

GRO-A

London

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Thursday, 3 December 1992

Dear Mr. Peter Brooke,

I write regarding the supply of appropriate medicine to people with conditions such as mine.

I am one of over a thousand people with haemophilia who became infected with Human Immunodeficiency Virus (HIV), following the use of contaminated medicine — *Factor VIII*. As you probably know this is a concentrated coagulation factor made from donated human blood. I am a person with severe haemophilia. If I knock, bruise or otherwise injure myself, I must give myself a rapid transfusion of this concentrate. It replaces the blood clotting factor missing in my own system. It slows internal bleeding in my joints and soft tissue. While it cannot prevent many crippling effects of haemophilia, it reduces the long-term damage that used to confine so many to wheelchairs at a very early age.

What you may not know is that taking *Factor VIII* has other side effects. In particular, because of the emphasis on imported blood, the medicine was invariably contaminated to a varying degree, with other material. Besides the HIV virus, many people with haemophilia now have severe liver damage due to infection with other viruses - typically hepatitis (strain B and now C). A weakened liver means greater susceptibility to infection, unable to eliminate the impurities in the medicines; and its tolerance is lowered (for example) to the sometimes severe side effects of HIV-combatting drugs such as AZT. There are also the usual physical effects of extreme tiredness that occurs after having a transfusion of standard *Factor VIII*.

For the past 1 ½ years I have been given a very highly purified *Factor VIII* product, a practice recommended by all the UK Regional Directors of Haemophilia Centres¹. Its high purity means that the doses I need to take are far smaller and administration is quicker and easier. The side effects experienced from the older version are dramatically reduced. Importantly, it reduces immunosuppression and 'inhibitor' development', both occur with the use of the old product. Almost a miracle product, you might think. The problem is that, as a newly licensed and highly technological drug, it is more expensive than the older version.

A recent leaked Department of Health document, to the Haemophilia Society shows that . . . ***specific funds earmarked for AIDS patients should not be used to meet the necessary extra costs for people with haemophilia, who are HIV positive.*** I am appalled by this statement. It shows ignorance of and indifference to the real medical benefits offered by the new product to us. People doubly challenged by haemophilia and the consequences of an acquired HIV infection. Using a purer product could also cut down on other complications which make people with haemophilia heavy users of medical services. Withholding the improved product is a clear example of false economy, and I would ask you to investigate this as a matter of some urgency.

¹ UK Regional Haemophilia Centre Directors Committee. Recommendations on Choice of therapeutic products for the Treatment of patients with Haemophilia A, Haemophilia B & von Willebrand's disease. *Blood Coagulation Fibrinolysis* 1991; 3, 205-14

The MacFarlane Trust hold the ex-gratia funds allocated by the government. This cannot be used to 'buy-in' the highly purified *Factor VIII*. Yet not adequately treating people with haemophilia who are HIV positive will, without doubt, shorten our lives. Of course, this would lead to far fewer HIV-positive people with haemophilia and by this means, a reduction in costs. Is this *really* what the Department of Health intends?

The Department of Health reiterate their belief that the scientific evidence is not sufficient to warrant a switch to the high purity *Factor VIII*. The medical press contests this². It sounds very familiar to the statements made in 1983/84, arguing that there was insufficient scientific evidence to warrant the switch to heat-treated *Factor VIII*. Since then nearly 100 people with haemophilia have died, or are dying because of AIDS. Acknowledged failure of this earlier scientific argument has been an horrendously expensive one, in any human terms.

What matters more, Mr Brooke - people or economics? I won't rehearse all the well-known arguments for economic efficiency. I already know the NHS, upon which I depend for my continued health, is over stretched. I don't want to have to argue that my life is worth more than that of a drug user. Nor that AIDS money going towards needle exchanges, or beds at the London Lighthouse, or AZT treatment, is not being well used. It is, and I am sure we both know that.

I want assurance that you, as my elected representative, will take whatever steps required to ensure people with haemophilia, who are HIV-positive, get treated with the needed highly purified *Factor VIII*.

I look forward to hearing from you in due course.

Yours sincerely

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(Mr)

I would like to mention that I did vote for you in the General election. I admired your courage and fortitude in the Anglo-Irish Negotiations, in which you created a bridge after a "small" gap of 400 years.

² Lee, Christine: High purity factor VIII concentrates and HIV infection. *British Medical Journal*, 1992, 304: 641