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Professor A. L. Bloom

Mr. D.G. Watters,
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20th January, 1983

Dear Mr. Watters,

Thank you very much for your letter of 19th January and for the cutting from the Observer. This cutting does seem to have caused some concern amongst the patients and indeed some medical administrators and physicians.

There may be a modicum of justification for this concern. You are no doubt aware of the background that a rather serious "new" disease began to be recognised towards the end of 1981 particularly amongst homosexuals in the U.S.A. The disease was characterised by a failure of normal immunity processes so that sufferers became susceptible to infections that most of us would just shrug off. In addition they became chronically unwell and the condition has quite a high mortality rate. At first it was thought possibly that the condition was due to a reaction to drugs etc or to some virus or other agent to which homosexuals were exposed. However later, as detailed in the Observer article, several groups of people who are clearly not homosexuals including various immigrant groups in the U.S.A. as well as the ten haemophiliacs, were identified as suffering from the disease. Clearly at the present time the cause is quite unknown and neither has it been proven that it is transmitted through contaminated blood products. The incidence of the condition in America is not known but seems to be about one per thousand of the severely affected treated patients. On this basis if the disease exists in the U.K. we could reasonably expect two or three cases amongst British haemophiliacs. So far none have been reported. Various laboratory changes concerning immunity were reported in the American patients but nevertheless these changes are by no means specific for this particular condition and the tests most easily undertaken, and hence reported, often give similar results in many other conditions including hepatitis or even stress.

The Haemophilia Centre Director's organisation is closely monitoring the possibility of this condition in the U.K. At the meeting of our Hepatitis Working Party this week, the meeting referred to in the Observer, it was decided to institute a retrospective survey to all Haemophilia Centre Directors and also a prospective survey in order to try to detect any possible emergence of this syndrome in this country. We do not know at the moment if the condition exists in lesser degrees of severity but we shall clearly have to keep on the look out for this. As the full blown condition has not yet been reported amongst British haemophiliacs it is not possible to state if the coagulation concentrations produced in this country are safer

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in this respect than the concentrates produced in the U.S.A. Indeed there is no evidence yet in fact to implicate the latter. However the Directors of several individual Centres are investigating possible markers of the condition in patients who receive various types of blood products. In the meanwhile there is certainly no need for the haemophilic community to be unduly concerned about this 'new' syndrome. They can rest assured that every effort is being made to monitor the situation in this country and to collaborate with the Centre for Disease Control in the U.S.A. Although no cases have been reported in the U.S.A., as far as I know, in haemophilia B, we are monitoring the situation in all these related conditions. As you and your colleagues in the Society know, coagulation factor therapy is so essential for the safety and well being of patients that there is no doubt whatsoever that their advantages far outweigh this disadvantage which at the moment seems to be potential rather than real in the U.K. at any rate. Further developments will depend upon identifying the responsible agent or constituent of concentrates, if it exists, and no doubt then steps can be taken to attempt to eliminate them in much the same way as steps are being taken to reduce the risk of hepatitis.

Finally I agree that after this publicity it would be helpful if an article was written for the Bulletin. Dr. John Craske, a consultant virologist at the Public Health Laboratories in Manchester, is Chairman of our Hepatitis Working Party and I think that he would probably be the best person to contribute this. He works closely with Dr. Rizza to whom I am sending a copy of this letter.

Yours sincerely,

A.L. Bloom

c.c. Dr. C.R. Rizza