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To Perly 27/1/92

STANDARD -
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HAEMOPHILIA & HIV
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PETER BOTTOMLEY ESQ MP

Thank you for your letter of 15 January enclosing one from Mr David G Watters, General Secretary of the Haemophilia Society about developments since the Government announced the special provision which it has made for those people with haemophilia who became infected with HIV.

I understand that the Macfarlane Trust has adequate resources at present for its work of helping to meet the special needs of haemophiliacs with HIV and their families. We shall continue to keep under review the amounts available to the Trust and will consider very carefully any proposals the Trust may put forward about its future funding.

I also understand, that following the Society's meeting with William Waldegrave on 12 November, officials have met with representatives of the Society and of the Haemophilia Reference Centre Directors Organisation and that work is in hand to revise guidance to ensure that people suffering from haemophilia will continue to have access to comprehensive care in the reformed NHS. Officials will keep Ministers informed of progress.

Clinicians are free to prescribe a high purity product for the treatment of haemophilia where they consider this to be indicated. Allocations to regional health authorities include funding to enable new treatments to be introduced. Of course, where there is a choice of medicines, clinicians are expected to be satisfied that the patient will benefit from the extra cost.

In making the decision on the product to be prescribed in the treatment of an individual haemophilia patient, the clinician is likely to take into account the recommendations of the Haemophilia Reference Centre Directors on choice of therapeutic products which the Society published in September 1990. I understand that although the Haemophilia Centre Directors were unable to make firm recommendations about the patient groups in which use of high purity products might be indicated, they were able to put forward suggestions which include young children.

We are not aware of any evidence that clinicians are giving inappropriate treatment to haemophilia patients on grounds of cost, and I understand that the Bio Products Laboratory is able to meet the demand from clinicians for high purity factor VIII manufactured from plasma derived from UK volunteer donors.

The Government has carefully considered the issue of screening international travellers to the UK and concluded that there are no good public health grounds for HIV related entry restrictions - a view shared by the World Health Organisation. The virus is acknowledged to be already present in almost every country, and in the absence of a cure or vaccine, the only way to prevent further spread of infection is for people to be aware of the risks and how to avoid them. Indeed, when other countries seek to impose HIV related entry restrictions, the UK Government, with its EC colleagues, plays an active role in trying to persuade them not to do so.

A further formal approach was made to the US Government in July 1991 seeking to persuade them to remove HIV related entry restrictions. I regret that after deliberation the US Government decided they were unable to change existing arrangements. We are keeping the situation in the US under review and will continue to press for change.

PETER BOTTOMLEY, M.P.

HOUSE OF COMMONS
LONDON SW1A 0AA

Baroness Hooper,
Parliamentary Under-Secretary
of State,
Department of Health,
Richmond House,
79 Whitehall,
London
SW1A 2NS

15/1/92

DEPT. OF HEALTH
RECEIVED
16 JAN 1992
CORRES
PRIVA

Dear Baroness Hooper,

Peter Bottomley has asked me to send you the attached letter he has received from David Watters, General Secretary of the Haemophilia Society.

As you will see from his letter Mr. Watters is concerned that people suffering from haemophilia should receive the highest purity blood products, especially the very young.

Mr. Bottomley would be grateful to have your comments on this request which he can then pass to Mr. Watters.

Yours sincerely

GRO-C

Patricia Greenwood (Mrs.)
Private Secretary

2212

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General Secretary:
David G. Watters, JP

Member of the World Federation of Hemophilia

Our Ref: DGW/pb

12 December 1991

Peter Bottomley, MP
House of Commons
London SW1A 0AA

ask DoH f advice on →

Dear Peter

This week is the anniversary of the Government's decision to grant financial compensation to those people with haemophilia who contracted the HIV virus as a result of NHS treatment. We felt that it would be appropriate to mark the occasion by thanking you once again for your support, which we have not forgotten, and to give you a brief update of the latest developments since then.

The Haemophilia Society was of course very pleased that it was possible to achieve an out of court settlement. The money has now gone to those infected and has brought an end to uncertainty and an element of financial security. Although the campaign is now over, it remains important that the funds in the original Macfarlane Trust (which was established to help the poorest of those infected with HIV) are topped up to enable it to continue to make payments to meet the health needs of those infected. We would wish to get in touch with you if this becomes urgent.

The ending of the compensation campaign has enabled the Society to devote more time to helping meet the needs of all people with haemophilia, as well as those who contracted HIV. We are closely monitoring the effect of the NHS reforms, where we are concerned that patients may be denied access to the specialist haemophilia Centre of their choice. The Society recently met the Secretary of State for Health to discuss these concerns. We are now due to hold discussions with DoH officials to re-write the circular which established the original system of specialist Centres for the treatment and care of haemophilia.

cont'd.../...

continuation:- 12 December 1991

Given our past experience, it is not surprising that we believe firmly that people with haemophilia should be able to receive the higher purity blood products that are now becoming available. These are more expensive than the intermediate purity products that many patients currently receive. The Society would like to see sufficient funding to ensure that haemophilia consultants can provide these products, especially in the case of young children where it may be possible to prevent future early joint damage developing. The compensation campaign suggests this makes economic sense too.

Finally, we remain concerned about the entry policy of the United States Government which obliges those with HIV to obtain a waiver even for a holiday. We believe this is a humiliating, unfair and quite ineffective restriction, unique in the west, and have been lobbying to get the position changed. We would certainly welcome any parliamentary support on this issue, as on the other points. In the meantime, I would like to thank you again for your support in the past, without which I am sure we would have faced an even more prolonged campaign for a decent level of compensation.

With Best Wishes,

GRO-C

David G Watters
General Secretary