BB, tainted blood, web sites. Seeing others in papers on TV etc has made me feel empowered.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

That I have it for ever -

I live with haemophilia - I am used to it. It pisses me off that my fridge is full of Baxter product.

In the main I just try and avoid fights and road traffic accidents.

The worst thing about my haemophilia is that it has caused arthritis which is my most daily debilitating condition.

41) What if anything has helped you to maintain a positive outlook on life?

That everyday is important, other people worse off than me, that I am still alive when many of my peers are not (sometimes this can also be very depressing), having good friends and support, pushing myself to do the things medics have told me not to do, travel, sunny days, the countryside, fresh air, other PWHHIVHCV who are there for me when I need, my wife,

I have developed a sense of pint always half full not empty since childhood. Haemophilia had a dramatic effect on my childhood which I feel put mechanisms in place for me to accept the shit in my life + concentrate on the nice things. This I think prepared me mentally in some way with HBV. HCV. HIV. nvCJD. arthritis, lack of justice, lack of concern.

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

Maybe from an early age I knew my life was not going to be easy. I had to either live with it or die with it.

HIS

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state 57

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify White English

3) What type of haemophilia do you have A, B, etc? Please specify A Severe.

4) What does the word "blood" mean to you?

Poison

5) What does the word "haemophiliac" mean to you?

Bleeding DISORDER with added Complicactions.

6) What do you think the word "haemophiliac" means to the general public?

To Some if you cut yourself you Bleed to Death.

Others Dont Know.

7) Are you HIV positive? Please circle YES or [✓ NO.]

8) Is/Was your wife/partner HIV positive? Please circle YES or [✓ NO.]

9) What do the words "HIV positive" mean to you? Please explain.

Just another infection on top of Haemophilia
and a Slow Painful Death.

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

a Needless infection inflected by the
N. H. S. on Top of other infections

H17

13) Have you ever been exposed to variant CJD through blood products? Please circle [✓ YES] or NO or DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you? Please explain.

a Very uncertain future.
unfortunatly the Medical Profession dont Know What is in store in the future

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO].

17) What does the word "disabled" mean to you? Please explain.

unable to reach ones patential in life. Discrimination, pain, suffering. which is only going To get worse due to other peoples ignorance.

18) Have you ever been a carer? Please circle YES or [✓ NO.]

19) If the answer to question 18 was YES, please answer the following question. Are/Were you a carer to your wife/partner? Please circle YES or [✓ NO].

20) Have you ever required a carer to assist with your daily living? Please circle [✓ YES] or NO.

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle [✓ YES] or NO.

22) What does the word "carer" mean to you?

Someone who looks after me 24 hours a day.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

extremely Poorly. its not affecting them so the dont seem to bother, They seem Totaly indeferent. I feel like a Number Not a person.

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO], DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

They wanted to Keep Haemophiliacs in the dark as long as possible to avoid Confrontation

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

Have They Responded ????

HB

27) Are you a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO.]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund?

TOTALY INadiquate and an INSult To all Haemophiliacs and their families

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

I am absolutly discusted. it is an insult. and it shows how little Respect the Government has for people they have sentenced To a life of pain and uncertenty.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

The blood Companies should be held accountable to the Haemophilia Community

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

extremely Poorly. it seems that they are in the Governments Pocket with Regard To Their funding

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

They haven't, they appear to be frightened of the Government.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

Some have done stories, they also seem to be frightened by the Government,

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

I feel that without the Comradeship and Support of other Haemophiliacs, the Manor House Group U.K Haemophilia action and Lord Morris of Manchester.

Whose Continued Support has never wavered we would not have got as far to find the truth as we have. We still have a long way to go.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

The Government and the N.H.S.

41) What if anything has helped you to maintain a positive outlook on life?

The though that I might be helping other people for a better future.

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

H 14

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state... 46..

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify... SCOTTISH..................................

3) What type of haemophilia do you have A, B, etc? Please specify... A & C...

4) What does the word "blood" mean to you? IT MEANS A PRECIOUS LIFE FORCE WITHOUT WHICH SURVIVAL IS IMPOSSIBLE. THE ONE SUBSTANCE PRODUCED BY THE HUMAN BODY THAT NO OTHER HUMAN BEING HAS THE RIGHT TO SULLY, TAMPER WITH OR DESTROY.

5) What does the word "haemophiliac" mean to you? IT HAS SADLY MEANT: A LIFETIME OF BLEEDING, PAIN, SUFFERING, MULTIPLE INFECTIONS FROM TREATMENT INJECTED BY NHS DOCTORS, BEING TREATED WITH CONTEMPT BY HAEMOTOLOGIST BECAUSE I WAS NOT ATYPICAL OF THE CONDITION AS A WOMAN WITH HAEMOPHILIA 'A', AND HAVING TO PROVE MY BEING A SYMPTOMATIC HAEMOPHILIAC BY BLEEDING FIRST AND THEN TREATED AFTER THE EVENT — REACTIVE NOT PROACTIVE. MY ENTIRE LIFE HAS BEEN A MEDICAL LEARNING CURVE FOR GP'S AND ANYONE I HAVE HAD CONTACT WITH IN THE COURSE OF HAEMOPHILIA CARE. I HAVE BEEN THE EDUCATOR!

6) What do you think the word "haemophiliac" means to the general public?

MANY PEOPLE STILL DO NOT UNDERSTAND WHAT IT IS, OR THE IMPLICATIONS OF SUFFERING FROM THE CONDITION. MORE DISTURBINGLY MANY HEALTH CARERS AND PROFESSIONALS STILL THINK AND ARE TAUGHT IT IS ONLY A MALE INHERITED BLEEDING DISORDER. ANY MEMBER OF THE PUBLIC I HAVE ASKED, REFERRED TO THE RUSSIAN ROYAL FAMILY

7) Are you HIV positive? Please circle YES or [✓ NO].

8) Is/Was your ~~wife~~/partner HIV positive? Please circle YES or [✓ NO].

9) What do the words "HIV positive" mean to you? Please explain.

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your ~~wife~~/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO].

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

"HELL COMETH from a VIAL". THIS TRULY IS WHAT I FEEL ABOUT BEING INFECTED WITH THIS VIRUS. NO WORDS CAN DESCRIBE THE PAIN, MENTAL AND PHYSICAL FATIGUE, THAT I EXPERIENCE EVERY DAY AS A RESULT OF THIS DISEASE WHICH WAS GIVEN TO ME COURTESY OF MY NHS TREATMENT. THROUGH MANY YEARS OF RESEARCHING AND HUNTING DOWN OLD BLOOD RECORDS I HAVE DISCOVERED THE TRUTH - BIOLOGICAL GREVIOUS BODILY HARM WAS INFLICTED ON ME AGED 17 YEARS OLD, 23 & 26 YEARS OLD WITHOUT MY CONSENT OR KNOWLEDGE BY DOCTORS WHO KNEW ~~THE~~ ALL ABOUT THE CONTAMINATION RISKS FROM USING IMPORTED AMERICAN POOLED PLASMA, BUT PREFERRED TO WITHOLD THIS VITAL INFORMATION FROM THE PATIENT.

H14

13) Have you ever been exposed to variant CJD through blood products? Please circle [✓ YES] or NO or DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you? Please explain. I FEEL REVULSION THAT YET ANOTHER KILLER DISEASE HAS BEEN ALLOWED TO CONTAMINATE THE VERY LIFE SOURCE WE HAVE COME TO RELY ON. LIKE ALL THE OTHER INFECTIONS IN BLOOD IT WAS PREVENTABLE. IT IS YET ANOTHER EXAMPLE OF GOVERNMENTAL INCOMPETENCE THAT HAS WREAKED HAVOC AND IN PARTICULAR ON A PATIENT GROUP WHOSE RELIANCE ON PLASMA IS GREATER THAN ANY OTHER WITHIN THE NHS. I HAVE HAD 6 EXPOSURES TO CJD THROUGH PLASMA AND LIVE IN FEAR OF DEVELOPING THIS DISEASE THE LETTERS CJD SHOULD MEAN "CRIMINAL JUSTICE DENIED"

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your ~~wife~~/partner disabled. Please circle YES or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain. IT MEANS FROM MY PERSPECTIVE, PREVENTION FROM BEING ABLE TO LEAD THE LIFE I HAD AN EXPECTATION OF, LOSS OF QUALITY OF LIFE FOR MY FAMILY. THE SLOW DESTRUCTION OF MY HEALTH AND THE EFFECT THAT HAS HAD ON MY HUSBAND AND CHILD. THE INABILITY TO PURSUE A CAREER AND FORCED TO RETIRE FROM WORKING LIFE AT 38 years OLD. I WAS BORN AN ABLE PERSON BUT THAT WAS CHANGED BY THE NHS TREATMENT THAT WAS SUPPOSED TO "MAKE ME BETTER", THE MEDICAL PROFESSION WHO KNEW THEY USED THE HAEMOPHILIA COMMUNITY AS GUINEA PIGS, AND THE GOVERNMENTS OVER THE PAST 30 YEARS, WHO SANCTIONED THE IMPORTATION OF PLASMA INFECTED WITH KILLER VIRUSES. NOW I AM DISABLED.

18) Have you ever been a carer? Please circle YES or [✓ NO]

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your [redacted]/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

[✓ YES] or NO.

21) If your answer to question 20 was YES please answer the following question. Is

/Was your [redacted]/partner your carer? Please circle [✓ YES] or NO.

22) What does the word "carer" mean to you? A TRUE CARER WHO TAKES CARE OF ALL YOUR PHYSICAL, EMOTIONAL NEEDS AND OFTEN SACRIFICES THEIR OWN, IS DESERVING OF THE TITLE CARER. THIS IS A DIFFICULT AND TESTING ROLE WHEN YOU ARE PRESENTED WITH THE HARSH REALITY OF DEALING WITH BLEEDING DISORDERS; MULTIPLE INFECTIONS AND PHYSICAL DISABILITY. I UNDERWENT THE HARROWING AND PAINFUL TREATMENT INTERFERON/RIBOVIRIN AND HAD TO TOTALLY RELY ON MY HUSBAND TO LOOK AFTER ME AND MY CHILD, WHILST TRYING TO WORK AND LOOK AFTER OUR HOME. THE EXPERIENCE WAS FRANKLY HELLISH AND TRULY TESTED MY HUSBAND'S PROMISE TO LOOK AFTER ME "IN SICKNESS AND IN HEALTH". HOW MANY RELATIONSHIPS DO NOT SURVIVE BECAUSE OF THE ENORMOUS TASK OF BECOMING A CARER? THE "CARER" IS GREATLY UNDERVALUED AND SADLY THE GOVERNMENT TAKE FULL ADVANTAGE OF THAT.

23) How do you think the medical profession has responded to the contamination of

haemophiliacs/wives/partners with blood borne viruses? I THINK IT IS FAIR TO SAY FROM MY OWN EXPERIENCE THE FOLLOWING: CONTEMPT, LACK OF COMPASSION AND EMPATHY, DENIAL OF THE TRUTH ABOUT THE TREATMENT USED ON HAEMOPHILIAC PATIENTS, REFUSAL TO ACCEPT RESPONSIBILITY OR ACCOUNTABILITY FOR USING CONTAMINAT BLOOD PRODUCTS. TOTAL LACK OF SUPPORT IN THE CALL FOR A HALT IN USING INFECTED PLASMA WHEN THEY KNEW THEY WERE ENDANGERING THEIR PATIENTS. REMOVAL OF MEDICAL RECORDS AND REFUSAL TO GIVE ACCESS TO HAEMOPILIACS MEDICAL FILES. THE MOST HEINIOUS CRIME OF ALL WAS TO DENY HAEMOPHILIACS INFORMED CHOICE OF TREATMENT WHEN THERE WERE SAFER OPTIONS BY QUOTING THE STATEMENT "THE BENEFITS FAR OUTWEIGH THE RISKS". I ALSO BELIEVE THEY HAVE CLOSED RANKS BY REFUSING TO SUPPORT A PUBLIC INQUIRY IN TO THE 1,400 DEAD HAEMOPHILIAC

[illegible]

IN THE UK, BUT WERE HAPPY TO GIVE CRUCIAL EVIDENCE ABOUT CONTAMINATION OF SEVERAL VIRUSES IN THE USE OF UNITED STATES PLASMA ON BEHALF OF HAEMOPHILIACS IN EIRE. THEY HAVE NO INTEREST ON WHAT EFFECT ON PARTNERS OR FAMILIES, BLOOD BORNE DISEASES HAVE HAD.

24) Do you feel that doctors treating you/your [redacted]/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your [redacted]/partner. MY PARENTS WERE NEVER ASKED FOR CONSENT OR GIVEN INFORMED CHOICE OF TREATMENT WHEN I WAS A MINOR – I WAS INJECTED WITH VAST AMOUNTS OF U.S PLASMA, MUCH OF WHICH I NOW KNOW WAS COLLECTED FROM AMERICAN PRISONS. I WAS DENIED INFORMED CHOICE AGAIN AGED 23 AT A HOSPITAL IN KENT, WHERE IN A MEETING SEVERAL YEARS AFTER EXPOSURE TO HEP B & C, THE HAEMATOLOGIST ACTUALLY ADMITTED THAT THE FACT THAT HE HAD DENIED ME THE RIGHT TO KNOW OF HEPATITIS RISK ~~AND IT~~ HAD BEEN "A MERE OVERSIGHT". THE SAME HAPPENED AGAIN AT A WELL KNOWN HAEMOPHILIA CENTRE IN LONDON IN 1985 AND I ALSO DISCOVERED A TEST RESULT FOR HEPATITIS G WHICH I HAD NOT CONSENTED TO.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses? I THINK THE GOVERNMENT KNOWS PERFECTLY WELL THEY ARE GUILTY OF CONTINUING A COVER UP OF THE BIGGEST MEDICAL TREATMENT DISASTER TO HAVE OCCURRED IN THE HISTORY OF THE NHS. THEY HAVE WILFULL DESTROYED PUBLIC RECORDS IN THEIR DETERMINATION TO KEEP THE TRUTH OF THIS DISASTER HIDDEN FROM THE GENERAL PUBLIC AND CONSISTENTLY DENIED ANY FORM OF JUSTICE FOR THE VICTIMS OF WHAT I CONSIDER A VIOLATION OF MY VERY LIFE SOURCE AND THAT OF MY FELLOW HAEMOPHILIACS WHOSE ONLY CRIME WAS TO BE BORN WITH AN INHERITED BLEEDING DISORDER.

THE RIPPLE EFFECT OF ALLOWING MULTIPLE BLOOD BORNE VIRUSES TO INFECT SO MANY IS BAD ENOUGH, BUT THE REFUSAL TO BE ACCOUNTABLE FOR THE LOSS OF 1400 LIVES TO DATE IS NOTHING LESS THAN PURE EVIL

27) Are you a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

28) Is/Was your [redacted]/partner a registrant of the Macfarlane Trust? Please circle YES or NO.

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your [redacted]/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO.]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund? 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 U.S. PLASMA. WHY DOES MY GOVERNMENT THINK MY LIFE IS WORTH A FRACTION OF THAT OF MY IRISH FAMILY??

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

I AM UTTERLY APPALLED THAT THE SACRIFICE AND DESTRUCTION SUFFERED BY SO MANY BEREAVED PARTNERS IN CARING FOR AND THEN LOSING LOVED ONES HAS GONE UNRECOGNISED. IT IS NOT JUST THE SAD LOSS OF A PARTNER BUT THE HARSH FINANCIAL LOSSES THAT HAVE RESULTED FROM NOT BEING ABLE TO WORK, SAVE FOR THE FUTURE AND PROVIDE FOR THEIR FAMILIES. SHAME ON THOSE WHO MADE THE DECISION TO EXCLUDE PAYMENTS AND THUS EVEN MORE FINANCIAL HARDSHIP.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

I AM ENRAGED THAT THEY CONTINUE TO MAKE BILLIONS OF DOLLARS FROM HUMAN BLOOD REGARDLESS OF THE MILLIONS OF LIVES THEY HAVE DESTROYED THROUGH THEIR GREED AND LUST FOR MONEY.

IT IS SCANDALOUS THAT THEY HAVE ESCAPED BEING BROUGHT TO JUSTICE FOR THEIR CRIMES AND THOSE RESPONSIBLE REMAIN AT LARGE.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

IN RETROSPECT THEY HAVE BEEN INEFFECTIVE, FAILED TO REACT AND RESPOND TO THE CARE AND PROTECTION OF MEMBERS WHEN IT WAS MOST NEEDED, AND REJECTED AND MARGINALISED MEMBERS WHO WERE BRAVE ENOUGH TO QUESTION THEIR MOTIVES AND BEHAVIOUR REGARDING SPONSORSHIP FROM THE PLASMA COMPANIES WHO WERE RESPONSIBLE FOR INFECTING THE MAJORITY OF THEIR MEMBERSHIP.

MY DISAPPOINTMENT IN ONE INSTANCE THAT I CAN RECALL, RELATED TO MY LOSS OF A JOB WITH AN AIRLINE COMPANY IN 1986 BECAUSE I DECLARED MY HAEMOPHILIA STATUS. THIS WAS CLEARLY DISCRIMINATORY AND I TOOK MY CASE TO THE SOCIETY FOR HELP. NOT ONLY DID THEY FAIL TO ASSIST ME, BUT BY NOT GETTING LEGAL OPINION WHICH THEY HAD ACCESS TO, THEY ALLOWED A LARGE EMPLOYER TO DISCRIMINATE AGAINST ME

36) Have you or your ~~wife~~/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses? ALTHOUGH I HAVE ENROLLED ALONG WITH OTHER SCOTTISH HAEMOPHILIACS TO BE LEGALLY REPRESENTED REGARDING THE INFECTED PLASMA I RECEIVED IN SCOTLAND, THE LAWYER INVOLVED IS ONLY DEALING WITH DECEASED HAEMOPHILIACS. SINCE I DON'T WANT TO BE REPRESENTED FROM THE GRAVE, I KNOW FOR SURE, NO PROPER CASE WILL BE PROCEEDING. THE ENGLISH GOVERNMENT HAVE SEEN FIT TO DENY LEGAL AID TO SUE THE NHS FOR MALPRACTISE, SO YET AGAIN I HAVE NO RIGHTS TO REPRESENTATION LEGALLY. I DO FIND IT STRANGE THAT THE HUMAN RIGHTS ACT "THE RIGHT TO LIFE" CANNOT BE CITED AS A ROUTE TO SEEK JUSTICE BUT I DOUBT THERE WILL BE ANY WILLING LAWYERS RUSHING TO REPRESENT VICTIMS LIKE ME, BECAUSE I CAN'T PAY THEM!

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses? HAVING CAMPAIGNED OVER 10 years FOR A PUBLIC INQUIRY, I HAVE GENERATED A LOT OF INTEREST FROM THE MEDIA ie TELEVISION COMPANIES, NEWSPAPER RADIO ETC. THE SUBJECT OF CONTAMINATED BLOOD IS OF MAJOR AND NATIONAL CONCERN, HOWEVER, IT IS NOT ONLY MY CONSIDERED OPINION, BUT THAT OF FELLOW CAMPAIGNERS, THAT THERE IS A HIDDEN AND POWERFUL GROUP OF INFLUENTIAL POLITICIANS CAPABLE OF STAMPING OUT DAMNING EVIDENCE AGAINST THE GOVERNMENT, THE DEPARTMENT OF HEALTH, THE NHS AND ANY ATTEMPTS BY OTHER KNOWLEDGEABLE PERSONS INVOLVED IN REVEALING ANY EVIDENCE THAT WOULD LEAD TO A FULL AND OPEN PUBLIC INQUIRY IN TO A 30 year BLOOD SCANDAL. THE MEDIA ARE NOT ABLE TO RESPOND BECAUSE THEY ARE PREVENTED FROM DOING SO.

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.) I HAVE FOUND THAT BY SPEAKING OUT PUBLICLY AND DEMANDING JUSTICE, THERE HAS BEEN GREAT SUPPORT FROM FELLOW HAEMOPHILIACS, FAMILY AND FRIENDS. THROUGH EDUCATING PEOPLE I HAVE EVOKED MUCH SYMPATHY AND UNDERSTANDING. I HAVE BEEN COMFORTED BY WORKING TOGETHER WITH ORGANISATIONS SUCH AS HAEMOPHILIA ACTION UK, THE MANOR HOUSE GROUP AND INDIVIDUAL CAMPAIGNERS.

KNOWING THAT YOU ARE NOT FIGHTING ALONE, EASES THE HUGE PRESSURE OF DEALING WITH THE EFFECTS OF LIVING WITH HCV INFECTION.

I DO THINK HOWEVER, WHAT HAS NOT HELPED HAS BEEN THE FAILURE FROM THE NATIONAL SOCIETY'S STANCE TO FULLY SUPPORT ALL THEIR INFECTED MEMBERS – HENCE THE RESUTING SPLINTER GROUPS FORMING BECAUSE THEY LOST FAITH IN THEIR ABILITY TO CONDUCT A MORE FORCEFUL AND CONSTRUCTIVE CAMPAIGN FOR JUSTICE, THIS HAS SADLY DISEMPOWERED MANY HAEMOPHILIACS, THUS BY DIVISION, THE GOVERNMENT HAS UTILISED THIS SITUATION AGAINST THEM.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac? MOST HAEMOPHIACS WOULD PROBABLY AGREE WITH ME IN SAYING THAT NOT BEING HEARD, LISTENED TO AND TREATED WITH RESPECT HAVE BEEN THE HARDEST THINGS TO DEAL WITH ALONG WITH HAEMOPHILIA, IF NONE OF THE ABOVE ARE IN PLACE. WHEN YOU ARE DEALING WITH HEALTH CARE PROFESSIONALS, THEN YOUR CARE WILL ALWAYS BE COMPROMISED! I KNOW THIS TO BE TRUE – SO MANY MISTAKES HAVE BEEN MADE, I HAVE LOST COUNT. I STILL HAVE TO FIGHT FOR MY RIGHT TO TREATMENT WHEN I NEED, DESPITE HAVING A SUBSTANTIAL BLEEDING HISTORY. I STILL HAVE TO STOP IGNORANT HOSPITAL STAFF WHO IGNORE MY MEDICAL RECORDS AND TRY TO INJECT ME WITH ANTI-CLOTTING AGENTS! I DARESAY THAT REGARDLESS OF THE PAST 50 YEARS OF EVOLVING HAEMOPHILIA CARE – THE PROBLEMS WILL CONTINUE!

41) What if anything has helped you to maintain a positive outlook on life?

A GOOD HEALTHY SENSE OF HUMOUR AND A BLOODY MINDED DETERMINATION NEVER TO GIVE UP ON WHAT LIFE I HAVE, DESPITE THE NHS, DOCTORS, THE UK GOVERNMENT AND THE PLASMA COMPANIES EFFORTS TO DESTROY AND TAKE IT AWAY. FROM ME.

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

H P

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state 52

2) What is your ethnic origin? (White British, Scottish Pakistani etc)
Please specify WHITE BRITISH

3) What type of haemophilia do you have A, B, etc? Please specify A

4) What does the word "blood" mean to you?

(TROUBLE)

5) What does the word "haemophiliac" mean to you?

SOMEONE WHO IS FACED WITH AN, UNCERTAIN FUTURE IN LIFE NOT BEING ABLE TO MAKE PLAN'S FOR THE FUTURE, A WALKING TIME BOMB. SOMEONE WITH THE WORD CAUTION TATTOOED ACROSS THEIR HEADS, HANDLE WITH CARE.

6) What do you think the word "haemophiliac" means to the general public?

MOST OF THE PUBLIC WOULD NOT KNOW WHAT HAEMOPHILIA MEANS.

H15

7) Are you HIV positive? Please circle YES or [✓ NO]

8) Is/Was your wife/partner HIV positive? Please circle YES or [✓ NO.]

9) What do the words "HIV positive" mean to you? Please explain.

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

TO BE (BREIF) IT MEANS NOT KNOWING WHAT THE FUTURE WILL BE, LIVING WITH FEELING UN-WELL ON TOP OF OTHER THINGS & FIGHTING TO BE TREATED THE SAME AS OTHER PUBLIC PEOPLE, IE (EQUALITY)

HIS

13) Have you ever been exposed to variant CJD through blood products? Please circle [✓ YES] or NO or DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you? Please explain.

IT MEANS THAT ONCE AGAIN I HAVE BEEN. EXPOSED TO ANOTHER. VIRUS THAT MAY OR MAY-NOT BE HARMFULL. (ITS THE NOT KNOWING) THERE ARE NO ANSWERS.?

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain.

DISABLED MEANS THAT I AM UNABLE TO DO THE EVERY-DAY THINGS THAT OTHER PEOPLE CAN-DO. THAT I ONCE WAS ABLE TO-DO, AND NOT BECAUSE I AM OLDER, ITS DUE TO PAIN DISCUMFORT & JOINT TROUBLE. & ALSO THOSE DAM VIRUSES

18) Have you ever been a carer? Please circle YES or [✓ NO.]

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

[✓ YES] or NO.

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle [✓ YES] or NO.

22) What does the word "carer" mean to you?

SOMEONE THAT CAN HELP ME WITH MY NEEDS WHEN I AM NOT WELL OR ABLE TO DO SO, & ALSO SOMEONE WHO UNDERSTANDS THE PROBLEMS I AM LIVING WITH. SOMEONE WHO CARE'S AND ALSO UNDERSTANDS.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

VERY, VERY, POORLY WE HAVE BEEN LEFT TO CARRY ON WITH LIFE, MADE TO FEEL GRATEFUL THAT WE ARE STILL ALIVE, GRATEFUL ALSO FOR THE GREAT BLOOD PRODUCT'S (I DONT THINK SO)

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO,] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

I THINK WE HAVE BEEN TEST STUDIES FOR THE REST OF THE GENERAL PUBLIC & DOCTORS HAVE THOUGHT THEY COULD DO AS THEY PLEASED WITH US WITHOUT HAVING TO ASK OUR PERMISSION.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

BADLEY. DISGRACFUL. FORGOTTEN TOSSED ASIDE.

H15

27) Are you a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund?

UNJUST & POOR WITH NO BACK-UP OF HELP, CRITERIA IS ALL WRONG. ONE OFF PAYMENTS DO-NOT JUSTIFY THE WRONG DOING DONE TO US, WHAT PRICE CAN YOU PUT ON A LIFE.

HIS

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

JUST GOES TO SHOW HOW THE GOVERMENT FEELS ABOUT THE HAEMOPHILI COMUNITY. IT MAKES ITS OWN RULES.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

VERY CONCERNED REGARDING THE MORE INFO WE ARE FINDING OUT.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

POOR I THINK ITS ONLY RUN AS A COVER FOR THE GOVERMENT, IT DOES NOT OR CAN NOT ACT ON OUR BEST BEHALF BECAUSE IT DOES NOT KNOW HOW TOO, HOW CAN THEY FEEL HOW WE FEEL? THEY ARE JUST SILENT CAMPAIGNERS. WITH NO VOICE.

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

OVER RULED & BULLIED BY THE GOVERMENT, EVEN WITH FACTS & THE TRUTH IE EVIDENCE THEY STILL LOOKED ON THE SIDE OF CAUTION.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

STARTED OFF WITH GOOD INTENSION THEN FADED VERY QUICKLY WHEN (BIG WIGS) GOT TO THEM.

HIS

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

JUSTICE, THE FIGHT GOES ON TO GET JUSTICE FOR WHAT HAS HAPPENED TO US. WE NEED TO KNOW WHY NOT JUST THE TRUTH FOR BEING THE WAY WE ARE NOW,

ALSO THE DETERMINATION OF A SMALL GROUP OF PEOPE CALLED M.H.G

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

VIRUSES (THE NOT-KNOWING)

& MEDICAL STAFF IN OTHER DEPARTMENS BEING AFRAID TO PROSSED WITH PROBLEMS HAEMOPHILIACS ARE FACED WITH. ALSO TRYING TO EYPLAIN TO PEOPLE ABOUT YOUR BLEEDING DISORDER & VIRUSES.

HIS

41) What if anything has helped you to maintain a positive outlook on life?

THE ROAD TO JUSTICE,
AND TAKE EVERYDAY AS IT COMES
IE THE GOOD & THE BAD CARRY ON
WITH LIFE & DONT BE AFRIAD.

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

H16

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state..41...

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify..BRITISH................................

3) What type of haemophilia do you have A, B, etc? Please specify...A........

4) What does the word "blood" mean to you?

It used to mean the Same as it probably meens to everybody, but now I think What is the next thing I'm going to get from it.

5) What does the word "haemophiliac" mean to you?

Same as above.

6) What do you think the word "haemophiliac" means to the general public?

Somebody Who is hiv pos has aids or Who is a Leapor.

H16

7) Are you HIV positive? Please circle [✓ YES] or NO.

8) Is/Was your wife/partner HIV positive? Please circle YES or [✓ NO.]

9) What do the words "HIV positive" mean to you? Please explain.

When am I going to die.

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

When is it going to kick in.

13) Have you ever been exposed to variant CJD through blood products? Please circle [✓ YES] or NO or DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you? Please explain.

I may have or probably do have cjd

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain.

Not being able to do things I used to be able to do, especially at the young age that I am.

18) Have you ever been a carer? Please circle YES or [✓ NO.]

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

YES or [✓ NO.]

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

Brushed it under the carpet.

H16

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES, [✓ NO,] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

Because I have found from Sarces thot was not the case.
They tested us, on regulor blood cheeks without us Knowing

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

what help we do get has been forced out of them, they do not want to Know.

27) Are you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO]

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

Generally good, but they change all of there policies from month-month, and Sometimes when you ask for help, you feel like you are begging.

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund? Atroshish, the Second payment Which we Should get now, we will only get when vertually dead, and its too late..

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund They should be ashamed of themselves, if their partners were here they would of been able to provide for them, now they have got nothing.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

They should be injected with the same thing we have, or put against a wall and shot, (but that would be too good for them).

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

Who are they?

A16

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

I like to think they are trying their best.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

mixed feelings good & bad.

H16

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

Its very long and drawn out, feels Like I'm banging my head against a brick wall, Starting to get very weary of it, as time is running out for people and we cannot do anything about it.

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

Living two lives.

41) What if anything has helped you to maintain a positive outlook on life?

my wife.

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state. 62

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify. WHITE ENGLISH

3) What type of haemophilia do you have A, B, etc? Please specify. A

4) What does the word "blood" mean to you?

WHILST 'BLOOD' IS OFTEN REFERRED TO AS A — 'LIFESAVER' IT IS IN MY OPINION — ALSO. "A SESSPIT OF INFECTION"

5) What does the word "haemophiliac" mean to you?

A PERSON WHO 'BLEEDS' OFTEN WITHOUT WARNING OR REASON, AND IS NOW KNOWN TO AFFECT 'FEMALES' AS WELL AS 'MALES'

6) What do you think the word "haemophiliac" means to the general public?

SOMEBODY WHO 'BLEEDS'

7) Are you HIV positive? Please circle ~~YES~~ or [✓ NO.]

8) Is/Was your wife/partner HIV positive? Please circle ~~YES~~ or [✓ NO.]

9) What do the words "HIV positive" mean to you? Please explain.

SOMEBODY WHO IS INFECTED WITH
THE 'AIDS' VIRUS

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or [illegible]

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle ~~YES~~ or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

"HCV POSITIVE" MEANS THAT I HAVE AS EQUALLY
A SERIOUS PROBLEM AS SOMEBODY INFECTED
WHITH 'HIV' I HAVE DONE A LOT OF RESEARCH
INTO TO THIS VIRUS, AND TO QUOTE THE WORDS
OF THE LATE 'DAME SHEILA SHERLOCK' —
"IT IS THE MOST LEAST OF THE VIRUSES THAT
I WOULD LIKE TO BE INFECTED BY"
'DAME SHEILA SHERLOCK' WAS A PROFESSOR
OF - 'HEPATOLOGY'

13) Have you ever been exposed to variant CJD through blood products? Please circle [✓ YES] or ~~NO~~ or ~~DON'T KNOW~~.

14) What do the words "exposed to variant CJD" mean to you? Please explain.

AS FAR AS I AM CONCERNED - VCJD' MEANS THAT I MAY. EVENTUALLY 'DIE' THROUGH BRAIN DISEASE DUE TO MY EXPOSURE, TO THIS DISEASE, THAT IS UNLESS HEPATITIS.C. DOESN'T GET TO ME FIRST.!

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or ~~NO~~.

16) Is/Was your wife/partner disabled. Please circle ~~YES~~ or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain.

SOMEBODY WHO CANNOT GET ON WITH LIFE AS IN THE SAME WAY AS NORMAL PEOPLE WOULD, IN THERE DAILY ONGOING LIFE, SUCH AS BEING ABLE TO TACKLE EVERYDAY ONGOING DAILY CHORES, ETC, ETC,

18) Have you ever been a carer? Please circle ~~YES~~ or [✓ NO.]

H11

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

YES or [✓ NO] ✓

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

IN LIGHT OF WHAT THE 'MEDICAL PROFESSION' IS AWARE OF INFECTION BY — 'BLOOD BORNE' VIRUSES, I THINK IT IS APPALLING THAT NOT ONE, AS FAR AS I KNOW, HAS EVER LEANT A WORD OF CONDEMNATION TOWARDS 'OUR' PLEAS OF SUPPORT IN OUR LONG BATTLE OF PLIGHT TO SECURE THE RIGHT TO JUSTICE AND MORE IMPORTANTLY — "A FULL AND OPEN PUBLIC ENQUIRY"! — CON/D - - .

H1

I BELIEVE ALL 'HAEMOPHILIAC'S' HAVE BEEN –
! "MEDICALLY RAPED" !

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following ~~YES~~ [✓ NO] ~~DON'T KNOW~~

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

YOU ONLY NEED TO GO BACK TO MY 'ANSWER'S' GIVEN IN Q23. IT IS BECAUSE OF WHAT WAS KNOWN IN THE EARLY-1970'S i.e. .... 1972 ONWARDS TO THE PRESENT. I HAVE INCLUDED THE 'PRESENT' BECAUSE I STILL BELIEVE THAT 'BLOOD BORNE' INFECTIONS ARE STILL GETTING THROUGH THE 'BLOOD' SUPPLY.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

WELL THE PLAIN AND SIMPLE ASWER IS THEY HAVEN'T, AND I THEREFORE GO BACK TO THE END OF – Q.23 WHERE I STATED, A 'FULL AND OPEN PUBLIC ENQUIRY' IS NEEDED NOW!
BECAUSE OF – "MEDICAL RAPE"!

HC1

27) Are you a registrant of the Macfarlane Trust? Please circle ~~YES~~ or [✓ NO.]

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle ~~YES~~ or [✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or ~~No~~.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle ~~YES~~ or [✓ NO.]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund?

I AM A BIG CAMPAIGNER AGAINST THE APPALLING WAY WE HAVE RECEIVED A 'PITTANCE' FIRST PAYMENT, AND ALSO THE LACK TO RECOGNISE THE 'WIDOWS' and 'BEREAVED' IN THE SKIPTON FUND, I POINTED THIS OUT IN A MEETING I HAD WITH THE SKIPTON FUND REPRESENTATIVES SOME TIME AGO UNDER MY ROLE AS ———

— VICE CHAIRPERSON

OF WHICH I AM THE FOUNDER MEMBER. HM

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund

I THINK I HAVE EXPLAINED THIS IN Q.32.

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs?

WELL I KNOW AS WE SPEAK THAT THERE IS ONGOING LITIGATION IN THE USA, AND HOPEFULLY WE WILL GET OUR 'JUST DESERTS' AS THEY SAY.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

WITH VERY LITTLE ASSERTED PRESSURE AS THEY DID WITH REGARDS THE - HIV CAMPAIGN, I KNOW FROM MY EXPERIENCE WITH THEM IN - 1990 - 1994 BEFORE I FORMED THE - MANOR HOUSE GROUP, WHERE I MADE IT CLEAR TO THEM ABOUT THE SERIOUSNESS OF - NANB HEPATITIS, AS - HEPATITIS.C, WAS THEN KNOWN.

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or ~~NO~~.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

WITH SPEAKING FROM MY OWN EXPERIENCE, WITH TRYING TO GET TO COURT HERE IN THE U.K. IT HAS BEEN ABSOLUTELY IMPOSSIBLE TO GET SOLICITORS TO DO WHAT THEY SHOULD DO, ie ... TO EVEN PUT MY CASE TOGETHER TO PRESENT (TO COURT) TO, AND WHICH IS A NON STARTER, THIS IS IN SPITE OF TRYING NO FEWER THAN (5) GROUPS OF SOLICITORS, I AM STILL WAITING 18 YEARS ON, THERE IS ONLY ONE ANSWER TO ALL THIS, ITS CALLED — CONSPIRACY!

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

I HAD A LOT OF COVERAGE WITH THE MEDIA IN THE EARLY 1990'S WITH REGARD'S HEPATITIS. C. ie ... T.V. SKY, ITN, BBC, CHA. 4. AND CABLE NETWORKS ALSO - NEWSPAPERS OBSERVER, THE MAIL, THE NEWS OF THE WORLD, MANCHESTER EVENING NEWS, THE NEWCASTLE JOURNAL, I BELIEVE THEY DID THERE BEST UNDER THE CIRCUMSTANCES, BUT ALSO BELIEVE THEY TOO COULD ONLY GO SO FAR, WITH THE GOVERNMENT ON THERE BACK'S ALSO.

WITH REGARDS MY OWN FEELINGS TO Q.39. (THE FOLLOWING QUESTION), ALL I HAVE MENTIONED IN Q.39 NUMBERED REFERENCE:- 1 TO 5 INCLUSIVE ARE EQUALLY GUILTY OF WHAT WAS KNOWN BETWEEN DATES EARLY - 1970'S TO THE PRESENT TIME, ARE ALL IN MY OPINION GUILTY OF:-

! CRIMINAL MANSLAUGHTER !

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

I BELIEVE OUR BIGGEST ENEMY ON THIS Q. HAS GOT TO BE OURSELVES, BY NOT SUPPORTING EACH OTHER IRRESPECTIVE OF WHAT 'Blood Borne' DISEASES WE HAVE BEEN EXPOSED TOO, ALSO -

1 THE NATIONAL HAEMOPHILIA SOCIETY IS THE BIGGEST FACTOR
2 THE D.H.S.S. AS IT WAS KNOWN, AND IS NOW, THE D.O.H.
3 THE GOVERNMENT WHO OWN AND CONTROL THE HEALTH DEPT, AS WELL AS - BPL
4 OUR SO CALLED CARING 'DOCTORS' WHO TREAT US.
5 AND WORST OF ALL THE CONSULTANTS, i.e. HAEMATOLOGIST'S, HEPATOLOGIST'S, HAEMOPHILIA TREATING CONSULTANTS BETWEEN - THE 1970'S TO PRESENT

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

WATCHING GOOD PEOPLE 'DIEING' THROUGH THESE HORRENDOUS 'BLOOD BORNE' DISEASES, AND KNOWING THAT THE 'POWERS THAT BE', JUST SIMPLY DO NOT CARE. THE MANOR HOUSE GROUP, HAS LOST 12 MEMBERS SINCE I FORMED IT IN - 1994, ALL DIED AS A DIRECT RESULT OF - HEPATITIS.C.

H1

41) What if anything has helped you to maintain a positive outlook on life?

I BELIEVE THAT FORMING THE MANOR HOUSE GROUP GAVE ME THE POSITIVETY TO CARRY ON, AND FIGHT FOR JUSTICE, FOR ALL HAEMOPHILICS WHO HAVE DIED FROM ALL BLOOD BORNE VIRUSES. MY ONLY REGRETS ARE WE ALL OF US, SHOULD HAVE PUT MORE TRUST IN EACH OTHER IN THE PAST, AND WHO KNOWS WE MAY HAVE WON THE BATTLE A LONG TIME AGO..!

WE MAY STILL DO.??

PETER MOSSMAN

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

H 21

QUESTIONNAIRE FOR HAEMOPHILIACS

1) What is your age? Please state..47..

2) What is your ethnic origin? (White British, Scottish Pakistani etc)

Please specify..WHITE BRITISH..

3) What type of haemophilia do you have A, B, etc? Please specify....B (XMAS DISEASE)

4) What does the word "blood" mean to you?

SOMETHING THAT HAS NOW RULED THE REMAINDER OF MY LIFE

5) What does the word "haemophiliac" mean to you?

SOMEBODY WHO IS PROBABLY HIV + HEP C (NOW)

6) What do you think the word "haemophiliac" means to the general public?

SOMEBODY WHO BLEEDS CONSTANTLY FROM ANY SORT OF CUT.

H21

7) Are you HIV positive? Please circle [✓ YES] or NO.

8) Is/Was your wife/partner HIV positive? Please circle YES or [✓ NO.]

9) What do the words "HIV positive" mean to you? Please explain.

AN ILLNESS WAITING TO HAPPEN AND PART OF MY LIFE NOT TO BE DISCUSSED

10) Are you HCV (hepatitis C) positive? Please circle [✓ YES] or NO.

11) Is/Was your wife/partner HCV (hepatitis C) positive? Please circle YES or [✓ NO.]

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

AS ABOVE TO NO 9 ANSWER

H 21

13) Have you ever been exposed to variant CJD through blood products? Please circle YES or NO or [✓ DON'T KNOW.]

14) What do the words "exposed to variant CJD" mean to you? Please explain.

BEEN GIVEN BLOOD WITH CONTAMINATION' CJD IN

15) Would you describe yourself as "disabled"? Please circle YES or [✓ NO.]

16) Is/Was your wife/partner disabled. Please circle YES or [✓ NO.]

17) What does the word "disabled" mean to you? Please explain.

SOMEBODY POORLIER IN BLEED RELATED INJURIES AND FURTHER ON IN HEP C ILLNESS

18) Have you ever been a carer? Please circle YES or [✓ NO.]

H'LI

19) If the answer to question 18 was YES, please answer the following question.

Are/Were you a carer to your wife/partner? Please circle YES or NO.

20) Have you ever required a carer to assist with your daily living? Please circle

YES or [✓ NO.]

21) If your answer to question 20 was YES please answer the following question. Is /Was your wife/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

AN INDIVIDUAL TO TAKE CARE OF DAILY NEEDS EG INJECTIONS — SHOPPING, A RANGE OF MOST DAILY HAEMOPHILIA RELATED TASKS

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

AS AN AFFECTED PERSON MY VIEW IS CLOUDED. BUT I FEEL POORLY AND HAS MAYBE IMPROVED IN LATER YEARS

24) Do you feel that doctors treating you/your wife/partner have always sought "informed consent" in relation to your medical treatment (where appropriate) and testing for HIV/HCV? Please circle one of the following YES [✓ NO] DON'T KNOW

25) If your answer to question 24 is NO. Please explain why you feel that "informed consent" was not sought by doctors treating you/your wife/partner.

I FELT MORE OF A GUINEA PIG IN EARLY YEARS AS THOUGH I WAS BEING USED TO HELP CONTAMINATED PEOPLE IN THE FUTURE, KNOWING I WAS PROBABLY GOING TO DIE SOONER RATHER THAN LATER

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

SAME AS Q23 BUT PROBABLY WORSE

27) Are you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

28) Is/Was your wife/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service and level of payment provided by the Macfarlane Trust?

I THINK MFT HAS NOT BEEN USED BY ME IN OVER 5 YRS AS I DONT THINK OF MYSELF AS POORLY OR DISABLED

30) Are you a recipient of the Skipton Fund? Please circle [✓ YES] or No.

31) Is your wife/partner a recipient of the Skipton Fund? Please circle YES or [✓ NO.]

32) If your answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund?

AS TO ANY MONETARY QUESTION I WOULD ANSWER IT WAS NEVER ENOUGH

33) What do you feel about the fact that most widows/ bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund .

ALTHOUGH NOT AFFECTED BY THIS I FIND IT DISGUSTING BUT KNOWING WHAT HAS HAD TO BE FOUGHT FOR IT COMES AS NO SHOCK TO ME AND SOMETHING I WOULD PROBABLY HAVE EXPECTED

34) What are your feelings with regard to the international plasma companies that supplied the contaminated treatment to haemophiliacs? .

THESE ARE THE PEOPLE I HOLD RESPONSIBLE FOR RUINING MY LIFE. SO ALL MY FEELINGS OF HATRED ARE WITH THESE ESPECIALLY WHEN NO PAYOUT WAS RECIEVED FROM THESE COMPANIES

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliac/wives/partners with blood borne viruses.

ALTHOUGH A HAEMOPHILIAC I TEND NOT TO INVOLVE MYSELF WITH THE HAEMOPHILIA SOCIETY SO AN ANSWER HERE WOULD NOT BE TRUE

36) Have you or your wife/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle YES or [✓ NO]

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

I FEEL WE HAVE ACTUALLY BEEN SHOWN IN A GOOD LIGHT AND SUPPORTED BY THEM APART FROM THE GUARDIAN WHO ONCE ADVERTISED HOW LUCKY WE WERE TO HAVE AIDS IN ENGLAND AND NOT IN AFRICA WHERE THEY REALLY SUFFER

H24

39) Please describe what you feel has empowered or disempowered HIV/HCV positive haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

40) What do you feel is the most difficult problem you have to deal with being a haemophiliac?

STIGMA, MISUNDERSTANG BY PEOPLE, PREVIOUSLY - ONLY HAVING BLEEDS BUT NOW - LOSING FRIENDS, BREAK UP OF MARRIAGE AND NOW WAITING TO DIE BEFORE I THOUGHT I WOULD

H21

41) What if anything has helped you to maintain a positive outlook on life?

WANTING TO BEAT THE N.H.S AND PROVING I COULD TRY TO BE AS NORMAL AS POSSIBLE,

THANK-YOU FOR IN FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Please circle the following description which is most appropriate to you

[✓ wife]/ partner/ widow / bereaved partner.

2) What is your age? Please state...55........

3) What is your ethnic origin? (White British, Scottish Pakistani etc) Please specify...WHITE BRITISH...................

4) What does the word "blood" mean to you?

SOMETHING THAT SHOULD KEEP YOU ALIVE

5) What does the word "haemophiliac" mean to you?

Someone who has to be very brave to cope with all the pain and suffering haemophilia throws at them, then everything else they have been given - HIV, HCV, CJD.

6) What do you think the word "haemophiliac" means to the general public?

Most would think you can bleed to death
The rest probably have no idea.

7) Are you HIV positive? Please circle one of the following YES, [✓ NO] DON'T KNOW.

8) Is/Was your haemophiliac husband/partner HIV positive? Please circle one of the following [✓ YES] NO, DON'T KNOW.

9) What do the words "HIV positive" mean to you? Please explain.

Waiting to die

10) Are you HCV (hepatitis C) positive? Please circle one of the following YES [✓ NO] DON'T KNOW.

11) Is/Was your haemophiliac husband/partner HCV (hepatitis C) positive? Please circle one of the following [✓ YES] NO, DON'T KNOW.

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

An earliet death and probably very painful.

13) Was your haemophiliac husband/partner ever exposed to variant CJD through blood products? Please circle one of the following YES, NO [✓ DON'T KNOW.]

14) What do the words "exposed to variant CJD" mean to you. Please explain.

Yet another virus coming through the blood chain.

15) Would you describe yourself as "disabled"? Please circle YES or [✓ NO].

16) Would you describe haemophiliacs as disabled? Please circle [✓ YES] or NO.

17) What does the word "disabled" mean to you? Please explain.

Not being able to work or do a lot of physical tasks due to joint deformity. Not being able to walk without aid.

P1

18) Have you ever been a carer? Please circle [✓ YES] or NO?

19) If the answer to Question 18 is YES, please answer the following question.

Are/Were you a carer to your haemophiliac husband/partner? Please circle [✓ YES] or NO.

20) Have you ever required a carer to assist with your daily living? Please circle YES or [✓ NO]

21) If the answer to question 20 was YES please answer the following question.

Is/Was your haemophiliac husband/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

Looking after someone you love helping in all their needs. Being there for them in bad and good times.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

Most don't really want to know, they go through the motions just so that it looks like they are interested.

24) Do you feel that doctors treating haemophiliacs and their wives/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for HIV/HCV? Please circle one of the following YES, [✓ NO,] DON'T KNOW.

25) If your answer to question 24 was NO. Please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/ wives/partners.

After accessing records you could see test results that we knew nothing about.

My husband was just told he was HCV Pos. He was never asked if he wanted to have a test.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

Very very poorly. If they had to live like we have for the past 20 odd years they would have a Public enquiry tomorrow. I don't think they fully understand the impact of this contaminated treatment on haemophiliacs and their families how they have to cope with HIV/HCV and other viruses as well as their haemophilia. Carers should get more for the job they do and widows should also be acknowledged.

27) Is/Was your haemophiliac husband/partner a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO?

28) Are/Were you a registrant of the Macfarlane Trust? Please circle YES or [✓ NO].

29) If the answer to question 27 or 28 was YES please answer the following question.

What do you feel about the service provided by the Macfarlane Trust?

Seems to be run on DSS guidelines. Cap in hand begging for anything you may need.

30) Are/Were you a recipient of the Skipton Fund? Please circle YES or [✓ NO]?

31) Is/Was your haemophiliac husband/partner a recipient of the Skipton Fund.

Please circle [✓ YES] or NO?

32) If the answer to question 30 or 31 was YES please answer the following question.

What do you feel about the level of payment(s) provided by the Skipton Fund?

Please explain.

Payments were very low considering the seriousness of the illness

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund?

The payments should have been across the board everyone including widows/bereaved partners should have received the same money.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment?

Utter disgust. I don't know how they sleep at nights. How someone can knowingly give someone contaminated treatment is beyond me. They should be made to have Factor 8 treatment. I wonder how many would do so willingly.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/wives /partners with blood borne viruses?

Very slowly. Seems as though they have sided with the government. at times.

36) Have you or your haemophiliac husband/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

Some should hang their heads in shame. The American Lawyers I think are Trying but lawsuits like these seem to go slower in America.

38) What do you think about the media response to the infection of haemophiliacs/wives partners with blood borne viruses?

Very positive at times.

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

Being able to access my husband's medical records helped also being in America and listening to the lawyers plead the case for all haemophiliacs. Seeing my husband's face a lot happier when he moved from the RVI to the Newcastle General for his HIV/HCV treatment.

40) What if anything helps you to maintain a positive outlook on life?

By saying in the very begining that nothing was going to happen to my husband even though all the doctors were saying he only had a few years to live. By Trying to prove them wrong and he would still be here today. Also my family especially now they are older and understand more. Being able to talk to other haemophiliacs and for them to listen to me.

THANK-YOU FOR FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Please circle the following description which is most appropriate to you

wife / partner/ [✓ widow] / bereaved partner.

2) What is your age? Please state...50....

3) What is your ethnic origin? (White British, Scottish Pakistani etc) Please specify... White British

1. - All of the following 'what does the word mean' questions except (4) the word has its normal medical/dictionary meaning in addition to the following emotive responses

4) What does the word "blood" mean to you?

Body's transport system

5) What does the word "haemophiliac" mean to you?

person suffering from haemophilia, a predominantly genetic disorder resulting in reduced (or no) clotting of the blood.

6) What do you think the word "haemophiliac" means to the general public?

Variable, some understand it, some don't. Generally though a perception that the bleeding is external.

7) Are you HIV positive? Please circle one of the following YES, [✓ NO] DON'T KNOW.

8) ~~Is~~/Was your haemophiliac husband/~~partner~~ HIV positive? Please circle one of the following [✓ YES] NO, DON'T KNOW.

9) What do the words "HIV positive" mean to you? Please explain. pain, fear, humiliation, intrusion, loss of control. A relentless, cruel and terminal game of 'space-invaders' where no matter how many attacks you fight off, they just keep coming, faster and harder. No matter how sharp your game, how bravely you play, eventually you are fighting on so many fronts you're overwhelmed. There is no rest, no respite, and no off switch.

10) Are you HCV (hepatitis C) positive? Please circle one of the following YES [✓ NO,] DON'T KNOW.

11) ~~Is~~/Was your haemophiliac husband/~~partner~~ HCV (hepatitis C) positive? Please circle one of the following [✓ YES,] NO, DON'T KNOW.

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain. The one we was told was harmless! Huge distended ~~[illegible]~~ abdomens and wasted arms. Exhaustion (or was that the HIV? The complaint that flares up wen't you're treated for HIV related lymphoma. The 2 for 1 disease according to, the government! The one on my husbands death certificate, given as secondary to haemophilia as though there was a causal link that somehow excluded infected blood.

13) Was your haemophiliac husband/partner ever exposed to variant CJD through blood products? Please circle one of the following YES, [✓ NO,] DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you. Please explain.

The dreaded 'next wave'. The uncertainty of living not knowing if my husband had it. Having samples stolen from his body (PM report) to find out but not being told the result. The awareness that successive govs. had learnt nothing from the two previous disasters except slicker ways to cover-up.

15) Would you describe yourself as "disabled"? Please circle YES or [✓ NO.]

16) Would you describe haemophiliacs as disabled? Please circle YES or NO. Some are, some aren't.

17) What does the word "disabled" mean to you? Please explain. My father only had one leg, I remember being 4 years old when I realised men had two legs! It was something you got on with, dad danced and climbed ladders and none of the neighbours even knew. When Graham became really ill, right up to the last few months, he commuted miles to work, made excuses to get the day off for hospital appointments and none of the neighbou knew. Sometimes I look at people and wonder "are you really as OK as you seem?"

18) Have you ever been a carer? Please circle [✓ YES] or NO?

19) If the answer to Question 18 is YES, please answer the following question.

~~Are~~/Were you a carer to your haemophiliac husband/~~partner~~? Please circle [✓ YES] or NO. in the last few months.

20) Have you ever required a carer to assist with your daily living? Please circle YES or [✓ NO.]

21) If the answer to question 20 was YES please answer the following question.

Is/Was your haemophiliac husband/partner your carer? Please circle YES or [✓ NO.]

22) What does the word "carer" mean to you? Near despair, Although I was only a carer for a few months, at the time I had an ~~un~~misdiagnosed fractured spine. My mother couldn't help as my father had a broken hip, broken shoulder (thanks to the hospital!) and terminal cancer and my friend's son had just died. It was a desperate struggle, no practical help was offered, I couldn't get help with housework but lots of offers of help in talking about it'. In the middle of the mayhem some woman phoned up asking "if I'd like to talk to someone?" I replied "yes, I'd like to talk to my husband and I will if you can organise the bloody shopping." Naturally that wasn't possible!

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses? Very variable, one wonderful doctor, Dr Sweetenham, was incredibly helpful, but he struggled to drag his staff along with him "Dr Sweetenham simply doesn't understand how difficult it is" ! I believe he did! Most were patronising, or misdiagnosing my husband's primary lymphoma tumour as an ear infection "you children go home and don't worry" Denial "I see your husband has picked up HIV along the way" on pointing out he didn't 'pick it up' he was given it "Well it's the same thing." Many apologetic for the profession. Fearful, no doctor wanted to treat my husband.

24) Do you feel that doctors treating haemophiliacs and their wives/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for HIV/HCV? Please circle one of the following YES [✓ NO,] DON'T KNOW. and No and Hell No!

25) If your answer to question 24 was NO. Please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/ wives/partners. letter between doctors "he seems to have picked up Hep B along the way, he doesn't know yet, we'll cross that bridge when we come to it" (NB apparently he was not infectious) After my husband died I discovered his notes were marked DNA (do not resusitate) neither my husband nor I were asked about this)

My husband was not told that a procedure he had, carried a high risk of death. He had the procedure and died on Christmas Eve. He would never have had it before Christmas, had he been told. Samples were taken from his body without my consent because Drs were afraid I'd "answer in haste" on replying "you mean you thought I'd say no," I was told that the body belonged to the coroner at that point and he had said yes.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses? Dishonestly.

Successive governments in refusing a public inquiry have shown contempt and disregard for haemophiliacs Even if they have nothing to hide, which I do not believe, there is sufficient concern to make an inquiry justified. An appalling lack of sensitivity and a failure to learn from their mistakes.

27) ~~Is~~/Was your haemophiliac husband/~~partner a~~ registrant of the Macfarlane Trust? Please circle [✓ YES] or NO?

28) ~~Are~~/Were you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

29) If the answer to question 27 or 28 was YES please answer the following question.

What do you feel about the service provided by the Macfarlane Trust?

It has peaked and troughed over the years. The early days when Tudor Williams was in post were possibly the worst. I remember we were told we had to have counselling (compulsory) if we were to recieve financial help. Things improved under

Ann Hiltersay and are now in decline again.

30) Are/Were you a recipient of the Skipton Fund? Please circle YES or [✓ NO?]

31) Is/Was your haemophiliac husband/partner a recipient of the Skipton Fund.

Please circle YES or [✓ NO?]

32) If the answer to question 30 or 31 was YES please answer the following question.

What do you feel about the level of payment(s) provided by the Skipton Fund?

Please explain.

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund? The whole basis of the Skipton payments, like the MFT payments was offensive, based on the remise that this was an 'out of the kindness of our heart' payment, whilst refusing to investigate and expose liability. To be excluded because your husband 'died too soon' is to be penalised for your loss.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment? Disgust. These people are no better than arms dealers or drugs traffickers. It was however in some ways predictable given the unrestrained power of large companies. Whether its Armapharma, or union carbide in Bhopal or Shell in Nigeria, the ethic is the same. Profit at all costs. The US and UK governments are party to this because they have taken no useful steps to make such companies accountable. All that money spent looking for the weapons of mass destruction and all the time, the biological weapons were in our fridges!

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/wives /partners with blood borne viruses? With cowardice. Not wishing to upset the apple-cart we were marginalised. Things have improved a tiny bit but they failed to show leadership or act as a rallying point. In occupying a position of authority and failing to take action, they undermined the efforts of those trying to get an inquiry.

36) Have you or your haemophiliac husband/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle YES or [✓ NO.] Not for the want of trying. I couldn't afford it and could not get legal aid.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses? I think we should not have been encouraged to settle after the original litigation ordering discovery of documents.

38) What do you think about the media response to the infection of haemophiliacs/wives partners with blood borne viruses? Variable. They have their own agenda. I was hurt by an article in the times (double spread) on sperm washing. We took part because we were told they were trying to promote the procedure and support moves to start it in the UK. The article came out under the headline "Dying for a baby - women are risking their lives" the exact opposite of what we were told. The 'observer' have been supportive and my local paper ran a good article but interest is short-lived. It is hard to get media attention now we live in a society where every day "is a day to bury bad news!"

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

Disempowered

1. Anonymity - without knowing who else was affected it has been hard to group together.
2. Fear - the stigma and prejudice have stifled many would-be campaigners.
3. Lack of leadership from the Haemophilia Society
4. Illness - campaigners becoming ill and wives and partners stretched to breaking point.

Empowered

1. Increasing amounts of available information
2. Shift in society's attitudes to HIV infection

40) What if anything helps you to maintain a positive outlook on life?

1, I am not always positive and I often feel like giving up the quest for an inquiry. Ironically in the early days my anger kept me going.

2. Family, especially my daughter who has been rock-solid through-out and herself started campaigning 2 years ago.

3. Friends

4. The cat!

5. Studying, learning new things.

6. This one sounds a bit crazy but here goes:- Awful as our suffering has been, and nothing excuses the actions of the drug companies and governments, I feel my life is like one of those picture quiz's where you are shown a hugely magnified part of a toothbrush or head of a screw and you have to guess what it is. From close up it makes no sense at all but stand back and a picture emerges. I believe, maybe I have to, that in some part of eternity this all makes perfect sense.

THANK-YOU FOR FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Which of the following descriptions is most appropriate to you:

wife / partner/ widow/ bereaved partner.

I am the widow of a deceased haemophiliac.

2) What is your age?

I am 68.

3) What is your ethnic origin? (White British, Scottish, Pakistani etc.).

White British.

4) What does the word "blood" mean to you?

Blood is our lifeline.

5) What does the word "haemophiliac" mean to you?

Someone suffering from an hereditary blood disorder, whereby their blood is unable to clot, so causing a lifetime of pain and discomfort.

6) What do you think the word "haemophiliac" means to the general public?

They have heard the word without really understanding it, perhaps assuming that it is someone who bleeds to death if they cut themselves.

7) Are you HIV positive?

No.

8) Is/ was your haemophiliac husband/partner HIV positive?

No.

9) What do the words "HIV positive" mean to you? Please explain.

A sexually transmitted disease. A drug addict's disease. No cure.

10) Are you HCV (hepatitis C) positive?

No.

11) Is/was your haemophiliac husband/partner HCV (hepatitis C) positive?

Yes he was.

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

A blood borne virus passed via contaminated blood, which attacks the liver leading to cirrhosis, oesophageal bleeding (varices), liver failure, liver cancer and possible liver transplantation, plus many other discomforts. No cure.

13) Was your haemophiliac husband/partner ever exposed to variant CJD through blood products?

Don't know.

14) What do the words "exposed to variant CJD" mean to you? Please explain.

Transmitted via contaminated blood, leading to serious health problems. Again, no cure.

15) Would you describe yourself as "disabled"?

No.

16) Would you describe haemophiliacs as "disabled"?

Yes.

17) What does the word "disabled" mean to you?

Someone suffering from a physical or mental impairment (whether visible or not) who may always need help and support.

18) Have you ever been a carer?

Yes.

19) If the answer to Question 18 is YES, please answer the following question: are/ were you a carer to your haemophiliac husband/partner.

Yes.

20) Have you ever required a carer to assist with your daily living?

No

21) If the answer to Question 20 was YES please answer the following question: is/was your haemophiliac husband/partner your carer?

n/a

22) What does the word "carer" mean to you?

Someone having always to be there to provide help and care to enable another person to cope with their life.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/ wives/ partners with blood borne viruses?

I do not believe they were fully open or honest concerning the risks involved in such treatment.

24) Do you feel that doctors treating haemophiliacs and their wives/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for HIV/HCV?

No.

25) If your answer to Question 24 was NO, please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/wives/partners.

Testing was carried out without the patient's consent; nor were they told the results of the tests. My husband discovered in January 1992 that he had been infected with HCV 10 years earlier in December 1981 following an operation for an ulcer. After that operation he was told he had hepatitis which would settle down eventually. On receipt of his medical records after his death, I was shocked to find a letter dated March 22nd 1979 stating that he had, in fact, already had a positive "Australian antigen" test, possibly due to receiving cryo-precipitate. This letter also stated that he had: dilated ducts and abnormal liver function tests usually indicative of serum hepatitis. Another letter dated February 5th 1982 stated that he had suffered an acute attack of non-A, non-B hepatitis as a result of receiving Factor VIII at the time of the operation for his ulcer and that his liver function tests were not yet back to normal. We were never informed of any of the tests taken.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

I think they have demonstrated a complete disregard of haemophiliacs and their families concerning the pain and sufferings that they have had to endure due to the infections in contaminated blood. The various governments over the years have always maintained "no fault" on their part regarding the distribution of contaminated blood used in the treatment of haemophiliacs, which ultimately led to the death of my husband at the age of 59; his death certificate reads: i) hepatocellular carcinoma; ii) cirrhosis of the liver; iii) hepatitis c; iv) haemophilia A.

27) Is/was your haemophiliac husband/partner a registrant of the McFarlane Trust?

No.

28) Are/ were you a registrant of the McFarlane Trust?

No.

29) If the answer to Questions 27 or 28 was YES please answer the following question: what do you feel about the service provided by the McFarlane Trust?

n/a

30) Are/were you a recipient of the Skipton Fund?

No.

31) Is/was your haemophiliac husband/partner a recipient of the Skipton Fund?

No.

32) If the answer to Questions 30 or 31 was YES please answer the following question: what do you feel about the level of payment(s) provided by the Skipton Fund? Please explain.

n/a

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund?

I find the decision to exclude widows unbelievable given the fact that we have suffered the most. I experienced all of my husband's sufferings. I cared for him. I gave up employment in order to do so. We had to live on Disability Living Allowance and what meagre savings we had. Due to the early surrender, on the likely - and ultimately correct - assumption that they would not have eventually been paid out upon his death given the nature of his illnesses, we had no insurance policies to cash-in. Similarly we had no mortgage protection as we were never able to secure such a policy given my husband's condition. I had to continue paying the mortgage after my husband's death. I live on just my state pension and a small works pension of £1,400pa (net) from a former employer. My husband has now been dead 12 years and what savings I did possess have now been completely exhausted. At the age of 68 I had to take out an interest-only mortgage to carry-out necessary repairs to my home costing me £68 per month, which I can ill-afford.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment?

They should be held responsible for supplying contaminated blood products along with the governments that bought and used them in the treatment of haemophiliacs. They should also be made to pay compensation for the lives they have ruined. After all, if customers purchase an item in good faith, only to then find it faulty, it is naturally assumed that they should seek recompense or redress. Similarly, HCV widows are owed for the loss of husbands. Someone must hold their hands up and admit responsibility for this disaster which in my opinion was manslaughter.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

The Society has never given us the support we truly deserved. They have never really fought our cause. Lord Morris, I feel, is the one person who has shown us the most support. In the 27 years since my husband was first treated with contaminated blood products I have had very little support.

36) Have you or your haemophiliac husband/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C?

Yes.

37) If the answer to Question 36 was YES please answer the following question: how do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

Although I believe the legal profession has generally been sympathetic to our cause, and fully understanding of the injury and injustice. Ultimately, though, they have been impotent in their ability to be successful as they have been hampered from really exposing the truth of this disaster, due to cover-ups and inaccessible information.

38) What do you think about the media response to the infection of haemophiliacs/wives/partners with blood borne viruses?

Generally the media response has been lukewarm. Part of the reason for this is that I don't think the media has ever been able to get to grips with the complexities of this tragedy and as a consequence have largely ignored it. However, I have also wondered if another reason for the media's general silence has been that they have been handcuffed from investigating the matter by the government.

Also it has been very difficult to garner media coverage simply because it is very painful for families to publicly expose their heartache. Like many people, I have related my story to the media and this has resulted in a family split which will never be resolved. I believe that the government has traded on the general reluctance of the haemophiliac community to expose itself to such scrutiny.

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question).

The Manor House Group's campaign for justice for HCV haemophiliacs and widow has empowered me greatly over many years and I thank them fo their support. I feel the Haemophilia Society has disempowered me through its lukewarm response over the years.

P8

40) What, if anything, helps you to maintain a positive outlook on life?

I never give up hope that one day my late husband will receive the justice he truly deserves. Although they are tragic, a written statement he made about his condition nine months before his death, gives me the motivation to continue fighting for him and this in turn leads me to continually live in positive hope.

He wrote: *"Being a haemophiliac has led to severe other problems with my health. Over the years since childhood, I have had innumerable bleeds into my joints which, in turn, have led to my joints being arthritic and painful. I am unable to use my arms for many everyday things like cooking, preparing vegetables, opening cans and sometimes it is even difficult to write.*

"In 1978, due to the use of contaminated blood products to control bleeding I contracted hepatitis. In 1981 the use of blood products during a stay in hospital again resulted in hepatitis which has caused cirrhosis of the liver.

"In 1991 it was necessary to have a knee replacement and this proved difficult due to excessive bleeding into the joint leaving it somewhat less flexible than anticipated. Apparently the bleeding was excessive due to reduced liver function. This has also left me with varices and resulted in several fairly severe bouts of internal bleeding and stays in hospital. I now have to maintain a salt free diet.

"As a result of the stiffness in my knee and being unable to bend properly, I now have a hernia for which my doctors are reluctant to operate due to the problems of controlling the bleeding.

"My health has deteriorated noticeably in the past 18 months to two years and I now have to go to bed fairly frequently during the day, as I become tired very easily because of my liver problems."

Being the widow of a haemophiliac infected with contaminated blood is not easy to come to terms with compared to being a widow due to more naturally accepted causes of death. It's hard sometimes to continue with life and to grieve naturally because you know that your husband didn't die from more common causes such as a heart attack, or an accident or cancer (although he did have cancer, this was as a direct result of being infected with HCV). You tend to feel that you are always fighting for justice and you do get days when you just want to surrender. Indeed you may even forget about it for a few days but then something happens to trigger it off again and it all comes flooding back. I want it to end. I want someone to say they are sorry. I want someone to tell the truth as to why this tragedy was allowed to happen. I want to get on with the rest of my life. It is the hope that I will achieve all of these things that ironically keeps me positive.

ENDS QUESTIONNAIRE

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Please circle the following description which is most appropriate to you

[✓ wife] / partner/ widow / bereaved partner.

2) What is your age? Please state.52

3) What is your ethnic origin? (White British, Scottish Pakistani etc) Please specify. White ENGLISH

4) What does the word "blood" mean to you?

Needless
INFECTION, CONTAMINATION,
Pain, Suffering, Death.

5) What does the word "haemophiliac" mean to you?

Somebody Who has a factor VIII Defiacincy
Somebody Who has been infected through Contaminated N.H.S. blood products with H.I.V. Hepatitis B, C, NvCJD and other Virus
Sombody who has been Neglected, ignored and Treated like a ~~(3rd)~~ Second Class Citizen by The very Government that allowed Haemophiliacs to become infected.

P11

6) What do you think the word "haemophiliac" means to the general public?

People who cut themselfs Bleed profusley, People to be shuned as they are infected and iffectaus.

7) Are you HIV positive? Please circle one of the following YES, [✓ NO] DON'T KNOW.

8) Is/Was your haemophiliac husband/partner HIV positive? Please circle one of the following YES, [✓ NO], DON'T KNOW.

9) What do the words "HIV positive" mean to you? Please explain.

People who may go on to develope aids people wh suffer through the breakdown of the immune systme, and eventualy die of the virus.

10) Are you HCV (hepatitis C) positive? Please circle one of the following YES [✓ NO], DON'T KNOW.

11) Is/Was your haemophiliac husband/partner HCV (hepatitis C) positive? Please circle one of the following [✓ YES], NO, DON'T KNOW.

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

This is a Virus that has been given to my Husband by the N.H.S, and as yet we have to be given the truth about why this Virus was allowed to be knowingly imported and given To Haemophiliacs by the N.H.S. it also means uncertainty, pain, Death.

13) Was your haemophiliac husband/partner ever exposed to variant CJD through blood products? Please circle one of the following [✓ YES] NO, DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you. Please explain.

frightening. yet another virus that has been given with a very uncertain outcome.

15) Would you describe yourself as "disabled"? Please circle YES or [✓ NO.]

16) Would you describe haemophiliacs as disabled? Please circle [✓ YES] or NO.

17) What does the word "disabled" mean to you? Please explain.

unable to lead an active life.

Having To Cope with not only Haemophilia but To Cope with the day-to-Day effects of H.I.V. H.C.V. NvCJD. infections. The tiredness and other medical Problems that are Caused by the viruses that have Contaminated Them.

18) Have you ever been a carer? Please circle [✓ YES] or NO?

19) If the answer to Question 18 is YES, please answer the following question.

Are/Were you a carer to your haemophiliac husband/~~partner~~? Please circle [✓ YES] or NO.

20) Have you ever required a carer to assist with your daily living? Please circle YES or [✓ NO.]

21) If the answer to question 20 was YES please answer the following question.

Is/Was your haemophiliac husband/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

I Care for My husband Most of the Time. it means that I go out on my own very little I can not Make plans to go anywhere. I am Not infected with any of the viruses that my Husband has been given by the N.H.S. but I have been effected, as I am Nearly as house bound as my husband, I feel as though at Times I like my Husband am a Second class Citizen as when The Government Set up The Skipton fund they ignored Carers and Bereaved Partners and Carers.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

with indifference and Contempt.

24) Do you feel that doctors treating haemophiliacs and their wives/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for HIV/HCV? Please circle one of the following YES, [✓ NO,] DON'T KNOW.

25) If your answer to question 24 was NO. Please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/ wives/partners.

I think informed Concent means that the Patient is Told what they are being Tested for what this would mean if a positive result is and what if any ~~this~~ Treatment would be available and what all the implications are. This in my husbands Case did not happen with regard to. H.C.V. H.I.V. NvCJD. and other viruses. with H.C.V. he was Tested many Times in the 10 years he had the virus and was not Told he had the virus. and he found out about NvCJD The Day after The News from The Government

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

as yet the Government has not yet Responded To the infection of Haemophiliacs all the have done is hoped that Haemophiliacs would go away to die and save them the embarrisment of Revealing the facts behind the worst medical disaster in the history of the N.H.S. The Government hope that Haemophiliacs will not expose their Cover up of the infection of 5,000+ Vunerable People.

27) Is/Was your haemophiliac husband/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ **NO**]**?**

28) Are/Were you a registrant of the Macfarlane Trust? Please circle YES or [✓ **NO.**]

29) If the answer to question 27 or 28 was YES please answer the following question.

What do you feel about the service provided by the Macfarlane Trust?

30) Are/Were you a recipient of the Skipton Fund? Please circle YES or [✓ NO?]

31) Is/Was your haemophiliac husband/partner a recipient of the Skipton Fund. Please circle [✓ YES] or NO?

32) If the answer to question 30 or 31 was YES please answer the following question. What do you feel about the level of payment(s) provided by the Skipton Fund? Please explain.

an insult.

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund?

all Carers, Partners, widows all of whom have been ignored by the Government Deserve inclusion in the Skipton fund.

This is an insult. Disgraceful.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment?

They knew the Risks. They did nothing.

CRIMINAL.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/wives /partners with blood borne viruses?

They have been Slow to React
They are still Slow to React unless
Pressurised.
They dont in my View Know
What infected Haemophiliacs and their
familyes go through.

36) Have you or your haemophiliac husband/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

I think they are limited in What
they can do by the Government
Cover up.

38) What do you think about the media response to the infection of haemophiliacs/wives partners with blood borne viruses?

again I think the press are ruled by the Government cover up.

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

I think that if it were not for Committed individuals and Groups such as the Manor House Group and U.K. ~~[illegible]~~ Haemophilia Action and Lord Morris of Manchester who have kept the pressure on the Government that Haemophiliacs would not have got as far in exposing this Scandal.

40) What if anything helps you to maintain a positive outlook on life?

The fact that one day. we will find out who took the decision to knowingly infect Haemophiliacs with blood borne viruses and why. it is getting harder to maintain a positive outlook on life as the Government seems intent on keeping the truth hidden.

Why?

THANK-YOU FOR FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Please circle the following description which is most appropriate to you

wife / [✓ partner] / widow / bereaved partner.

2) What is your age? Please state......46......

3) What is your ethnic origin? (White British, Scottish Pakistani etc) Please specify......WHITE BRITISH......

4) What does the word "blood" mean to you?

"LIFE"! WITHOUT IT WE DIE, WITH INFECTED BLOOD WE DIE SLOWLY, PAINFULLY & MISERABLY

5) What does the word "haemophiliac" mean to you?

BEFORE I MET COLETTE (MY WIFE) THE WORD HAEMOPHILIAC DID NOT MEAN ANYTHING TO ME HOWEVER SINCE KNOWING COLETTE AND UNDERSTANDING WHAT THE CONDITION IS, THE WORD "INFECTED" SPRINGS TO MIND MORE. I NOW ASSOCIATE HAEMOPHILIA AND PEOPLE WITH HAEMOPHILIA TO CARRY INFECTION.

6) What do you think the word "haemophiliac" means to the general public?

THE GENERAL PUBLIC DO NOT KNOW ENOUGH IF ANYTHING ABOUT HAEMOPHILIA, AND ARE GENERALLY NOT INTERESTED UNLESS IT AFFECTS THEM. THEY MAY FEEL SORROW FOR 2 MINS BUT THAT IS AS FAR AS IT GOES!

7) Are you HIV positive? Please circle one of the following YES, [✓ NO,] DON'T KNOW.

8) Is/Was your haemophiliac ~~husband~~/partner HIV positive? Please circle one of the following YES, [✓ NO,] DON'T KNOW.

9) What do the words "HIV positive" mean to you? Please explain.

AIDS, GAY MEN, DRUG USERS, NEEDLE SHARING. THE RICH & FAMOUS SUFFERING HIV AIDS, INFECTED MEN BUT ALSO ENCOURAGING ~~PEOPLE~~ THEM TO CARRY ON WITH THEIR WAY OF LIFE, EVEN THOUGH THE RISK OF TRANSMITTING THE INFECTION IS VERY HIGH. AGAIN PEOPLE AND THE GENERAL PUBLIC ARE APATHETIC UNTIL IT AFFECTS THEM.

10) Are you HCV (hepatitis C) positive? Please circle one of the following YES [✓ NO,] DON'T KNOW.

11) Is/Was your haemophiliac ~~husband~~/partner HCV (hepatitis C) positive? Please circle one of the following [✓ YES,] NO, DON'T KNOW.

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

DESPITE BEING AN INFORMED PERSON THE ABOVE WORDS MEAN TO ME DRUG ABUSE, NEEDLE SHARING CAREFREE NOT WILLING TO BE RESPONSABLE FOR THEIR ACTIONS. I KNOW MANY HAEMOPHILIACS ARE HCV POSITIVE AND HOW THEY CONTRACTED THE INFECTION BUT SADLY I FEEL THE MEDIA STILL PLAY THE DRUGS & ALCOHOL ABUSE CARD WHEN REPORTING,

13) Was your haemophiliac [redacted]/partner ever exposed to variant CJD through blood products? Please circle one of the following [✓ YES], NO, DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you. Please explain.

GOVERNMENT LIES! PAIN & SUFFERING. ALL OF THESE INFECTIONS MENTIONED SO FAR HAVE BEEN CREATED OR ALLOWED TO SPREAD MUCH MORE THAN THEY SHOULD OF DONE BECAUSE OF POOR GOVERNMENT CONTROL & LACK OF CARE FOR UK CITIZENS.

15) Would you describe yourself as "disabled"? Please circle YES or [✓ NO]. NOT PHYSICALLY MY IMMEDIATE RESPONSE WAS NO. HOWEVER MY REACTION TO THAT WAS YES I DO FEEL DISABLED?

16) Would you describe haemophiliacs as disabled? Please circle [✓ YES] or NO.

17) What does the word "disabled" mean to you? Please explain.

DISFIGGURED, UNABLE TO WORK, TO CARRY OUT OR HAVE WHAT WOULD BE CONSIDERED A NORMAL LIFE! QUESTION 15 - WOULD I DESCRIBE MYSELF DISABLED? PHYSICALLY NO, BUT MENTALLY YES, BECAUSE AGAIN EVEN AS AN INFORMED PERSON I STILL STRUGGLE TO SEE OR RECOGNISED A DISABLED PERSON

UNLESS THEY HAVE A MISSING LIMB, OR HAVE TO BE PUSHED AROUND IN A WHEELCHAIR. YET MY WIFE'S DISABILITY AFFECTS MINE & OUR DAUGHTER'S LIFE. MY WIFE'S DISABILITY PUTS PRESSURE ON MINE ~~&~~ OUR DAUGHTER'S DAY TO DAY EXISTANCE. WE DON'T SEEM TO HAVE AS MUCH FUN!

18) Have you ever been a carer? Please circle [✓ YES] or NO? BUT NOT AS MUCH AS I THINK I SHOULD HAVE BEEN.

19) If the answer to Question 18 is YES, please answer the following question.

Are/Were you a carer to your haemophiliac [redacted]/partner? Please circle [✓ YES] or NO.

20) Have you ever required a carer to assist with your daily living? Please circle YES or [✓ NO.]

21) If the answer to question 20 was YES please answer the following question.

Is/Was your haemophiliac [redacted]/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

HAVING TO GIVE UP WORK TO CARE FOR YOUR LOVED ONE.

BEING UNABLE TO CARE FOR YOUR LOVED ONE AS MUCH AS YOU WOULD LIKE DUE TO THE PRESSURE OF WORK, FINANCIAL PRESSURES, CHILDREN ENTERTAINING / CARING.

HOPEING ONE DAY THE PRESSURES OF TRYING TO BE A CARER & PROVIDER WILL GET EASIER!

23) How do you think the medical profession has responded to the contamination of haemophiliacs/[redacted]/partners with blood borne viruses?

SWEET F. A. !

24) Do you feel that doctors treating haemophiliacs and their [redacted]/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for HIV/HCV? Please circle one of the following YES, [✓ NO,] DON'T KNOW.

25) If your answer to question 24 was NO. Please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/ [redacted]/partners.

IT HAS BEEN FRIGHTENING TO DISCOVER OVER THE YEARS THAT DOCTORS KNOWINGLY INFECTED PATIENTS WITH CONTAMINATED BLOOD PRODUCTS. I HAVE EVEN WITNESSED A DOCTOR CLAIMING "IT WAS WORTH THE RISK" TO USE CONTAMINATED CLOTTING FACTOR BUT DIDN'T FEEL IT NECASSARY TO INFORM THE PATIENT OR THE PATIENTS FAMILY OF THE RISK SO THEY COULD MAKE AN INFORMED DECISION.

26) How do you think the government has responded to the contamination of haemophiliacs/[redacted]/partners with blood borne viruses?

TOTAL DISGRACE & DISREGARD FOR HUMAN LIFE IN A PATIENT GROUP THAT WAS VERY VULNERABLE & RELIENT ON THE NHS & GOVERNMENT. TO TAKE CARE OF THEM, NOT TO KILL THEM!
THE FACT THAT THE GOVERNMENT IS STILL NOT WILLING TO HOLD A PUBLIC ENQUIRY MEANS TO ME THAT N°10 HAS SOMETHING TO HIDE.

27) Is/Was your haemophiliac [redacted]/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO]?

28) Are/Were you a registrant of the Macfarlane Trust? Please circle YES or

[✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question.

What do you feel about the service provided by the Macfarlane Trust?

30) Are/Were you a recipient of the Skipton Fund? Please circle YES or [✓ NO?]

31) Is/Was your haemophiliac ~~husband~~/partner a recipient of the Skipton Fund.

Please circle [✓ YES] or NO?

32) If the answer to question 30 or 31 was YES please answer the following question.

What do you feel about the level of payment(s) provided by the Skipton Fund?

Please explain. DISGRACEFUL, WHEN YOU COMPARE PAYMENTS THAT ARE MADE TO PEOPLE WHO ~~HAVE~~ ~~SUFFERED~~ IN MY OPINION ~~FOR~~ DONT DESERVE TO RECEIVE 100'S OF THOUSANDS OF POUNDS FOR DEFAMATORY REMARKS AND YET ~~[illegible]~~ HAEMOPHILIACS DIE & GET A PITTANCE

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund?

IT MEANS LIFE MEANS NOTHING TO THE GOVERNMENT IF ANYTHING THEY SHOULD HAVE RECEIVED DOUBLE THE AMOUNT. I DONT UNDERSTAND HOW THIS PATIENT GROUP AND THEIR FAMILIES CAN BE TREATED WITH SUCH CONTEMPT.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment?

I DONT KNOW HOW THESE PEOPLE SLEEP AT NIGHT. NOR DO I UNDERSTAND HOW GOVERNMENTS HAVE ALLOWED THESE ORGANISATIONS TO GET AWAY WITH IT, AND CONTINUE TO GET AWAY

WITH IT FOR SO LONG.
I AM CONVINCED THAT THESE PLASMA COMPANIES INFLUENCED THE BRITISH GOVERNMENT NOT TO BECOME SELF SUFFICIENT.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/[redacted] /partners with blood borne viruses?

TOO LAID BACK, NOT ~~ON~~ PROACTIVE OR DETERMINED ENOUGH TO SEEK THE TRUTH ABOUT HOW THIS PATIENT GROUP COULD BE INFECTED NOT JUST ONCE BUT 3 TIMES, BY THE SAME SOURCE. "THE NHS" THEY SHOULD BE CALLED "THE HAEMOPHILIAC PRINTING COMPANY" BECAUSE ALL THEY DO IS PRINT LEAFLETS.

36) Have you or your haemophiliac [redacted]/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/[redacted]/partners infected with blood borne viruses?

I DON'T BELIEVE THE LEGAL PROFESSION AS REPRESENTED THIS GROUP OF PEOPLE WITH ENOUGH BELIEVE OR DETERMINATION TO GET TO THE TRUTH WHAT EVER THE COST!

WHY CAN'T THE UK LEGAL SYSTEM RIDE ON THE BACK OF THE IRISH SUCCESS.
WHAT ARE THEY SCARED OF ?

38) What do you think about the media response to the infection of haemophiliacs/[redacted]partners with blood borne viruses?

WHAT MEDIA PRESSURE ? RESPONSE. THE MEDIA IS MORE INTERESTED IN POSH'S HAIR-EXTENSIONS THAN TRYING TO BRING THE GOVERNMENT TO TASK.

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

DISEMPOWERED BY THE NATIONAL HAEMOPHILIAC SOCIETY FOR NOT PULLING EVERYONE TOGETHER. IT SHOULD OF BEEN ONE OF THE MAIN AIMS TO GET ALL GROUPS SINGING FROM THE SAME HYMN SHEET. THEY FAILED MISERABLY AND THAT IS ONE REASON WHY AT EVER PROTEST MARCH, EVERY NEWS PAPER ARTICLE THE CAMPAIGN IN MY OPINION WOULD TAKE ONE STEP FORWARD & 10 STEPS BACK BECAUSE THE SOCIETY FAILED TO ENDORSE & DRIVE THE FIGHT!

40) What if anything helps you to maintain a positive outlook on life?

I DO FIND IT VERY DIFFICULT TO MAINTAIN ANY KIND OF POSITIVE OUTLOOK IF IT WASN'T FOR COLETTE & REBEKAH, I WOULD HAVE GIVEN IN AGES AGO. I SUPPOSE ONE THING THAT DRIVES ME ON IS THE BELIEF THAT ONE DAY WE WILL GET JUSTICE. SADLY I DON'T BELIEVE IT WILL BE IN THE LIFE TIME OF MANY OF THE INFECTED HAEMOPHILACS.

IN THE EARLIER DAYS OF CAMPAINING I HAD A REAL DESIRE TO KEEP FIGHTING IN THE BELIEF THAT THE GOVERNMENT HAD TO GIVE IN. THIS FIGHT GAVE ME A POSITIVE APPROACH. SADLY THE LIGHT THAT ONCE SHONE BRIGHT IS NOW ONLY A FLICKER STRUGGLING TO STAY ALIVE.

THANK-YOU FOR FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

(13 [redacted] 3

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Please circle the following description which is most appropriate to you

[✓ wife] / partner/ widow / bereaved partner.

2) What is your age? Please state 50

3) What is your ethnic origin? (White British, Scottish Pakistani etc) Please specify WHITE BRITISH

4) What does the word "blood" mean to you?

THE UN-KNOWN, UNPROVEN & UNTESTED.

5) What does the word "haemophiliac" mean to you?

BLEEDER, THE older haemophiliac has had to endure a lot of changes from when he was younger ie treatment new products all of which were not proved to be too good regards the viruses, someone that needs to be carful in life make the right decitions about the job they may be able to do may-be for the older haemophiliac its far to late to make any decisions in life may-be they have already been made for them?!

P.T.S.

6) What do you think the word "haemophiliac" means to the general public?

I would be suprised if the general pubic know what the word means, never mind how it afects some one..

7). Are you HIV positive? Please circle one of the following YES, [✓ NO] DON'T KNOW.

8) Is/Was your haemophiliac husband/partner HIV positive? Please circle one of the following YES, [✓ NO], DON'T KNOW.

9) What do the words "HIV positive" mean to you? Please explain.

10) Are you HCV (hepatitis C) positive? Please circle one of the following YES [✓ NO,] DON'T KNOW.

11) Is/Was your haemophiliac husband~~/partner~~ HCV (hepatitis C) positive? Please circle one of the following [✓ YES], ~~NO, DON'T KNOW.~~

P13

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

It means another virus my husband has got to endure & live with more problems & worry

13) Was your haemophiliac husband/~~partner~~ ever exposed to variant CJD through blood products? Please circle one of the following [✓ YES], NO, DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you. Please explain.

It means that my husband has come in-to contact with someone's blood by injecting, himself to help stop his bleeding, once again blood we thought that was clean.

15) Would you describe yourself as "disabled"? Please circle YES or [✓ NO.]

16) Would you describe haemophiliacs as disabled? Please circle [✓ YES] or NO. (Older comunit
not so much to youngster's

17) What does the word "disabled" mean to you? Please explain.

Someone who cant work or look after themselfs' due to their health & condition of (haemophilia) & (viruses)

PT

18) Have you ever been a carer? Please circle [✓ YES] or NO?

19) If the answer to Question 18 is YES, please answer the following question.

Are/~~Were~~ you a carer to your haemophiliac husband/~~partner~~? Please circle [✓ YES] or NO.

20) Have you ever required a carer to assist with your daily living? Please circle YES or [✓ NO.]

21) If the answer to question 20 was YES please answer the following question.

Is/Was your haemophiliac husband/partner your carer? Please circle YES or NO.

22) What does the word "carer" mean to you?

Having responcability for looking after one's best interest ie health & general every-day needs., (food, washing & cooking cleaning shoping getting them about driving) everthing that a person cannot do for him or herself.

PIS

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

not with (compassion) no way, not ever
sympthy, they treat us with contempt,
most will say they are only blood doctor
& send you to some other doctor to
deal with you problems, its called pass-
-ing the book

24) Do you feel that doctors treating haemophiliacs and their wives/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for ~~HIV/~~HCV? Please circle one of the following YES [✓ NO] DON'T KNOW.

25) If your answer to question 24 was NO. Please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/ wives/partners.

mistakes were made many years ago &
may-be even now they are still made but
Doctors of to-day (some) are more awar
of rules & regulations, old haemophil
doctors & units made their own rules
& regulations for themselfs & their patients
they did not - request concent for care
or the rubbish they were injecting into
our husbands or partners arms.

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

they just want them all to die so it may never be found out why it all happend to such a small comunity one that was most vanriable, you're got the viruses, now here's a few bob go-away and dont botter us again.

27) Is/Was your haemophiliac husband/partner a registrant of the Macfarlane Trust? Please circle YES or [✓ NO]?

28) Are/Were you a registrant of the Macfarlane Trust? Please circle YES or NO.

29) If the answer to question 27 or 28 was YES please answer the following question. What do you feel about the service provided by the Macfarlane Trust?

30) Are/Were you a recipient of the Skipton Fund? Please circle YES or [✓ NO]?

31) Is/Was your haemophiliac husband/partner a recipient of the Skipton Fund.

Please circle [✓ YES] or NO?

32) If the answer to question 30 or 31 was YES please answer the following question.

What do you feel about the level of payment(s) provided by the Skipton Fund?

Please explain.

a Joke (insult) no. after care why)

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund?

Discusting they deserve the same level of payment of all wifes & partners equality of both trust & fund there should not have been any difference to any-one with any virus all should have been treated the same.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment?

they knew what they were doing was wrong & they should be accounted for & the profits of those companies should be given back to the haemophiliacs.

PB

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/wives /partners with blood borne viruses?

Slow at first if it wasn't for the certain few who stood by what they were saying then nothing even to-day would have been done but then again its not what you know but who you know & the smal campaigner quest was made, very hard, we weren't funded like the society.

36) Have you or your haemophiliac husband/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

ith Contempt, because even though they now the truth it is the goverment that put the wind up them if they spoke out of ne it was not to be made public?

38) What do you think about the media response to the infection of haemophiliacs/wives partners with blood borne viruses?

not good in the way families & people were left to get on with their life when they had gone public, & then left to face the doctors & goverment's who they had pointed the finger at in the first place. to find out they would be shunned.

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

beilive in themself's for what they were doing by trying to bring to Justice the truth of what went wrong & why we still need answers & I sure we will get them we are not all washed up yet, the fight must go on.

40) What if anything helps you to maintain a positive outlook on life?

what helps me to keep a positive out look on life is that my husband is still fighting for Justice in his own way regording his health & if he keeps going on with his haemophilia & his viruses then surly I can, (hope & determination) that one day all will be answered so we might get on with life in our own ways.

THANK-YOU FOR FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

P 14

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Please circle the following description which is most appropriate to you

[✓ wife] / partner/ widow / bereaved partner.

2) What is your age? Please state...32...

3) What is your ethnic origin? (White British, Scottish Pakistani etc) Please specify......BRITISH.........................

4) What does the word "blood" mean to you?

If I here the word blood, I think hiv + all other problems we have to deal with.

5) What does the word "haemophiliac" mean to you?

Someone Who has a lot of problems to deal with.

6) What do you think the word "haemophiliac" means to the general public?

They think all haemophiliacs have aids.

7) Are you HIV positive? Please circle one of the following YES, [✓ NO] DON'T KNOW.

8) Is/Was your haemophiliac husband/partner HIV positive? Please circle one of the following [✓ YES] NO, DON'T KNOW.

9) What do the words "HIV positive" mean to you? Please explain.

Its a worrying word, hiv leads to a lot of different complications, as we are finding out.

10) Are you HCV (hepatitis C) positive? Please circle one of the following YES [✓ NO,] DON'T KNOW.

11) Is/Was your haemophiliac husband/partner HCV (hepatitis C) positive? Please circle one of the following [✓ YES,] NO, DON'T KNOW.

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

Just another problem to worry about.

13) Was your haemophiliac husband/partner ever exposed to variant CJD through blood products? Please circle one of the following [✓ YES,] NO, DON'T KNOW.

14) What do the words "exposed to variant CJD" mean to you. Please explain.

It is just Something else to worry about.

15) Would you describe yourself as "disabled"? Please circle YES or [✓ NO.]

16) Would you describe haemophiliacs as disabled? Please circle [✓ YES] or NO.

17) What does the word "disabled" mean to you? Please explain.

my husband used to be very active, I never would of said he was 'disabled' but due to various problems he can do less and less all the time.

18) Have you ever been a carer? Please circle [✓ YES] or NO?

19) If the answer to Question 18 is YES, please answer the following question.

Are/Were you a carer to your haemophiliac husband/partner? Please circle [✓ YES] or NO.

20) Have you ever required a carer to assist with your daily living? Please circle YES or [✓ NO.]

21) If the answer to question 20 was YES please answer the following question.

Is/Was your haemophiliac husband/partner your carer? Please circle YES or [✓ NO.]

22) What does the word "carer" mean to you?

I have to look after my hubby, when he is poorly, or when he can't go upstairs to fetch something I go, Just generally do things, he should be able to do.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

They don't want to Know.

24) Do you feel that doctors treating haemophiliacs and their wives/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for HIV/HCV? Please circle one of the following YES, [✓ NO,] DON'T KNOW.

25) If your answer to question 24 was NO. Please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/ wives/partners.

They called them in for Routine check-ups, took their blood, and they Knew long before they told them the outcome, Bastards!

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

The goverment are crap, why don't they just own up to being idiots.

27) Is/Was your haemophiliac husband/partner a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO?

28) Are/Were you a registrant of the Macfarlane Trust? Please circle YES or [✓ NO.]

29) If the answer to question 27 or 28 was YES please answer the following question.

What do you feel about the service provided by the Macfarlane Trust?

you don't really like to ask for things, it feels like begging with all the forms to be filled in for a new dryer!! They also should give more monthly so that we can live comfortable for whatever time we have left together.

30) Are/Were you a recipient of the Skipton Fund? Please circle YES or [✓ NO?]

31) Is/Was your haemophiliac husband/partner a recipient of the Skipton Fund.

Please circle [✓ YES] or NO?

32) If the answer to question 30 or 31 was YES please answer the following question.

What do you feel about the level of payment(s) provided by the Skipton Fund?

Please explain. Absolutely disgusting, you cannot ever put a price on Somebody life like that.

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund? Disgusted, they have as much right to that money (as pathetic as the amount was) as their partners.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment?

They should all be in jail, or dead.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/wives /partners with blood borne viruses?

We never hear or deal from them.

36) Have you or your haemophiliac husband/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] or NO.

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses? I'm not sure, the solicitors action is ongoing and has been for a very long time (too long). lets put an end to this and carry on with life!

38) What do you think about the media response to the infection of haemophiliacs/wives partners with blood borne viruses?

Not really heard a lot in the media.

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

40) What if anything helps you to maintain a positive outlook on life?

many haemophiliacs have died whilst I have Known my husband, I consider him to very lucky in that way (not in many others), I don't really have a positive outlook, he does probably more than me I think,
I constantly worry about which disease or problem he will get next.

THANK-YOU FOR FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

QUESTIONNAIRE FOR WIVES/PARTNERS AND WIDOWS/BEREAVED PARTNERS OF HAEMOPHILIACS

1) Please circle the following description which is most appropriate to you

wife / partner/ widow / bereaved partner.

2) What is your age? Please state...50**....**

3) What is your ethnic origin? (White British, Scottish Pakistani etc) Please

specify....IRISH**.................................**

4) What does the word "blood" mean to you?

The red fluid that supplies oxygen to the heart, that carries many different antibodies to the various parts of the body
Supplies the energy to muscles for motive actions

The highway to existance as a mammal actions, heart, mind, and reaction, all need the fluid of life, Blood,

5) What does the word "haemophiliac" mean to you?

a person whose blood does not have the ability to clot. When any mammal has lesions either internal or exteral without the capability of clotting the ~~mammal~~ Person would eventual bleed until such a time, the brain would be starved of oxygen and death would follow as a result.

6) What do you think the word "haemophiliac" means to the general public?

I believe the public would only remember the factor eight scandle of blood product contanication, the unmeadeate thing that would spring to their mind would be H.I.V

7) Are you HIV positive? Please circle one of the following YES, [✓ NO] DON'T KNOW.

8) Is/Was your haemophiliac husband/partner HIV positive? Please circle one of the following [✓ YES], NO, DON'T KNOW.

9) What do the words "HIV positive" mean to you? Please explain.

It means the "death penalty" no possibility of a family or a normal relationship more hospital visits, "stigma attached to it" a sexual transmitted disease, predominately within the gay community rarely within the hetrosexual community. drug addicts Who would have thought that a haemophileac with all the problems associated with it would end up in such dire straights Normal life ceased to exists for the next 15-20 years

10) Are you HCV (hepatitis C) positive? Please circle one of the following YES [✓ NO], DON'T KNOW.

11) Is/Was your haemophiliac husband/partner HCV (hepatitis C) positive? Please circle one of the following [✓ YES], NO, DON'T KNOW.

12) What do the words "HCV (hepatitis C) positive" mean to you? Please explain.

another death sentence, heaped on top of all the existing problems. yet another situation that has to be dealt with, a disease of the liver. caused by factor 8 not been screened properly, after all the pain of H.I.V yet another mistake.

13) Was your haemophiliac husband/partner ever exposed to variant CJD through blood products? Please circle one of the following YES, NO, [✓ DON'T KNOW]

14) What do the words "exposed to variant CJD" mean to you. Please explain.

Mad cow's disease, another mistake. I'm sure that my husband was exposed I have no proof of this. however the symptoms that he displayed as his illness advanced showed clear signs and co-incided with those that were described within the media publicity of the day
Yet another mistake by the Health Service and Government!

15) Would you describe yourself as "disabled"? Please circle [✓ YES] or NO.

No one could deal with the trauma such as this and not end up with a permanent legacy and flashbacks

16) Would you describe haemophiliacs as disabled? Please circle [✓ YES] or NO.

17) What does the word "disabled" mean to you? Please explain.

Someone whose health in any form puts them at a disadvantage to that of an able bodied/mind person, this has degrees of disadvantage that is measured by the benefits system, many occasions this process produces unfair results. medical practitioners and experts should be more involved in the process

18) Have you ever been a carer? Please circle [✓ YES] or NO?

19) If the answer to Question 18 is YES, please answer the following question.

Are/Were you a carer to your haemophiliac husband/partner? Please circle [✓ YES] or NO.

20) Have you ever required a carer to assist with your daily living? Please circle YES or [✓ NO.]

21) If the answer to question 20 was YES please answer the following question.

Is/Was your haemophiliac husband/partner your carer? Please circle YES or [✓ NO.]

22) What does the word "carer" mean to you?

a carer has many meanings, those that care for others. that the local authorities determine are unable to care for themselves and need the protection of the state / public, the community care act enabled this, following the acceptance of the human rights act in 1996. for my-self, it meant 24-7 'care' of my partner/husband will very little reward or respite.

23) How do you think the medical profession has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

We have had no support whatsoever, we have saved the government untold millions and in return they appear to be oblivious to our everyday needs.

There is no real support network, no interaction between what we were put through and the lasting effects that this has on anyperson

24) Do you feel that doctors treating haemophiliacs and their wives/partners have always sought "informed consent" (where appropriate) in relation to their medical treatment and testing for HIV/HCV? Please circle one of the following YES [✓ NO,] DON'T KNOW.

25) If your answer to question 24 was NO. Please explain why you feel that "informed consent" was not sought by doctors treating haemophiliacs/ wives/partners.

My husband was 'never' told that he was H.C.V positive he had to ask, even after the medical profession new, they tried to keep it from us, similarly he was never refered to an H.I.V. clinic, he had to persue this in-order to get the appropriate treatment. Allways it was a battle the curtains were closed once the contamination was realised, they new that compensation would be an issue therefore from day one they closed ranks the fight was on

26) How do you think the government has responded to the contamination of haemophiliacs/wives/partners with blood borne viruses?

By compairision to any other group thalidamide etc, very poorly and that exists to-day, the levels of compenstion compared to the hours of work in caring for a loved one is placed in such low esteem and value by the goverment. should such 'care' been provided by the state, the minimum cost would exceed £290.00 per week, thats the cost of a day in hospital x by week x years the cost would equate to £1,000,000s.

27) Is/Was your haemophiliac husband/partner a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO?

28) Are/Were you a registrant of the Macfarlane Trust? Please circle [✓ YES] or NO.

29) If the answer to question 27 or 28 was YES please answer the following question.

What do you feel about the service provided by the Macfarlane Trust?

The trust has responded with adequate support, however the social service dept's are almost un-aware of its existence and we have to constantly suffer the opening of wounds by having to explain to the social services where my money is sourced and why the interest is exempt from social service calculation of benefits in addition, the trust appears not to voice its muscles in gaining adequate compensation and support. to those left behind, often the visual appearance of the beneficiaries of the trust betrays the actual turmoil that goes through the mind. the damage done will last the rest of their life

30) Are/Were you a recipient of the Skipton Fund? Please circle YES or NO?

31) Is/Was your haemophiliac husband/partner a recipient of the Skipton Fund.

Please circle YES or [✓ NO?]

32) If the answer to question 30 or 31 was YES please answer the following question.

What do you feel about the level of payment(s) provided by the Skipton Fund?

Please explain.

33) What do you feel about the fact that most widows/bereaved partners of HCV infected haemophiliacs were excluded from receiving payment from the Skipton Fund?

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 time of there lives, during which time we were the unforgotten army of carers that were left to cope with the most devastating things that one could every encounter within a life time, it would appear that successive governments have exploited the love of the partners of the people that received contamination of factor 8.

34) What are your feelings with regard to the international plasma companies that supplied contaminated treatment?

unlike, the drug companies that produce defective drugs and face colossal compensation claims and rewards these people - corporations have the external appearance of getting of the hook very lightly to the great disadvantage of those affected.

35) How do you feel the national Haemophilia Society has responded to the contamination of haemophiliacs/wives /partners with blood borne viruses?

The society still wrote letters four years after my husbands death, Whilst he was alive the society didn't do much for my partner. The only comfort was that they put me in touch with Carole.

I invited the Society to the hospital to see just how my partner was treated they failed to shown then, and the support since has been the same.

36) Have you or your haemophiliac husband/partner ever been involved in legal action in relation to contamination with HIV and/or hepatitis C? Please circle [✓ YES] * or ~~NO.~~ * only with the group

37) If the answer to question 36 was YES please answer the following question. How do you feel the legal profession has represented haemophiliacs/wives/partners infected with blood borne viruses?

They sold the group short, we were told If we didn't accept the offer we were on our own. Blackmail is the term that should be used clearly exploited!

40) What if anything helps you to maintain a positive outlook on life?

My own optimism that everything that happens must have an ultimate purpose,
It is difficult, the legacy that being a a carer in this situation obviously has effects that will last for the rest of my life.
I take life day by day, treasuring the good days trying to put behind me the bad days.

The stress that was induced through this time of my life will of course have lasting effects until the day I die thats something we have to exist with, and learn to live with,

My only wish is that the social services, and associated departments are made wholly aware of these facts, and leave us to decide where and when we feel well enough to move one with ourlses

THANK-YOU FOR FILLING IN THIS QUESTIONNAIRE

Carol Grayson 25/7/2006

38) What do you think about the media response to the infection of haemophiliacs/wives partners with blood borne viruses?

The media interest involve the sensationalism of the viruses, which of course has a public response that creates fear, rather than understanding, once the mileage in the fear factor disappeared so did the media coverage.

39) Please describe what you feel has empowered or disempowered HIV/HCV haemophiliacs and their families in their fight for justice and recognition of their infection? (You may wish to consider particular organisations in relation to this question.)

It is somewhat difficult to evaluate what any organisation has contributed to the fight for justice, when dealing with an emotive situation that has clear consequence for anyone trying to obtain justice. (In this country and that of most of the western world the claimants would be subject to public scrutiny should they take on the blood processing companies) Trusts etc would argue that they are doing their utmost whilst maintaining anonymity of the claimant, ~~et~~ in our case we are in a catch 22 situation that has been

Carol Grayson

From: "Martin Harvey" <Martin@macfarlane.org.uk>
To: "Carol Grayson" <c.grayson625@btinternet.com>
Sent: 07 August 2006 14:14
Subject: RE: dissertation

Carol

Thank you for your note, my comments are as follows:-

1) Clearly successive governments have continued to support the Macfarlane Trust and it is fair to say that the level of support has broadly kept in line with inflation. What I believe has not happened is that the required level of support in terms of cash values, from the inception of the Trust, was never properly analysed and as a result although the cash flowing has kept pace with, say, the RPI the ability of the Trust to meet the increasing demands of support through longevity and other factors identified in the Long Term Review (as explained in the recent submission for an increase in the level of funding) has been problematic for the Trust in operational terms in trying to meet the implied commitments of governments since the late 80s and, more importantly, has placed the beneficiary community as a whole in a position which some might see as running counter to the spirit of various implied commitments given.

2) From my own point of view, I believe the Trust since its inception has responded well within the means available to it. Our emphasis has shifted to try and generate a culture of support that helps people to live rather than (certainly in 1988) helping people to pass on. Again, the business case submitted to the DH fully reflects these objectives.

An area of difficulty for the Trust is trying to meet the needs of individuals and working within a policy framework where, by its nature, one size has to try and fit all which of course is not the case.

I am quite prepared to accept that while I may think the Trust has responded well within the means available, I fully concur with the long-held view that our registrants should not have to rely upon a charitable trust that (by its own analysis) cannot meet all the demands placed upon it and the feeling of "begging" for assistance flows through.

All beneficiaries, not unreasonably, believe their case to be one that the Trust should support. I can do no better than quote one of our member trustees who said that "I(he) is running out of reasons to say no". Within the policy faremwork, difficult choices have to be made.

3) The constraints are both financial in terms of both resources for support and resources for management in the sense that we do not have sufficient to employ the skill-base we need thus the reason for outsourcing the professional support services (counselling, advice on benefits etc) to the likes of the THT where we can procure and afford a national service but where it would be impossible to employ the sort of professional cover the THT, for example, can provide.

I am not sure that what we are providing at the moment is wrong, what we need is enhanced funding to do more. Again, I would refer to the business case.

Carol, thank you for the chance to comment.

Martin Harvey
Chief Executive
Direct Dial: 020 7808 1179
e-mail: martin@macfaralne.org.uk

BS

From: Carol Grayson [mailto:c.grayson625@btinternet.com]
Sent: 01 August 2006 17:01
To: Martin Harvey
Subject: dissertation

Hi Martin,
My dissertation is entitled "Blood flows not just through our veins but through our mind. How has the global politics of blood impacted on the UK haemophilia community?

I would be grateful if you could give me a written comment on the following questions.

1 How do you feel successive governments have responded to the infection of haemophiliacs with HIV/HCV?

2 How do you feel the Macfarlane Trust has responded to the needs of infected haemophiliacs and their families?

3 What constraints have been placed on the Trust and what services would you like to provide if financial limitations were not an issue.

Please could you also send these questions to Peter Stephens if he wishes to comment. My new e-mail address is c.grayson625@btinternet.com

Rang Stopes- Rowe, quote " I couldn't possibly comment. We make government policy not comment on it." He then wished me luck with my dissertation!

Thanks

Carol