[redacted]

58

From: [redacted]
Sent: 16 December 2003 09:03
To: Minister for Health and Community Care
Cc: Deputy Minister for Health and Community Care; PS/HD Health; Press Health; [redacted] Keel A (Aileen) [redacted] Gordon IW (Ian); [redacted]

Subject: HCV ex gratia scheme - draft letter to HCCC

[redacted]

When I spoke to colleagues in DoH yesterday they seemed to think there was a real prospect that the press announcement would occur on either Thursday or Friday this week. That being the case, things could develop quite quickly and I am taking the precaution of sending you this draft letter now, even though the press release that will be attached to it is not yet available. The issue date and times needs to be timed to be coincident with the press announcement (and not precede it).

I intend to send a letter to Philip Dolan under my own name, unless Mr Chisholm would prefer for it to go out under his signature.

[redacted]

Letter to HCCC re scheme param...

Coat tails re loss of amount

28

From: [redacted]
Health Planning & Quality
11 December 2003

Comment: This information should only be included here if your name and the date would not otherwise appear on page one.

Minister for Health & Community Care

'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION

Purpose

Comment: Minutes should ALWAYS begin with sections on Purpose and Priority and end with a Recommendation OR Conclusion.

To seek Ministers endorsement of the detailed parameters that will apply to the scheme and for the proposals for administering it.

Priority

Comment: Where possible, put minutes forward at least 5 working days before a response is required.

Immediate. Department of Health(DH) are proposing that there is a joint announcement by the four UK Health Ministers on either 18 or 19 December and Mr Chisholm will wish to inform cabinet colleagues before this.

Discussion

1. This minute outlines the proposals jointly agreed by officials of the Scottish Executive, DH, Welsh Assembly government and Northern Ireland administration. The basic parameters already announced in Scotland are retained (i.e. £20k basic award, £25k on reaching medical trigger, no payments to those who clear the virus spontaneously or to dependants of those who died before 29 August) but are augmented to cover detail on eligibility, supporting evidence and on how the scheme would be administered.

2. Proposed parameters are attached as Annex A, proposed administration as Annex B and commentary on both at Annex C. These are summarised at Annex D.

3. Officials in the other administrations will simultaneously be submitting minutes to their Health ministers making the same proposals. It is expected that John Reid, Secretary of State, will then contact the other Health ministers to seek agreement to the proposals and the date and content of a joint announcement.

4. Following on the announcement, work will proceed to establish the administration of the scheme and to amend social security regulations and regulations that apply to housing improvement and repair grants and to residential care charging. Once the scheme administration has been established and legislative changes are in hand, it is proposed that there will be a high profile media initiative to inform potential beneficiaries as to what they need to do to apply for awards. This will be backed up by proactive approaches to people are very likely to have been infected (including all haemophiliacs) and to people who have already registered an interest.

Comment: This section MUST BEGIN ON THE FIRST PAGE. If – but only if – it involves more than 5 lines of text it can continue onto a second page. If the *Recommendation or Conclusion* section involves 5 or fewer lines of text, the minute MUST BE RESTRICTED TO ONE PAGE – although the Minister's comment box and the copy list may extend onto a second page. Include either a Recommendation OR a Conclusion – a Recommendation if the minute recommends a specific course of action, a Conclusion if it does not.

Recommendation

Comment: The whole of this section should be typed in bold type. Where appropriate, it should include cross-references to material set out in annexes. Where the minute recommends a specific course of action, provide a precise statement of ALL the recommendations which the Minister is being asked to agree (set out point by point). Where the minute invites the Minister to express a view or make a decision (but does not recommend a specific course of action) provide a precise statement of ALL the issues on which a view or decision is sought (set out point by point). If the minute is for information only, provide a clear, succinct distillation of key facts and conclusions.

5. **That Ministers endorse the attached proposals for administering the scheme and for the detailed parameters that will apply to it.**

[redacted]
Health Planning & Quality [redacted] 12 December 2003

Copy List:	For Action	For Comments	For Information		
			Portfolio Interest	Constit Interest	General Awareness
First Minister					X
Deputy First Minister					X
Minister for Finance and Public Services					X
Minister for Parliamentary Business					X
Deputy Minister for Parliamentary Business					X
Deputy Minister for Health & Community Care					X

PS/Perm Sec	[redacted] Directorate of Performance Management & Finance
Cabinet Secretariat	[redacted] Directorate of Performance Management & Finance
PS/FCSD	**Dr Aileen Keel, DCMO**
PS/HD	Ian Gordon, Directorate of Service Policy & Planning
Andrew Baird, Head of Press	[redacted] Health Planning & Quality
Press First Minister	[redacted] Constitution Unit
Press Health	[redacted] OSSE
Jeane Freeman, Senior Special Adviser	[redacted] Community Care Charging
Sam Ghibaldan, Senior Special Adviser	[redacted] Development Department (Housing Division)
Douglas Campbell, Senior Special Adviser	
Matthew Clark, Special Adviser	
Liam McArthur, Special Adviser	
Policy Unit	
PFO	
Lord Advocate	
CMO	

Comment: Annex D of the Guidance on Preparation of Minutes to Ministers provides advice on the construction of copy lists – including a flow chart which provides an easy-to-use mechanism for applying the guidance. For Ministers, mark the relevant box (or boxes) with an 'X' to indicate why the Minister is being copied in. Where a paper contains details of Financial Implications, the Minister for Finance and Public Services must be included on the copy list – and the Portfolio Interest box should be marked with an 'X'. Delete any unused rows or insert additional rows if required. For officials, include details of their Department and Division. Only use group names in copy lists if there is a relevant e-mail distribution list.

Comment: Click in the field below and then click on Option(s) from the toolbar to select a pre-set copy list. Note that you may choose any combination of Options. However, since Options 2 and 3 are subsets of Option 1 you should NOT select Options 2 or 3 if you have already selected Option 1. OPTION 1_Officials: Select this option if the minute relates to a matter which is, or may become, the subject of significant media interest. OPTION 2_Officials: Select this option if the minute conveys advice on a significant or sensitive policy issue and you have not already selected Option 1. OPTION 3: Select this option if there are significant or sensitive presentational issues and you have not already selected Option 1. OPTION 4: Select this option if there are significant financial implications. Once you have selected the relevant options, you will need to complete any variable fields within the pre-set lists (eg 'Relevant Press Office Desk'). If you select more than one option, please re-order the names appropriately and check for duplicates. Remember that ALL minutes to Ministers should ALSO be copied to other Ministers with an interest, PS/Relevant Departments, Relevant Group Heads, Relevant officials in other areas and relevant Special Advisers. More detailed guidance on the construction of copy lists is set out in Section 5 of the Guidance on Preparation of Minutes to Ministers.

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ANNEX A

'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION

PROPOSED SCHEME PARAMETERS

Eligibility date

- No payments will be made in respect of people who died before 29 August 2003.
- Where people die before the scheme is in a position to make payments, and their circumstances and medical condition would have satisfied the eligibility criteria on 29 August 2003, then the awards will be made to their dependants.
- Once the scheme is in a position to make payments, then awards will only be made in situations where a claim has been received from the infected person. If the infected person dies without making a claim then an award will not be made to their dependants.

Eligibility for Basic Award of £20,000

Criteria

- Potential beneficiaries will receive the basic award of £20,000 if they have been infected with Hepatitis C as a result of being provided by the NHS with blood or blood products before September 1991.
- People who have been infected with Hepatitis C as a result of the virus being transmitted from a person who themselves was infected as a result of being provided by the NHS with blood or blood products before September 1991 will be treated identically to those directly infected.
- People who have received payments from the Macfarlane Trust, Eileen Trust or Special Payments Scheme in respect of infection with HIV, and who have also been infected with Hepatitis C, will be treated identically to those who have only been infected with Hepatitis C.

Required supporting evidence

- Claimant received relevant treatment – *statement by clinician*
- Claimant infected with Hepatitis C – *statement by clinician*
- People who have had a liver transplant – *would only need to establish that they had originally been infected with Hepatitis C, not that they are still infected.*
- People who have cleared the virus as a result of treatment – *would only need to establish that they had originally been infected with Hepatitis C, not that they are still infected.*

- The Hepatitis C infection was caused by the NHS treatment:
  - For people who have received a pooled product – *statement by clinician confirming that the claimant had tested PCR positive would suffice as proof of causation.*
  - For other people – *causation should be corroborated by reference to archived samples where these are available.*
- Where definitive evidence on any of the above is lacking, then such evidence as does exist should be accepted if it establishes the facts "on the balance of probabilities".
- "Balance of probabilities" should be determined by reference to general rules set down by an appointed independent panel or, where more appropriate, decided by the panel on a 'case by case' basis.

Eligibility for additional payment of £25,000

Criteria

Potential beneficiaries who satisfy the basic eligibility criteria will receive the additional award of £25,000 when it is established that they have cirrhosis, liver cancer or have received a liver transplant.

Required supporting evidence

- cirrhosis:
  - liver biopsy results (if already carried out in the course of normal treatment), OR
  - results of non-invasive tests (as specified by hepatologists expert group) that have been carried out in the course of normal treatment.
- liver cancer – statement by clinician
- liver transplant – statement by clinician.
- in the event that doubt still remains about any relevant medical aspect, then an appointed expert medical panel will adjudicate on a 'case by case' basis – using the "on the balance of probabilities" principle.
- the medical panel may commission additional non-invasive tests specifically for the purpose of informing their judgement.

Exceptions to the general scheme parameters

- People who have cleared the virus spontaneously will not be eligible for either the £20,000 or the £25,000 award.
- People who have received a liver transplant will receive both the basic and additional awards.

Variations to awards

- People who have received compensation as the result of a successful legal action against the NHS (or an out of court settlement in relation to a legal action) in respect of a situation satisfying the basic eligibility criteria for this scheme would have that compensation/settlement deducted from the total award made under this scheme.
- People who have received compensation as the result of a successful legal action against a product supplier in respect of a situation satisfying the basic eligibility criteria for this scheme, would have that compensation deducted from the total award made under this scheme.

Conditions attached to awards

- People who receive payments under the scheme would undertake not to institute future legal proceedings against the NHS or Ministers in relation to the situation that formed the basis of those payments.

Lifetime of scheme

6. Given that it may take 20-30 years for Hepatitis C infection to progress to the stage where the additional £25,000 payment would be made, it will be necessary to maintain the capability to make payments under the scheme for at least another 20 years and probably longer – although the number of payments in the latter years will be very small.

ANNEX B

'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION

PROPOSED ADMINISTRATION ARRANGEMENTS

Single UK scheme

1. It is proposed the four UK administrations operate essentially identical schemes with identical awards and that the most efficient way of dealing with this is for payments on behalf of all four administrations to be handled as part of a single UK scheme –administered by a single independent Trust.

2. It has been suggested that this might be named Skipton Trust. The basis for this is that the substantive negotiations between officials of the four administrations took place in Skipton House, London. This would continue the precedent set by the Eileen Trust which was named after Eileen House.

3. The Macfarlane Trust has agreed to take on the task of setting up and administering the new Trust.

Financial arrangements

4. The four administrations would be billed by the Trust for awards paid out to beneficiaries attributable to the relevant country. The logical method of attribution would be that the beneficiary had been infected as a result of treatment in that country. An alternative would be that the beneficiary was currently resident in that country. This alternative method would only be acceptable if significant savings in administrative process were likely and estimates showed that the method would not materially alter the split between the four countries.

5. Department of Health would take the lead in dealing with the new Trust. The four administrations would contribute to the establishment and running costs of the Trust and possibly also to an initial working capital fund. It is likely that the basis for these contributions would be the population ratios between the countries.

Verification of claims

6. Claimants would be asked to submit evidence in support of their claims via a standard form – which would be vetted as a clerical exercise and, where appropriate, corroborative evidence (such as archived specimens) accessed and checked.

7. An independent panel (or possibly two separate panels) would decide on medical and non-medical evidence where it was not straight forward.

ANNEX C

'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION

KEY ISSUES

Comment: Where the minute invites the Minister to take a decision, or express a view, on a substantive issue this note should outline the key issues that the Minister will wish to take into account in reaching that decision/view. The note MUST NOT EXCEED ONE PAGE. Where necessary, more detailed information should be provided in further annexes and cross-references included in this note. The Key Issues note should however be capable of being read independently of the annexes. SUB-HEADINGS MAY BE DELETED IF NOT REQUIRED.

Comment: Outline here any particular sensitivities associated with the proposals.

Sensitivities

1. The Haemophilia Society has been made aware of the likely scheme parameters and believes them to be unacceptable. This is principally because they feel the awards are too low and because no payments are to be made to the dependants of those who died before 29 August. Payments to dependants of the deceased were included in their own proposals to DH, in the recommendations of the Expert Group to the Scottish Executive, and the MacFarlane and Eileen Trusts made such payments.

Financial Implications

2. Statistical estimates indicate that 1165 people infected in Scotland might still be alive. It is assumed that 580 of these would come forward within the first 3 years of the scheme – requiring an outlay by the Scottish Executive of £15m on awards. In the unlikely event that all the 1165 claimed the eventual cost to the Scottish Executive of making awards would be £30m. These estimates exclude cost associated with awards to those contracting the virus from someone who was themselves infected via blood or blood products, but these are thought to small.

Presentation and Parliamentary Implications

3. In the event that all four UK Health Ministers agree that the scheme should proceed on the basis described, then Press Health and special advisers will need to liaise urgently with the other administrations (particularly Department of Health) to develop a common approach to the media. This approach should attempt to emphasise positive aspects (compassionate gesture, non-bureaucratic path for making claims, independent nature of administration and scrutiny arrangements) whilst recognising that challenges will be made regarding award levels being too low and dependants of the deceased being excluded.

4. These challenges may be also be made in the Scottish Parliament. However, the Health and Community Care Committee has recently decided that it does not intend to pursue the 'HCV from Blood' issue any further unless new evidence comes to light. The Committee's decision includes an acceptance of the broad parameters of the ex gratia scheme as already announced – including the level of awards and the decision not to make awards to the dependants of those who have died before 29 August 2003.

Legislative Implications

5. [redacted]

[redacted]

6. DH advise that Department of Work and Pensions (DWP) have agreed to amend their social security legislation so that beneficiaries of the scheme will not lose means tested benefits. The amended legislation will come into effect in April 2004. Residential care charging regulations will be amended at the same time. Regulations on housing improvement and repair grants will also need to be amended so that payments to beneficiaries of the scheme are excluded from means testing.

Consultation

7. OSSE, Performance Management and Finance, Constitution Unit, Dr Keel (DCMO), Press Health, Community Care Charging, Development Department (Housing Division) have been consulted on relevant aspects of this submission.

Commentary on scheme parameters

Underlying philosophy

8. The underlying philosophy spelled out in previous public statements in Scotland is that establishment of the scheme is as follows:

- This is a compassionate gesture – not a tacit acknowledgment of liability or wrong doing.
- As such, awards are ex gratia payments – not compensation.
- Expenditure on scheme has to be balanced against the needs of other healthcare priorities (and the needs of other patients).
- This means only limited funding can be spared.
- Within the constraints of limited funding, the people who should be targeted for financial assistance are those who are still alive and suffering the adverse effects of being infected with Hepatitis C.

Medical trigger for additional £25,000 award

9. Expert hepatologists took the view that the stages of liver damage preceding cirrhosis were difficult to assess with non-invasive tests. Decompensated cirrhosis was easy to assess but by the time this stage had been reached life expectancy was low. Cirrhosis at the stage prior to decompensation therefore offered the best option for the medical trigger.

10. The experts believed that a number of non-invasive tests that are routinely carried out as part of normal treatment regimes could provide useful evidence of cirrhosis. In most cases combination of the results from a number of such tests would be sufficiently conclusive for the purposes of the scheme. This would avoid a situation where invasive liver biopsies (carrying a high risk for haemophiliacs) need to be conducted specifically to establish eligibility.

Co-infection with HIV

11. SCIEH report that 6.9% of those people infected with Hepatitis C via blood in Scotland who are still alive are co-infected with HIV. These people will have received payments from either the Macfarlane or Eileen Trusts in relation to their HIV infection. Experts do not believe that co-infection of itself results in significant additional suffering, but the treatment for Hepatitis C has more debilitating side effects than the treatment for HIV.

12. Macfarlane Trust has made it a condition of their involvement in scheme administration that their registrants are treated identically under the scheme as those only infected with Hepatitis C and John Reid, SoS Health, has indicated that England is prepared to concede this point.

Clearing the virus under treatment

13. Experts do not believe that people who have cleared the Hepatitis C virus under treatment continue to experience any residual ill health as a result of their infection. They do carry a small increased risk of liver cancer, but in the event that this was realised they would be eligible for the additional £25,000 award.

14. These people will have experienced past suffering as a result of their infection and the treatment, but this does not satisfy the underlying principle of the scheme to target those currently suffering. However, making them ineligible for the basic award would create an anomaly. This is because some people might receive the basic award and then subsequently clear the virus under treatment – putting them at an advantage over those who cleared the virus before the scheme cam into operation. It might also lead to people refusing treatment until after they had received the basic award. John Reid, SoS Health, has indicated that England is prepared to pay this category of patient.

Commentary on standard of evidence

15. The passage of time since the original infection means that potential beneficiaries face real problems in producing irrefutable evidence. In particular, clinicians who treated them may be retired or deceased, and hospitals may have difficulty in finding their medical records or may have legitimately destroyed them. In recognition of this it is proposed that the lower standard of "on the balance of probabilities" (rather than "beyond reasonable doubt") is adopted for evidence.

16. It is certain that virtually all blood products produced from pooled donations will have been infected with Hepatitis C. It is proposed that where claimants have received such products then no further evidence will be required to establish that they were infected via blood products. Virtually all haemophiliacs will fall into this category.

Health Planning & Quality
12 December 2003

ANNEX D

'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION

SUMMARY

Eligibility and awards

- £20,000 to people who were infected with Hepatitis C as a result of being provided by the NHS with blood or blood products before September 1991.
- £20,000 to people who have been infected as a result of the virus being transmitted from a person who themselves was infected as above.
- Additional £25,000 to people who are eligible for the £20,000 award when their condition progresses to cirrhosis, liver cancer or if they have received a liver transplant.
- No payments to those who have cleared the virus spontaneously.
- People co-infected with HIV will be dealt with in the same way as those infected only with Hepatitis C.
- People who have had a liver transplant will receive both the £20,000 and £25,000 awards.
- People who have cleared the virus under treatment will be dealt with in the same as those who still have the virus.

Payments to the 'deceased'

- No payments to dependents of people who died before 29 August 2003.
- Where people eligible on 29 August 2003 die before the scheme is in a position to make payments, awards will be made to their dependants.
- Once the scheme is in a position to make payments, awards will only be made to dependants where a claim has been received on behalf of the infected person prior to their death.

Variations and conditions

- People who have received compensation as the result of a successful legal action against the NHS (or an out of court settlement in relation to a legal action) would have that deducted from the total award.
- People who have received compensation as the result of a successful legal action against a product supplier would have that deducted from the total award.
- People who receive payments under the scheme would undertake not to institute future legal proceedings against the NHS or Ministers in relation to the situation that formed the basis of those payments.

Evidence

- Generally evidence will be judged on the balance of probabilities.
- It would be presumed that claimants with Hepatitis C who have received pooled products were infected by the product. (Virtually all haemophiliacs will fall into this category).
- No requirement for invasive tests to establish cirrhosis.

Administration

- Single UK scheme operating to common parameters in Scotland, England, Wales and Northern Ireland.
- Administered by a single independent charitable Trust.

Health Planning & Quality
12 December 2003

Hep C scheme.

[redacted]

From: [redacted]
Sent: 09 December 2003 15:45
To: Minister for Health and Community Care
Cc: Deputy Minister for Health and Community Care; PS/HD Health; [redacted]; Press Health; [redacted]
Subject: FW: Hep C scheme - further announcement
Importance: High

[redacted]

As discussed, [redacted] agreed with Mr Chisholm that we did not need to formally consult with cabinet on the issues covered by the submission mentioned below and associate announcement, since they have already agreed the principle of this scheme, broad principles of eligibility and the size of the awards – all that will be covered in the submission will be the details of eligibility and the proposed method of administering the scheme. Instead Mr Chisholm would write to cabinet colleagues informing them of what was in the submission and what he intended to do about it

I should be grateful for an urgent steer on whether, in responding to the proposed DH schedule below, we need to factor in any time to allow cabinet to respond to the letter from Mr Chisholm. As you can see what is proposed is very tight.

[redacted]

Any comment you wish me to include in the response?

[redacted]

Role of Westminster special advisers in early days of announcement

-----Original Message-----
From: [redacted]
Sent: 09 December 2003 11:45
To: [redacted]
Cc: [redacted]
Subject: Hep C scheme - further announcement

[redacted],

John Reid has agreed the proposal to include both co-infectants and those who have cleared the virus after treatment in the eligibility criteria of the hep C scheme. He has also agreed that dependants will not be added. Following this, he has indicated that he is keen to make a further statement on the hep c scheme and we are taking this as meaning before Christmas. I'd be grateful if you could let me know urgently if you foresee any difficulties with this or any insurmountable obstacles or delays ([redacted], I've not forgotten about the cabinet delay).

The likely programme is -

* Submission to the four Ministers with common annexes detailing the proposed eligibilty criteria and payment structure late this week/early next week
* Once agreed, media handling strategy prepared and announcement date set middle of next week
* Simultaneous announcement made ?18/19 Dec (either in

Parliaments/Assembly, at a press conference or through media statements?)

The Secretary of State's special advisers are currently considering when to make the announcement and are aware that it will need to be UK wide. I will let you know asap when we hear. In the meantime, grateful for your comments re. the above.

Thanks

[redacted]
GTN [redacted]

Jeane Freeman's secretary will copy to another adviser. 12/11 JJ

[redacted]

From: [redacted]
Sent: 12 November 2003 14:17
To: Minister for Health and Community Care
Cc: Deputy Minister for Health and Community Care; PS/HD Health; [redacted] Freeman J (Jeane)
Subject: HCV ex gratia scheme - paymens to dependents

Importance: High

[redacted]

It would be very helpful if you were able obtain a view on an important detailed aspect of the proposed scheme. It concerns how the 29/8 eligibility date works in practice. Ordinarily I would have run this past Jeane Freeman (since she was involved in the original decision on the 29/8 date). However, it looks as though the joint submissions to the 4 UK health ministers may be finalised some time next week – and, since Jeane is on leave until the 17th, that may be too late to influence the content of those submissions.

I am currently in discussions with other UK officials re the possibility of the scheme operating as below:

- No payments will be made in respect of people who died before 29 August 2003.
- Where people die before the scheme is in a position to make payments, and their circumstances and medical condition would have satisfied the eligibility criteria on 29 August 2003, then the awards will be made to their dependants.
- Once the scheme is in a position to make payments, then awards will only be made in situations where a claim has been received from the infected person. If the infected person dies without making a claim then an award will not be made to their dependants.

Following the announcement on 29/8, Mr Chisholm addressed the Health Committee and said:

"The first principle was that it should go to those who are still alive and suffering, although I hope my announcement of 29 August as the start date for the scheme reassures people that ***no one will be affected by the amount of time that it will take to get the administration of the scheme up and running".***

I have interpreted that as translating to the first two bullet points above (NB this would allow for posthumous applications and posthumous awards to be made in the period between 29/8 and the date when the scheme is in a position to make payments).

The question is – what happens after the scheme is in a position to make payments. I believe there are 3 possible options:

1] The scheme only pays out to those still alive. That means if someone dies between submitting their claim and receiving the payment, the claim fails and the dependants get nothing. This puts huge pressure on the scheme to process claims quickly. It could lead to accusations of trying to save money by slow bureaucratic processes.

2] The scheme pays all claims where the person satisfied the eligibility criteria on 29/8 – irrespective of whether the person is still alive at the time of making payment. This would allow posthumous claims by dependants even where the eligible person had not claimed prior

to death. This could be seen as contradicting the philosophy of not paying dependants of those who died before 29/8.

3] The 3rd option is as presented in the final bullet point above. This is a compromise – only allowing posthumous awards where the eligible person had submitted a claim prior to death.

If Ministers or advisers believe the 3rd option is the wrong one then it would be useful to know this week so that I can feed that into the discussions on the 'common submission to the 4 Health Ministers.

[redacted]

[redacted]

From: [redacted]
Sent: 27 October 2003 17:08
To: Minister for Health and Community Care
Cc: Deputy Minister for Health and Community Care; PS/HD Health; Press Health; [redacted] Keel A (Aileen) [redacted]
Subject: HCV from blood - Meeting between Melanie Johnson and Haemophilia Society [29 Oct 2003]

I attach a 7 page Urgent submission

[redacted]

Submission-rogress and MJ me.

From: [redacted]
Health Planning & Quality
27 March 2003

Header
Minster for Health & Community Care

'HCV FROM BLOOD' – MEETING BETWEEN HAEMOPHILIA SOCIETY AND MELANIE JOHNSON

1. To advise Ministers of a meeting between the UK Haemophilia Society and Melanie Johnson, MP, Parliamentary Under Secretary of State (Public Health), to discuss proposals for a UK-wide ex gratia payment scheme for people who have contracted HCV from treatment with blood products.

Priority

2. Urgent – relates to a meeting on 29 October.

Discussion

3. The meeting between Melanie Johnson and Michael Connarty MP – Chairman of the All-Party Parliamentary Group on Haemophilia and Karin Pappenheim – Chief Executive of the Haemophilia Society will take place on 29 October. A representative from the Manor House Group may also attend. The purpose of the meeting is to reiterate the Society's concerns about the parameters of the scheme (notably the size of the proposed awards and the fact that it will not pay the dependants of those who die before 29 August 2003) – as already noted in the Society's letter to Mr Chisholm of 30 September. There may be coverage in the Press that will have repercussions for Scotland.

4. There has been no public announcement concerning the details of the scheme beyond those already made by Mr Chisholm. However, the Society has been made aware (**on an 'in confidence' basis**) of official thinking on key aspects of the scheme – on the understanding that these were all subject to legal advice and ultimate sanction by Ministers.

5. I attach as Annex 1 an extract from the briefing provided to Melanie Johnson by DH officials. This can be used to inform any response to media approaches following from the meeting. It will clearly be important for Press Health to liaise with the DH Press Office to ensure a consistent approach and to avoid pre-empting the future announcements planned for the four UK Health Ministers.

6. The DH briefing also indicates the current state of play on scheme parameters following the most recent discussions between officials from the four UK administrations. A definitive proposal will be put to Ministers when a] further information is available on the willingness of the Macfarlane Trust to administer the scheme, b] detailed advice from expert hepatologists is finalised, and c] full consultations have taken place to establish legal, medical and financial constraints. Hopefully this will occur in less than three weeks time.

Conclusion

7. Ministers are asked to note a] the lines prepared by DH for the forthcoming meeting with the Haemophilia Society b] current thinking on scheme parameters.

Comment: This information should only be included here if your name and the date would not otherwise appear on page one.

Comment: Click here once then press the F11 key for link to field for Protective Marking in Header area. Please remember to type Protective Marking required in the Header and Footer areas of this document. See Security Intranet page on Protective Markings for full list of possibilities. If no marking is required please delete the fields in the Header and Footer areas. Finally, remember to delete this Hyperlink once Protective Markings are complete.

Comment: Headings should be short and descriptive – use significant key words.

Comment: Where possible, put minutes forward at least 5 working days before a response is required.

Comment: This section MUST BEGIN ON THE FIRST PAGE. If – but only if – it involves more than 5 lines of text it can continue onto a second page. If the Recommendation or Conclusion section involves 5 or fewer lines of text, the minute MUST BE RESTRICTED TO ONE PAGE – although the Minister's comment box and the copy list may extend onto a second page. Include either a Recommendation OR a Conclusion – a Recommendation if the minute recommends a specific course of action, a Conclusion if it does not.

Comment: The whole of this section should be typed in bold type. Where appropriate, it should include cross-references to material set out in annexes. Where the minute recommends a specific course of action, provide a precise statement of ALL the recommendations which the Minister is being asked to agree (set out point by point). Where the minute invites the Minister to express a view or make a decision (but does not recommend a specific course of action) provide a precise statement of ALL the issues on which a view or decision is sought (set out point by point). If the minute is for information only, provide a clear, succinct distillation of key facts and conclusions.

[redacted]
Health Planning & Quality
[redacted]

27 October 2003

Copy List:	For Action	For Comments	For Information		
			Portfolio Interest	Constit Interest	General Awareness
Deputy Minister for Health & Community Care					X

PS/HD
Press Health
[redacted] Health Planning & Quality
Dr Aileen Keel, DCMO
[redacted] Performance Management and Finance

Comment: Annex D of the Guidance on Preparation of Minutes to Ministers provides advice on the construction of copy lists – including a flow chart which provides an easy-to-use mechanism for applying the guidance. For Ministers, mark the relevant box (or boxes) with an 'X' to indicate why the Minister is being copied in. Where a paper contains details of Financial Implications, the Minister for Finance and Public Services must be included on the copy list – and the Portfolio Interest box should be marked with an 'X'. Delete any unused rows or insert additional rows if required. For officials, include details of their Department and Division. Only use group names in copy lists if there is a relevant e-mail distribution list.

ANNEX A

'HCV FROM BLOOD' – MEETING BETWEEN HAEMOPHILIA SOCIETY AND MELANIE JOHNSON

Comment: Headings should be short and descriptive – use significant key words.

EXTRACT FROM **BRIEFING PROVIDED FOR MELANIE JOHNSON BY DH OFFICIALS**

Comment: Repeat the heading used in the covering minute.

The Report "The Haemophilia Society's Hepatitis C Working Party"

The report was received in the Department from the Haemophilia Society on 31st May 2002 and detailed a package based on an estimate of 3641 people with haemophilia and hepatitis C as at 1 January 1993, **costing £522.6 million over ten years**. The model provided for five levels of payment to be made according to the stage the liver disease has reached with a formulae being used to calculate the amount of the award. The payments begin with £7,500 for those with hepatitis C and progresses through various disease states to decompensation of the liver, liver cancer or those who have undergone a liver transplant who would receive **£60,000**. There was also an allowance for dependants and family, for loss of earnings, inconvenience of drug therapy, expenses and costs towards care. The Scheme assumes payments would be made to dependants and family of those who have died regardless of whether HCV was identified as the actual cause of death.

Parameters , Exceptions and Variations to the Hepatitis C Scheme

1. Payments are £20,000 and £25,000 if a claimant reaches the medically defined trigger which at the moment is recognised as cirrhosis .

   Michael Connarty and Karin Peppenheim will reject this as being unacceptable and push for the five tier payments contained in the Haemophilia Society's report.

   The figures we are proposing will cost the Department £200m in total.

   The Haemophilia Society figures cost the Scheme at over £500m which the four Health Administrations cannot afford.

   The full payment of the proposed scheme i.e. £45,000 is in line with the minimum amount paid under the HIV Scheme.

The exact parameters for the second payment are still being worked up by a group of liver experts. The society will complain that only one haemophilia doctor has been involved – this is because the discussions are centered on liver disease.

2. People who have cleared the virus spontaneously would not be eligible for any payment.

   The Society appear to accept this point

3. People who have received payments linked to HIV infection from the MacFarlane Trust, Eileen Trust or the associated Government scheme of payments shall not be eligible for the basic payment. They will receive the additional payment if they reach the medically defined trigger point.

   This point will be contested on the grounds that co infection present a greater risk to their health and liver disease has become the leading cause of death within this group.

   The meeting of liver experts felt that although co infected patients progressed more quickly to cirrhosis this did not take into account treatments for HIV patients which may temper the effect of the hepatitis C infection

   The decision not to give them the basic payment is based on the fact that they have already received a payment for HIV.

   To make the basic payment could add an additional £9m to the cost of the scheme but this needs to be properly costed.

4. People who clear the virus under treatment shall only receive the second payment if they progress to the relevant point.

   The Society argue that these people should have the full payment because of the suffering caused during the course of the treatment.

   We cannot accept this position in that it could set a precedent for payment for past pain and suffering.

   In any event claimants will get the second payment in the unlikely event that they develop to the medical trigger caused by the hepatitis C virus from blood or blood products.

5. People who receive a liver transplant shall receive both the basic and the additional payment.

   The Society is happy with this proposal

6. People who have received compensation as a result of a successful legal action against the NHS (or an out of court settlement in relation to a legal action) shall have that compensation/settlement deducted from the total award made under this scheme.

The Society is happy with this proposal

7. People who have received compensation as a result of a successful legal action against a product supplier shall have that compensation deducted from the total award made under this scheme.

The Society is happy with this proposal

8. People who receive payments under this scheme shall undertake not to institute further legal proceedings against the NHS or Ministers as a result of being infected with Hepatitis C from blood or blood products received before 1991.

   The Society is happy with this proposal

9. No payments shall be made to relatives, dependants or estates of claimants who meet the eligibility criteria who deceased before 29 August.

   The Society is opposed to this proposal.

   This will be the main sticking point on which we cannot concede on grounds of cost.

   To do so could add approximately £360m to the cost although precise figures have still to be worked out.

   Social Security provisions exist for dependants of patients who have died following NHS treatment.

10. The proposed Scheme will cover the whole of the UK.

The Society support the fact that there will be single Scheme for the whole of the UK rather than four separate schemes.

All four Health Departments will help finance the Scheme on the basis either of current place of residence of claimants or address of health establishment where the infection occurred – this has still to be decided.

11. The Scheme will be administered by the MacFarlane Trust on behalf of all four Administrations.

The Society position is that the Trust should not administer the Scheme if their main concerns is not addressed.

The Macfarlane Trust have been approached the run the Scheme.

Their initial reaction was to express concern that they would be unable to do so if no payments were made to dependants or co infectants.

We have yet to receive their final answer.

If the MacFarlane Trust decide not to administer the Scheme then we will look to set up a separate Trust independent of MacFarlane.

11. Those claimants who had signed waivers as HIV patients on receiving payments from either the Macfarlane of Eileen trusts would still be eligible to make a claim under this scheme.

The Society is happy with this provision.

12. The Scheme is not time barred in that all payments must be made within a set time frame.

The Society is happy that there is no time frame within which to make a claim. This is particularly relevant for the second payment.

The amount of payment will remain the same whenever it is claimed – in other words the amount will not move with inflation.

The Scheme will remain in force until the last patient is presumed to have died.

13. The level of payments will be subject to disregard for social security and tax credit purposes.

The Society is happy with this provision.

Discussions have taken place with DWP and the Treasury and Secretary of **State is writing to Andrew Smith and Dawn Primorolo asking for this to be taken forward.**

The relevant changes to the relevant DWP Regulation will come into effect 1 April 2004.

14. Intimates infected, say either sexually or mother to baby, should receive payment under the Scheme.

The Society has not raised this issue but it is something we are looking into.

15. The eligibility criteria are those infected with blood and blood products before the appropriate safety tests were introduced in 1991.

The Society is happy with this.

16. Claimants will need to provide evidence that they meet the various criteria in the Scheme

The Society are content that claimants who received blood products from pooled blood before the relevant date need only provide basic back up data.

[redacted]

[redacted]

-----Original Message-----
From: [redacted]
Sent: 27 October 2003 09:11
To: Minister for Health and Community Care
Cc: [redacted] PS/HD Health; Press Health; Gordon IW (Ian); Deputy Minister for Health and Community Care
Subject: 'HCV from blood' - possible Cabinet paper

[redacted]

I attended a meeting of UK officials on Friday to discuss detailed proposals for the ex gratia scheme. I now looks as though we might be in a position to make submission to the 4 UK health ministers around about 12 November. I am assuming that Mr Chisholm will wish to put the matter to Cabinet shortly afterwards. Pleas could you check that he does wish to put it to Cabinet – in which case I will attach a draft cabinet paper to the submission and provisionally book a slot at the 18 November Cabinet meeting.

I will provide briefing on progress later this week.

[redacted]

[redacted]

From: [redacted]
Sent: 23 October 2003 16:28
To: Minister for Health and Community Care
Cc: Deputy Minister for Health and Community Care; PS/HD Health; [redacted]
Keel A (Aileen); Press Health; [redacted]
Subject: UK Haemophilia Society view on Hep C ex gratia scheme

[redacted]

Further to my recent note on the meeting last week between UK government, Scottish Executive and Welsh Assembly government officials on the one hand and representatives of the Macfarlane Trust and haemophilia charities on the other – I have now received a copy of the UK Haemophilia Society's response. This was sent to DoH as they chaired the meeting. A copy of this letter is in the mail to both you and Press Health.

The letter details five major concerns:

- size of payments,
- no provision for dependants of those who have died before the eligibility date,
- no payments to those who have cleared the virus as the result of treatment,
- use of cirrhosis as the trigger point excludes many who are at an advanced stage of the disease,
- those co-infected with HIV will only receive the 2nd payment

The letter concludes that the Society "would not find it possible at the moment to support the government's proposed package and hopes to have urgent discussions with ministers and officials about these points".

As regards the size of payments and the lack of provision for dependant of those who died before the eligibility date, the Scottish Executive position has already been well rehearsed in public (most recently by the FM at FM's questions). The payments are to be made from the Health budget and the **Scottish Executive has to balance the benefit of the payments being made as part of this compassionate gesture against the impact on its ability to provide care and treatment for other patients**. This means resources are limited and need to be targeted where they can be of most benefit i.e. at **those who are still alive and suffering from the effects of the Hepatitis C virus.**

As regards the other points, **no final decision has been taken on these** [although it now seems certain that medical advice will indicate that cirrhosis is the only indicator robust enough to be used as a trigger in the context of an ex gratia payment scheme. It looks as though there is a good chance that medical experts may be able to recommend non-invasive tests to establish cirrhosis – rather than having to rely on liver biopsy]

I shall be in London tomorrow to discuss with officials from the other 3 UK administrations what stance DoH should adopt in its discussions with the Macfarlane Trust when it meets them on Wednesday [redacted] can contact me if there is an urgent need). I hope to be in a position to make definite proposals soon after on the detail of the ex gratia scheme.

There is a good chance that (because of the Haemophilia Society's stance) Macfarlane may refuse to take on administration of the scheme. Without prejudice to tomorrow's discussions, I think it is likely that:

- officials will give DoH a mandate to make urgent arrangements to set up a completely new Trust if MacFarlane declines

- the other 3 UK administrations will not endorse any improvement on the basic parameters defined in Mr Chisholm's previous statements (£20k;£25k; no payments to the 'deceased' or to those who have cleared the virus spontaneously)
- the other UK administrations will not see Haemophilia Society endorsement as being essential to the scheme proceeding

[redacted]

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[redacted]

From: [redacted]
Sent: 16 October 2003 08:48
To: Minister for Health and Community Care
Cc: Deputy Minister for Health and Community Care; PS/HD Health; Gordon IW (Ian); [redacted] Keel A (Aileen); [redacted] Press Health
Subject: Hep C Ex Gratia Scheme - recent meetings in London

[redacted]

Just a short note to confirm our telecon yesterday.

Two meetings took place in London this Tuesday 914/10). Both were attended by officials from DoH, SEHD and the Welsh Assembly government and were conducted **in confidence.**

The first involved leading hepatologists and was also attended by a haematologist representing the interests of the Haemophilia Society. Its main purpose was to discuss the medical trigger for the scheme and also medical issues around co-infection with HIV and clearing the virus as a result of treatment. The meeting was very useful and the experts will report back with recommendations on what non invasive tests can usefully be used to establish cirrhosis.

The second involved officials of the Macfarlane Trust and of haemophilia charities (Philip Dolan attended from Scotland). The purpose was to discuss the possible role of Macfarlane in administering the scheme. This meeting was fairly positive. Macfarlane officials will report back after they have consulted their Trustees. Similarly haemophilia charities will report back to Trustees to formulate an official reaction to the scheme.

I will put together a submission for Ministers when the final outcome of these meetings is known. I expect this to be in about two weeks time and the hope is that at that stage we shall be in a position where officials of all four administrations can make detailed recommendations to the four Health ministers – preparatory to a public announcement.

[redacted]