Press release.
Letter 18 June
BLO 4 * - Joan, can you pl. file on the left hand side of the files. thanks

GRO-C

Blood Policy – updated 22 June 2004

HEPATITIS C EX-GRATIA FINANCIAL ASSISTANCE SCHEME

Lines to take

Why isn't the scheme providing payments to widows or dependants?

In your letter you express disappointment that the ex-gratia financial assistance scheme has not been extended to dependants of those who have died following inadvertent infection with hepatitis C. This was not an easy decision to make, but I think it is important to stress that the underlying principle of the payments is that they should be targeted to help alleviate the suffering of people living with the virus.

The payments are not designed to compensate for bereavement, although I fully appreciate the hardship and pain experienced by families who cared for loved ones who have died. I realise that this is little consolation, but hope that you can understand that the health care budget is not unlimited.

The payments too small

I believe that the scheme strikes the right balance and ensures that we are able to make value for money payments while not adversely affecting the rest of the health service. The payments are fair and reasonable and I hope that they will go some way to help improve the lives of those who have been inadvertently infected.

Comparisons with Ireland/Canada

You ask why the payments are less than those made in other countries, in particular [the Republic of Ireland or Canada]. It is important to make a distinction here. The awards being made in, for example the Republic of Ireland and Canada, follow public inquires and criminal charges which established that wrongful practices were employed. The payment structures of these schemes are therefore based on claims for punitive damages. We do not acknowledge any such wrongful doing in England so these schemes are not comparable with our ex gratia scheme.

Further/Alternative line - Comparisons with Ireland/Canada

During a debate in the House of Lords on 25 March, the Parliamentary Under Secretary of State for Health, Lord Warner, made clear the Government's position on this issue. I would not wish to add to this response, but you may be interested to note the reference in the Official Report, which can be found under Column 796 of the Lords Report for 25 March 2004.
Lord Warner's answer –

My Lords, I am grateful to the noble Earl for giving me the opportunity to clarify the issue. My understanding of the position in Ireland, which has been *corroborated by officials in the Department of Health and Children in Dublin since my last utterances on the subject in the House, is that the Irish Government set up their hepatitis C compensation scheme following evidence of negligence by the Irish Blood Transfusion Service.*

A judicial inquiry, the Finlay report, found that "wrongful acts were committed". It is important to stress that the blood services in the UK have not been found to be similarly at fault. Compensation is therefore being given in very different, specific circumstances in Ireland that do not apply in the UK. I do not believe that the Irish scheme creates any precedent for us.

The awards being made in Canada follow a class action brought against the Canadian Government. The compensation from the federal Government is limited to those infected between 1986 and 1990. Subsequent inquiries found that wrongful practices had been employed, and criminal charges were made against organisations including the Canadian Red Cross Society. Those conditions in Ireland and Canada do not apply in the UK.

Insurance

In your letter you mention that you are having difficulty with insurance applications. We understand from the Association of British Insurers that applicants who are infected with hepatitis C should not automatically face increased premiums or refusal of cover. Because many people with hepatitis C will live out their normal lifespan and only a minority will develop advanced liver disease, there is a range of outcomes for insurance applications depending on the individual case. These will range from standard rates to a small weighting through to a greater weighting or refusal of cover. Please bear in mind that payments made by the Skipton Fund are not designed to compensate for refusal of cover.

Waiver

Recipients of payments made under the hepatitis C ex gratia payment scheme, known as the Skipton Fund, will not be required to sign any form of waiver. The decision not to include a waiver was taken to reinforce the fact that these are unconditional ex gratia payments, with 'no strings attached'.

The cut-off point of 29 August is unfair

In your letter you express disappointment that the payment scheme has not been extended to dependants of those who have died following inadvertent infection with hepatitis C. The announcement of a scheme on 29 August 2003 occurred after the Secretary of State had revisited this issue, and heralded the introduction of a scheme from that date. The difficult decision not to extend the scheme to people who had died before this date meant that it became an unavoidable cut-off point. We realise that these circumstances are not ideal, but have attempted to provide a pragmatic solution.

Current Position

On 3 June, I announced that the Skipton Fund, the body set up to administer the hepatitis C ex-gratia financial assistance scheme will launch and begin to process applications by 5 July. On 18 June officials wrote to (xxxxxx if on the mailing list) to update him/her on developments and how s/he should proceed with making a claim.

{contact either Philippe Bergeron or Zubeda Seedat to check if someone is on the mailing list}

For anyone who would like to make a claim – who is not on our mailing list

xxxx will be pleased to know that on 3 June, I announced that the Skipton Fund, the body set up to administer the hepatitis C ex-gratia financial assistance scheme will launch and begin to process applications by 5 July. I am enclosing a copy of the press release about the launch of the Skipton Fund.

I understand that xxxx contact~~s~~ details have not been registered on the Department's mailing list, therefore xxxx will need to contact the Skipton Fund directly for a copy of the Registration Form. The contact details for the Skipton Fund are included in the enclosed press release.

Will you review the eligibility criteria for the scheme?

I have to say that we do not have any plans to extend the eligibility criteria of the payments. I recognise that xxxx will be deeply disappointed by this response. I hope, however, that s/he will accept that careful consideration was given to the eligibility criteria before we reached our decision.

For persistent writers

I have great sympathy for those who lost loved ones as a result of these tragic events. However, I also realise that these words bring little consolation. Instead, I feel it is important to reiterate the reasons behind the decision not to extend the payment scheme to families of those who have died.

In making the decision it was essential for the four UK health departments to strike a balance between a desire to act compassionately and the need to provide a high quality service to all patients. The funds that have been allocated for ex-gratia payments, and the consequent scope of the scheme and the size of the awards, reflects the decision on where that balance should lie.

The available funds are being targeted to help alleviate the suffering of those living with hepatitis C infection. This group had to take priority, and therefore the scheme was not designed to compensate for bereavement

Why have you not consulted people on the scheme?

Since the announcement of the scheme officials have held meetings with a number of charitable organisations including the Haemophilia Society and haemophilia groups in Scotland and Wales, the Hepatitis C Trust, the Macfarlane Trust and the Primary Immunodeficiency Association. We chose to meet with these groups because of their involvement in the setting up of similar schemes and/or because of their large representative constituencies.

We have also considered the views of other groups and individuals through correspondence. We would be pleased to consider any further views you may have in writing.

Hepatitis B (NOTE: THIS IS THE LINE THAT WE HAVE BEEN USING BUT MAY NEED REVISING – please check with Zubeda Seedat before using this line)

I'm sorry to have to confirm that people infected with hepatitis B as a result of treatment with NHS blood or blood products will not be eligible for this scheme. The Government has great sympathy for people who were inadvertently infected with hepatitis B before the introduction of national screening in 1972, but has no plans to introduce a similar scheme for hepatitis B.

You may wish to contact the British Liver Trust who will be able to help with any questions you have about the hepatitis B virus. I have listed their address below.

British Liver Trust
Ransomes Europark
Ipswich
IP3 9QG
Tel. 01473 276326

I am sorry that I cannot help any further but wish you well for the future.

Alternative Hepatitis B line -

I am sorry that xxx contracted hepatitis B through contaminated blood. The decision to set up an ex-gratia payment scheme for people who were infected from hepatitis C through NHS blood and blood products was made by the Secretary of State for Health, following a careful review of the papers. As you may be aware, many patients were inadvertently infected with hepatitis C before the introduction of a national screening test in 1991. The review did not include those people who contracted hepatitis B.

I am sorry that xxx will be disappointed by this reply.

Sympathetic opening line on haemophilia patients infected with HIV and Hep C

I am very sorry that xxxxx was infected with hepatitis C. The Government takes the issues around haemophilia and blood products very seriously, and has great sympathy for anyone who has suffered harm as a result of NHS treatment. Ministers do understand the hardship and great distress that people with haemophilia and their families have suffered, first from HIV and then from hepatitis C, and deeply regret that so many people were infected through blood products.

Public Inquiry

I am aware that some people would like the Government to set up a public inquiry into this issue. We have great sympathy for those infected with hepatitis C and have considered the call for a public inquiry very carefully.

However, as previously stated, the Government does not accept that any wrongful practices were employed and does not consider that a public inquiry is justified. Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time.

It is important to stress that despite the Department of Health 's decision to make ex gratia payments, the position with regards to accepting liability has not changed. The Government does not accept that any wrongful practices were employed and does not consider a public inquiry justified. Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time.

Self sufficiency in blood products

Xxx has raised the issue of self sufficiency in blood products. In order to fully respond, I feel it is prescient to wait for the completion of an informal review of internal papers commissioned by Yvette Cooper in 2002.

This review is being undertaken by the Department of Health to clarify the facts surrounding the drive for self-sufficiency in blood products in the UK in the 1970s and 1980s. A draft report has been prepared, however there are a number of outstanding issues that need to be addressed before the report can be finalised. I am aware that it has been some time since the review was first commissioned and have therefore asked officials to commission further work so that we can complete the report as quickly as possible. We will of course, let xxxxx know when the report has been completed.

Exclusion of gay men donating blood

Thank you for your letter of xxx to xxx enclosing correspondence from your constituent xxxxxxxxx about gay men donating blood.

The Government has a duty to ensure that any rules applied to blood donation by the National Blood Service (NBS) achieve a balance between risk reduction and security of supply. The self exclusion criterion concerning gay men has been reached through a close analysis of the epidemiology of confirmed HIV and Hepatitis B positive tests among blood samples from people donating blood at UK Blood Service sessions.

The Government has been advised that every year from the analysis of nearly 3 million donations collected by the UK and Irish Blood Services, about 40 donations are confirmed to be positive for HIV. Of these, approximately half are given by men who, following further enquiries by the NBS, reveal that they are gay men. Some are donating for the first time but some have given at least once in the previous two years and tested negative on the previous occasion. These figures indicate that some gay men are still giving blood in spite of the current rules.

I am aware that gay men have supported safer sex campaigns that have been very successful in reducing HIV transmission in the UK, but still around 1,500 gay men are diagnosed with HIV each year. Safer sex will keep most gay men free from infection, but the risks are still higher than for other groups. There may well be healthy gay men who would otherwise be suitable for giving blood but who are excluded from the rule.

Current screening tests for blood still fail to pick up people with very early infection. This is called the window period when people with HIV have not yet developed markers of HIV infection. We are also concerned about viral hepatitis (hepatitis B virus and hepatitis C virus). Advances in technology and science are helping to reduce this significantly, but it is still a risk.

All the exclusion criteria for blood donors have been discussed by the Joint UK Blood Transfusion Services and National Institute of Biological Standards and Control Professional Advisory Committee (JPAC). This group comprises of over 100 members, and includes experts from outside the Services and in some cases "lay" membership. The overriding remit of the JPAC is to set standards to ensure as far as possible the safety of the blood supply, and the welfare of the donors themselves. The criteria has also been discussed by the Government's Expert Advisory Committee on Microbiological Safety of Blood and Tissue for Transplantation (MSBT) and the Expert Advisory Group on AIDS (EAGA). EAGA membership includes representatives from the HIV/AIDS voluntary sector.

The decision by the NBS is based on scientific grounds. The NBS donor exclusion criteria will be reviewed annually in the light of updated epidemiological evidence

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Regular (persistent) correspondents

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