

## UNIVERSITY OF GLASGOW

HAEMOSTASIS AND THROMBOSIS  
RESEARCH UNIT

REGIONAL HAEMOPHILIA  
REFERENCE CENTRE



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April, 1985

CONFIDENTIAL

Dear

*PHOTOCOPY FILE Haem Duesdas AIDS Weekly Punter 19e*

As you may know, there has been recent publicity in the newspapers and television concerning an increased risk of the disease known as Acquired Immune Deficiency Syndrome (AIDS) in haemophiliacs who have received treatment with clotting factor concentrates in the past 5 years. As one of our patients who has received treatment with clotting factor concentrates in the past 5 years, you may be concerned about the risk of developing AIDS.

Because of this, we have bought from our funds a copy of the booklet "AIDS and the blood", which has been recently published by the Haemophilia Society, and enclose this for you to read. We suggest that you read it, since it gives reliable information and advice. Unfortunately, some of the television and newspaper reports on AIDS have been alarmist and misleading. We also enclose a booklet on haemophilia and the Haemophilia Society, which you may consider joining if you are not already a member.

As you may know, we have a Haemophilia Clinic on Ward 2 on Monday and Friday afternoons. We try to see all our patients there at least once a year, and we are always happy to see and advise you. We have already seen and advised many of our patients about AIDS. If we have not yet discussed AIDS with you, we should be happy to do so at your next clinic appointment this year, or sooner if you wish. If, after reading this letter and the booklet, you would like to see us before your next appointment to ask advice, please ring Sister Campbell (extension 5127) to arrange this.

SUMMARY OF ADVICE ON AIDS

- (1) In recent months it has been recognised that AIDS is caused by a newly-discovered virus (a virus is a small germ). The increased risk of AIDS in haemophiliacs is probably due to transmission of this virus from certain blood donors by clotting factor concentrates. The virus can also be transmitted by sexual intercourse, particularly between homosexuals, but also sometimes by male-female intercourse.
- (2) The risk of the disease AIDS in haemophiliacs appears to be very small and less than the risks of bleeding. We therefore recommend that you should continue treatment for bleeds. Several steps have been taken to reduce the risk of exposure to viruses during treatment of bleeds:-
  - a) All blood donors discovered to be at risk of AIDS are being excluded from blood donation.
  - b) All factor concentrates are now heat-treated to destroy the virus.
  - c) Mild haemophiliacs are treated with plasma or cryoprecipitate (which is made from much fewer blood donations than concentrates), or with a drug called DDAVP which does not come from blood donations.

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- (3) We do not yet have a blood test to tell us which patients carry the virus particle in their blood, but hope to have this within the next few months. However, we and other haemophilia centres do now have a blood test which detects antibody to the virus. If this antibody test is positive, this means that the person has been exposed at some time to virus particles. A positive test does not mean that the person will develop AIDS. Recent studies in the USA and England have found that over half of regularly treated haemophiliacs have positive antibody tests. We have recently tested stored blood samples from many of our patients, of whom about 10% have positive antibody tests. The reason why fewer Scottish patients have positive tests compared to English patients is probably due to the fact that we have largely used Scottish concentrate in recent years rather than concentrate from the USA.
- (4) It is important that we see you regularly at the clinic, at least once a year. This allows us to check on your general health, give you up-to-date information, and answer your questions. If you wish to know the result of your antibody test when it is available, then we shall tell you. However, we would emphasise that the antibody test is not a test for AIDS. Many people develop antibodies against viruses and remain well. People with positive antibody tests should not worry unduly.
- (5) We recommend as of now that you should take certain precautions, to reduce the small possibility that someone who carries the virus in their blood may transmit it to other persons:-
- (a) Because sexual intercourse has been shown to be involved in the spread of the virus, we recommend the wearing over the penis of a contraceptive sheath (condom), and this should be flushed down the toilet after use. We have arranged that anyone attending our Haemophilia Clinic can obtain contraceptive sheaths free of charge from the Family Planning Clinic, Glasgow Royal Infirmary, 10 Alexandra Parade. This clinic is on Monday and Friday afternoons (the same times as the Haemophilia Clinics). We suggest that you do not use rectal or oral intercourse since the risk of virus transmission may be higher than with vaginal intercourse (see page 39 of the booklet).
  - (b) If you wish to consider having a family, we suggest that you discuss this with us in advance (see page 41 of the booklet).
  - (c) We recommend that you use your own toothbrush, which should not be used by others.
  - (d) We recommend that you and your relatives in close contact should not donate blood or carry organ donor cards at present.
  - (e) Patients receiving home treatment are being advised to take care when preparing and giving treatment.
  - (f) In the next year or so, the above advice may well be given only to those people who are shown to carry the virus in their blood. However, until the test for the virus is available it seems sensible to give this advice at present to all haemophiliacs who have received clotting factor concentrates in the last 5 years.
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(g) No changes need occur in your day-to-day life with friends, neighbours, at school or at work.

Finally, we realise that your wife/sexual partner(s) may be concerned about the possibility that they may be exposed to the virus. We would be happy to talk with them about such concerns.

Please let us know if we can advise or help you further.

Yours sincerely,

Dr G D O'Lo'we

Dr C D Forbes.

P.S. The enclosed booklets are sent to you free of charge. However if you would like to contribute the cost of the booklet (£1.50) to research on haemophilia and on AIDS, send this to the Haemophilia Unit at the above address.