

SofS

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Copy: see end of submission

Briefing for SofS meeting with Paul Goggins at the end of December

Issue

1. You have agreed to meet with Paul Goggins, Brian Iddon and some hepatitis C infected haemophilia patient representatives.
2. Brian Iddon was one of three MPs who met with MS(PH) in October. At that meeting, the agenda was:
 - Increased HIV Payments (Macfarlane & Eileen Trusts)
 - Skipton Fund review
 - Parity with Ireland
 - Exclusion of widows
 - Insurance

Increased HIV Payments (Macfarlane and Eileen Trusts)

3. The Government response confirmed the intention to give each HIV infected individual a flat rate payment of £12,800 via the Macfarlane and Eileen Trusts. We are also increasing the overall funding to both Trusts to enable them to make higher payments to dependents.
4. MS(PH) has agreed that the Trusts may offer additional discretionary 'top-up' payments to infected individuals, hence £12,800 is now the minimum amount each infected individual will receive. We will work with the Trusts to ensure the new payment structure is implemented as quickly as possible.
5. We had hoped to be able to make the increased payment in December, but because of an unforeseen problem with HM Treasury having to lay contingent liability for Trustees for this year's payment before Parliament for 14 sitting days, it is unlikely this will now be cleared until January. We have been working closely with the Trusts who are aware of the situation.

Criticisms:

- Increase in Macfarlane and Eileen Trusts funding for those with HIV does not meet need.
- Campaigners want parity with the (more generous) compensation scheme in Ireland (see para 13).

Key points:

- £12,800 represents an increase to every infected individual and removes the need for them to make repeat applications.
- The payments will be back-dated to the date of the Government response (20 May 2009), are tax free and are ignored by DWP for the purpose of assessing benefits.
- MS(PH) has agreed that the Trusts can make discretionary top-ups, so the £12,800 flat rate will become the *minimum* amount paid to each infected individual.

Suggested lines to take:

- We carefully considered Lord Archer's recommendations, and published our response to his report on 20 May.
- To help those affected by HIV and Hepatitis C, almost £150 million has already been given out in lump sums and discretionary payments. We recognise that further financial assistance is needed which is why we intend to increase annual payments to £12,800 for those infected with HIV.
- The Trusts have freedom to make additional discretionary payments to infected individuals on top of the £12,800 flat rate.

Skipton Fund review

6. The Skipton Fund makes payments to people infected with hepatitis C from contaminated blood and blood products. Every person in the UK who was alive on the 29 August 2003 and whose Hepatitis C infection was found to be attributable to NHS treatment with blood or blood products before September 1991, are eligible for the payments. It pays in two stages:
 - Stage 1 – £20k on diagnosis of hepatitis C infection
 - Stage 2 – £25k if people go on to develop serious illness as a result, namely cirrhosis or liver cancer.
7. Payments are made only to those infected with hepatitis C. There are no payments to dependents, including to those of people who died before the fund was announced on 29 August 2003.
8. The current stage 1 payments are made irrespective of whether the infected individual is subsequently cleared of the virus following treatment.
9. So far, 4,057 people have received stage 1 payments and 769 have also received a stage 2 payment. As these are one-off payments, the Fund has no information about how many of these people are still alive.
10. New registrations are infrequent now, but there could still be some in future. Up to 20% of stage 1 recipients could progress to stage 2 over the next decade.

11. The Government's response committed to review the Skipton Fund in 2014 (when the Fund will have been in existence for ten years), so there is still no support to those who died before 29 August 2003 who currently cannot claim (an anomaly the widows were campaigning to be rectified).
12. In recent weeks, there has been an increase in correspondence seeking to highlight the differences between the ex-gratia payment schemes for HIV and hepatitis C. **We think you will be heavily lobbied on this point.**

Criticisms:

- The Skipton Fund should be reviewed now – to wait longer is “kicking it into the long grass”.
- No payments to widows/dependents and nothing for those who died before 29 August 2003.
- Campaigners want parity with the (more generous) compensation scheme in Ireland (see para 13).

Key points:

- Almost £100m has been paid out via the Skipton Fund since it was set up.
- The payments are tax free and are ignored by DWP for the purpose of assessing benefits.

Suggested lines to take:

- When the Macfarlane and Eileen Trusts were established, there was no effective treatment for HIV, and life expectancy was short.
- By contrast, in 2004, when the Skipton Fund was established, there were already NICE-recommended drug treatments for hepatitis C
- Only a minority of hepatitis C infection results in serious liver disease (about 20% of Skipton Fund recipients).
- We have committed to review the financial relief scheme (the Skipton Fund) for people infected with hepatitis C in 2014.

Parity with Ireland

13. Lord Archer's recommendation to mirror the payments to those made by Ireland is a little misleading as the circumstances there were different, but campaigners have nevertheless latched onto these significantly larger sums.
14. In Ireland, contrary to the position in the UK, the Irish Blood Transfusion Service (IBTS) was found, by a judicial inquiry, to have been responsible on two occasions (1977 and again in 1991) for failures which resulted in the large-scale contamination with hepatitis C of a blood product used to treat pregnant women. The Finlay inquiry concluded that “wrongful acts were committed”. The Irish Government therefore set up a hepatitis C compensation scheme in 1997 for the

infected women following this conclusion, and because of the threat of litigation (which the Irish Government believed it would lose). The compensation scheme was later extended to all people infected with hepatitis C through blood products and blood transfusion, as some infected women had donated blood and thereby infected others.

15. We continue to receive correspondence and PQs questioning our various Parliamentary responses, but all our lines have been cleared by officials in the Republic of Ireland's Department of Health and Children.
16. The compensation scheme in the Republic of Ireland was set up in the light of evidence of mistakes by the Irish Blood Transfusion Service, a very specific circumstance and unique to them. The payment schemes in the UK had no such history, and were established purely in recognition of the unfortunate position of those who were infected.

Criticisms:

- Campaigners want parity with the (more generous) compensation scheme in Ireland.
- They do not see the difference between events in the two countries

Key points:

- Action was taken as soon as possible in the UK to introduce testing and safety measures for blood and blood products as these became available. The introduction of heat treated product in 1985 was a key factor in protecting our supply.

Suggested line to take:

- Payments made by the Republic of Ireland are a matter for them and were introduced following the evidence of an expert group and put on a statutory basis following a judicial inquiry, which found failures of responsibility by the Irish Blood Transfusion Service. The situation in the UK was different, and Lord Archer has not apportioned blame.

Exclusion of widows (see also Skipton Fund review at para 6)

17. There is an anomaly in the current Skipton Fund scheme that excludes otherwise eligible people (or their estates) because they died before the scheme was announced on 29 August 2003. Baroness Campbell of Surbiton is one of these widows.
18. Campaigners have long campaigned for this anomaly to be rectified, which was endorsed in Lord Archer's recommendations.

Criticisms:

- That those who died before August 2003 should be entitled to payment.
- That dependents generally should be supported.

Key points:

- None – this anomaly remains unrectified

Suggested line to take:

- This will be addressed during the 2014 review.

Insurance

19. The Association of British Insurers (ABI) has assured us that insurers do not treat haemophiliacs or those infected only with HIV or hepatitis C differently from people with other pre-existing conditions. In all cases, a person's insurability and level of premiums are determined through assessment of their individual risk.
20. The Irish compensation scheme makes insurance available to all infected individuals. This is either by the Government funding the excess cost of premiums (compared to non-infected people) or by making insurance available where no commercial product exists.
21. We do not propose that the UK should have a separate scheme. We asked legal colleagues if they were aware of any Government operated insurance schemes with which we might draw comparison. Advice was that HMG generally refrains from any intervention in the insurance market.
22. As far as we are aware, there are no such Government backed or operated schemes related to health and it could set precedents for other patient groups (e.g. Thalidomide) if we were to do so for haemophiliacs.

Criticisms:

- That infected people cannot always get insurance and if they do, the premiums are higher than for those who are not infected
- People infected through the blood supply are not treated any differently by insurance companies than other patients with HIV, hep C or any other long term condition.

Key points:

- Some patients cannot obtain certain types of insurance as a result of the severity of their haemophilia
- Others will have to pay higher premiums as a result of their HIV and/or hepatitis C

Suggested line to take:

- The increased payments we are making will help people infected with HIV to meet higher insurance premiums they may face.

Additional information

Brian Iddon

23. We believe MacoPharma may have lobbied Brian Iddon. The company manufactures a prion filter and claims this will remove abnormal prion proteins, which are associated with variant Creutzfeldt Jakob disease (vCJD) infection, from blood. A number of laboratory and clinical studies have been conducted by NHS Blood and Transplant and the Health Protection Agency to determine the safety and quality of filtered blood, and the efficacy of the filters. SaBTO (our expert committee) reviewed all the available evidence from these studies in the closed section of their meeting on 27 October 2009 and has published their recommendation which is, subject to satisfactory completion of clinical safety trials, that prion filtration be implemented for those born since 1996. The reason for this date is because this group is highly unlikely to have been exposed to BSE through diet because of the introduction of strict animal feed controls in 1996.

Lord Morris – Contaminated Blood Bill (Private Members Bill)

24. Lord Morris has laid a Private Members Bill, which had its second reading in the House of Lords on Friday 11 December 2009. This Bill seeks to put Lord Archer's recommendations on a statutory footing.

25. Second reading was fairly well supported and it is considered likely that sympathetic Lords will use committee stage to air the whole of this issue in greater depth.

26. Committee Stage has been scheduled for Friday 7 January 2010.

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