Tuette

Haemophilia Action UK have sent a very detailed letter alleging in a conspiracy in the 1970s. A local journalist has contacted press office with similar questions. Officials h Whewell PH) Pr/Off PH 6.6 are working on or

Sarah Whewell PS(PH) Pr/Off

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detailed handline

Date: 22 March 2002 Shalegy Authai Cc: Mary Agnew PS/PS(PH) charted au Mary O'Mahony PH 6 initial N Vicki King PH 6.6 Amal Rushdy PH 6.6 Charles Lister PH 6.6 Robert Finch PH 6.6 Olivier Evans PH 6.6 Margaret Ghlaimi PH 6.6 00 51 Tammy Wilson Press Off

GRO-C

PS(PH) 99579 - HAEMOPHILIA ACTION UK

1. You asked for advice following the receipt of a letter dated 22 February from Carol Grayson of Haemophilia Action UK. Ms Grayson has requested a meeting with PS(PH) to discuss issues concerning haemophiliacs who were infected with hepatitis C and HIV from NHS blood products.

2. A copy of Ms Grayson's letter has also been forwarded separately for Ministerial reply by Lord Morris of Manchester (President of the Haemophilia Society).

Recommendation

3. A meeting with PS(PH) is not recommended

4. Haemophilia Action UK (Carol Grayson and others) met PS(L) in May last year, together with their MP Jim Cousins. The issues that were covered at that meeting are on the same theme as those in her current correspondence. At the meeting PS(L)agreed to write to Ms Grayson after giving consideration to all the points she had raised. A copy of that correspondence is attached (PS(L)'s office have provided this).

5. PS(PH) attended a meeting with the All Party Group on Haemophilia on 14 March 2002 and some of the issues raised by Ms Grayson were discussed. Ms Grayson's MP Jim Cousins is a member of the All Party Group. In turning this request down there remains the possibility that he may then ask for a meeting with PS(PH). (PS(PH) will be meeting the Manor House Group – another haemophilia group campaigning on compensation and treatment issues - on 18 April)

Background

Haemophilia Action UK

6. Haemophilia Action UK are a very active, Newcastle based campaign group. They

are not affiliated to the Haemophilia Society or the Manor House Group but joined with them for a demonstration march to DH, No 10 and Parliament in April 2001. We understand that there are plans for a similar demonstration in May 2002.

7. Ms Grayson is the partner of a co-infected haemophiliac (he has HIV, hepatitis B & C). She is very articulate and speaks very forcefully. She maintains that the Government imported plasma from "the slums of Africa and....skid row America" which was then used to treat haemophiliacs and hence infect them with HIV and hepatitis C. In the past she has produced a letters and photographs from the sister of an alleged USA prisoner who she claims was a plasma donor despite having hepatitis B & C.

8. Ms Grayson is convinced that there is a conspiracy to hide information about the importation of blood products in the 1970s. She has been in contact with Lord Owen who was Minister for Health at that time and who made attempts to make the UK "self sufficient" in blood products so that imports from the US could cease. The local newspaper in Newcastle "The Journal" has covered her story in depth and continues to publish articles.

9. She is also campaigning for a full public inquiry, compensation for haemophiliacs with hepatitis C and provision of recombinant clotting factors for all haemophiliacs (not just for new patients and those aged up to 16 as currently agreed).

Lord Owen - "Self sufficiency" in UK plasma

10. When Lord Owen was Minister of Health in 1975 he made a commitment to make the UK "self-sufficient" in clotting factors within 18 months. He announced the allocation of special finance of up to $\pounds 500,000$, about half of which would be recurring, in order to increase the existing production of plasma derived clotting factor 8.

11. The money was linked to a target of 275,000 blood donations to be used annually for the preparation of Anti-Haemophilic Globulin concentrate and 100,000 donations for cyroprecipitate. This target was achieved within the 2 year timescale envisaged by Lord Owen and, as a direct result, the Bio Products Laboratory increased its production of concentrate from 5 million international units in 1976 to 11 million international units in 1977. However, given the rapid growth in demand for these products (denied by Ms Grayson in her letter) at the time, this was not enough to achieve self sufficiency.

12. Self-sufficiency continued to be the aim of Ministers for a number of years and NHS production of concentrate continued to increase. But the rapidly rising demand for clotting factors at that time meant that commercial products continued to be imported. Failure to achieve self sufficiency was linked to the massive increase in demand for clotting factors at the time not to any failure to implement Ministerial initiatives.

13. It is important to note that self sufficiency in blood products would not have

prevented haemophiliacs from being infected with hepatitis C. Blood products are made with pooled plasma (around 20,000 donations per pool). Even if the UK had been self sufficient, the prevalence of hepatitis C in the donor population would have been enough to spread the virus throughout the pool. That is why the infection of haemophiliacs with hepatitis C is a world wide problem.

14. There are allegations that there has been a secret inquiry, this is not true. Relevant documents containing information about the use of the "Lord Owen money" have been copied and passed by the Department to the Haemophilia Society. Copies of these documents are being sent over to you to be sent with the letter from PS(PH) to Ms Grayson.

Documents referred to in Ms Grayson's letter

15. We have concerns that Ms Grayson has evidently obtained Government documents from the 1970s/1980s and is basing some of her arguments on information gleaned from these papers. Officials have looked at some files from that period to establish how the money allocated by Lord Owen was spent, and papers on this issue have been passed to the Haemophilia Society. However, given pressures on time and resources, we have not looked in detail at the decisions made during that period, an exercise requiring several weeks of work. We have therefore not responded to the some of the detailed questions in Ms Grayson's letter which are partly based on those documents. We recognise that this is not a sustainable position and will provide further advice on handling shortly.

Conclusion_

16. We recommend that PS(PH) decline this request for a meeting but provide a response on the main issues raised in Ms Grayson's letter.

17. A draft letter is attached for PS(PH) signature.

Jill Taylor PH6.6 Room 631B SKH Ext<u>GRO-C</u> Yes it is norskie All for Joglo look its are herry Joglo look its are he