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The  
Haemophilia  
Society

**HÆMOFACT**

**ADVICE ON SAFER SEX**

**SPECIAL ISSUE**

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P.O. Box 9 16 Trinity Street London SE1 1DE



## HTLV-III AND AIDS

As we now know people with haemophilia and von Willebrand's syndrome are in the 'at risk' groups for exposure to HTLV-III. Consequently, we must adapt and make changes if we are to protect our sexual partners from exposure to HTLV-III.

HTLV-III virus is not AIDS but the most probable causative agent for the development of AIDS. Only a very small number of those who are exposed to the virus (HTLV-III) go on to develop further symptoms of AIDS itself.

AIDS is a new viral disease in which the body's defence mechanisms are altered in such a way that uncommon infections can occur. HTLV-III is simply the name given to the virus believed to be responsible for AIDS and the antibody is simply a marker of the presence or former presence of the virus. The virus (HTLV-III) is transmitted in blood and semen and found in other body fluids.

Probably the most significant threat that AIDS poses is the fear and uncertainty which it creates. Because HTLV-III and AIDS are sexually transmitted the emotions which they arouse touch on the most private and vulnerable areas of our lives. This not only affects us as individuals in an 'at risk' group but also the people who staff haemophilia centres — none of us volunteered to be in the front line fight against AIDS.

Remember that you are not alone — thousands of other people now share your fears, anxieties and dilemmas. Like you they have had the experience of overcoming many medical and social problems which others never have to face. You belong to a community of survivors; you already have the expertise — you just need to apply it to a new situation. Don't let a virus kick you around — fight back by taking sensible precautions and protecting your partner and so your family. If you need to talk things over go to your centre to get in touch with the Haemophilia Society and when you need support don't forget your listener probably needs your support too!

This guide to a responsible sex life has been written for a heterosexual audience. For the gay community the Terrence Higgins Trust. (BM AIDS, London, WC1N 3XX) has produced a well informed booklet "AIDS Medical Briefing" which includes a comprehensive section on gay sexual practices and the reduction of the risks of transmission of HTLV-III.

### Acknowledgments

The Society is indebted to the following for their help and guidance in preparing this pamphlet:—

Dr Peter Jones; Dr Richard Tedder; Mrs [GRO-D] Mrs [GRO-D]  
[GRO-D]; Mrs [GRO-D]; Sister Maureen Fearn



Above all, try to keep well informed about AIDS, To help you do this the Haemophilia Society regularly produces HAEMOFACT with news updates and advice, and of course your Haemophilia Centre should always be able to give advice to you if you ask for it.



## GENERAL ADVICE

Continue to Treat Bleeding Episodes to avoid long term joint damage etc. *By now you should ONLY be receiving heat-treated materials, whether imported or British, IF THIS IS NOT SO, raise the matter with your Centre Director.*

All evidence to date indicates that HTLV-III is found in body fluids so if the need arises great care should be taken in handling blood, semen, urine, faeces and vomit.

Lead a Healthy Lifestyle because this will help your immune system to protect you. Get plenty of wholesome food, exercise, rest and sleep, avoid excesses of alcohol or other drugs which lower immunity; maintain a high standard of hygiene and do not share razors or toothbrushes (both of which may be contaminated with blood) and see your dentist regularly because oral hygiene, which is important at any time, is even more so now. Above all, talk over your fears and anxieties about HTLV-III with those closest to you and try to reduce the stress.

## MATERNAL TRANSMISSION

*Because there is evidence of transmission from mother to baby, pregnancy should be avoided at present.* If you are already pregnant you will obviously want to discuss this with your partner's Centre Director. It is not yet known if the virus (HTLV-III) is transmitted by breast milk but your Centre Director will be able to give you advice on your own position.

## SEXUAL TRANSMISSION

Just as there is no test for AIDS — so there is no test for HTLV-III infectivity. *Until there is such a test the only safe course is to behave as though you may be infectious. Because exposure to HTLV-III may have a cumulative effect the fact that you have not taken precautions before does not mean that you need not take them from now on.*



The advice given below may mean making unwelcome, but necessary, changes in your life but please read on . . . . .

Because the majority, if not all, haemophilia centres are now using heat treated blood products, sexual transmission of HTLV-III virus is the main risk factor. Testing of the sexual partners of people with haemophilia for HTLV-III antibody is being carried out and, although results so far are encouraging, there are cases in which sexual transmission has occurred. *It is most important to realise that the need to modify sexual behaviour applies to all those who are sexually active whatever their HTLV-III antibody or antigen (virus) status may be. This is so because the precise significance of HTLV-III antibody positivity or negativity is not yet understood.*

For sexual transmission to occur, body fluids containing HTLV-III (especially blood and semen) must enter your partners' body through the vagina, anus, mouth, eyes or breaks in the skin (cuts, grazes, open wounds etc). A sheath or condom should therefore be used as a barrier in any penetrative sexual activity.

*Do not rely on this barrier as a method of birth control. Any sexual activity **NOT** involving penetration or internal exchange of body fluid ought to be of low or no risk assuming that your partner's body surfaces are uninjured. Any sexual activity which tends to break the skin or mucous membranes will increase risk and for this reason *anal intercourse in particular is considered a high risk activity.**

Blood and semen are the main 'culprit' fluids identified so far, but **all** body fluids and products *may* contain an element of risk if they are exchanged *frequently*. It is thought that saliva is not a significant risk factor unless it contains some blood (from bleeding gums or other lesions in the mouth or throat).

To summarise the above we give the following estimated risk categories:

#### **HIGH RISK**

Vaginal intercourse **without** the use of a sheath or condom or any act which draws blood or which causes semen or blood to enter a sexual partner's body. Anal intercourse should be regarded as a high risk even when a sheath is used as a barrier.

#### **MEDIUM RISK**

Oral sex by the woman to the man is in this category, even if withdrawal before orgasm is practised.

#### **LOW RISK**

Vaginal intercourse with condom or sheath, oral sex by the man to the woman when no blood is present in saliva.

#### **NO RISK**

Mutual or solo masturbation. General body contact, stroking, caressing, bodykissing. Although orgasm on your partners' body is safe (providing you have avoided body openings or any injury site) remember that semen can transfer from one place to another with or without your help. Don't let it because the virus will survive as long a fluid stays fluid.

#### **ACCIDENTAL RISK**

If an accident occurs, you should wash as thoroughly as possible with copious amounts of water and, if practicable, soap and water.

**NEVER** use bleach — or any other fluid apart from soapy water — on your own body or that of your partner.

There is no need to panic but if you are concerned do not hesitate to contact your local Haemophilia Centre Director who will, in due course, arrange for you to be tested.



### ADDITIONAL SOURCES OF INFORMATION AND ADVICE

Your Centre will be able to refer you to specialist counsellors if you are having sexual problems and your General Practitioner can often be very helpful in discussing sexual matters.

The Marriage Guidance Council are training counsellors especially to deal with worries about AIDS and sexual relationships. Local addresses for these counsellors can be obtained from the Marriage Guidance Council:—

For England, Wales and Northern Ireland  
Herbert Gray College  
Little Church Street  
Rugby  
Warwickshire, CV21 3AP  
Tel: 0788 73241

Or from the Scottish Marriage Guidance Council  
26 Frederick Street  
Edinburgh  
EH2 2JR  
Tel: 031 225 5006

In addition most good bookshops stock reliable and authoritative books and publications dealing with sex, its pleasures and problems.

### BOOKS AND PUBLICATIONS ON HTLV-III, AIDS AND SEX

AIDS AND THE BLOOD: A Practical Guide-by Dr Peter Jones (free to membrs or £2.00 post paid).

HAEMOFACT — an information series on AIDS, frequently updated and free to members.

THE BULLETIN — the Society magazine, issued three times a year.

The Marriage Guidance Council General List of Books and Booklets contains many appropriate titles about sexual relationships and their problems. This may be obtained by writing to the above addresses.



### THE HAEMOPHILIA SOCIETY AND YOU

If you are **not** already a member of the Haemophilia Society we feel you should know more about us . . . . .

The Society has been in existence for over thirty-five years and its main function is to protect the interest of people with haemophilia and their families by: making representations to the Government; securing high standards of treatment; making publications available to members, doctors, nurses, social workers, physiotherapists and other health care professionals; providing help to people with haemophilia; limited support to vital research projects.

More especially the Society can help you by: keeping you up to date on developments in treatment and care through our literature — this applies particularly to the problems of HTLV-III and AIDS, answering any questions you have by letter or telephone; advising teachers, social workers, health visitors, employment workers and employers on the implications of haemophilia; giving grants for certain financial problems; through local groups, giving you an opportunity to discuss problems and share difficulties; directing you to other sources of help.

We provide many other services to our members but probably the most important now is supplying them with accurate, up-to-date information about HTLV-III and AIDS. We are the only organisation committed to providing this service to people with haemophilia.

### MEMBERSHIP

*This is available to anyone. People with haemophilia may become members without payment but in the normal course of events there is an annual subscription (currently £5).*



## THE MAIN HAEMOPHILIA CENTRES ARE:

AREA	NAME & ADDRESS	TEL No.	EXTENSION
London	Royal Free Hospital Pond Street, London NW3 2QG	01 794 0500	
London	St Thomas' Hospital London, SE1 7EH	01 928 9292	GRO-C
Manchester	The Royal Infirmary Manchester, M13 9WL	(Manchester) 276 1234	
Newcastle	Royal Victoria Infirmary Newcastle upon Tyne Tyne & Wear, NE1 4LP	(Newcastle.U.Tyne) 325131	GRO-C
Oxford	Churchill Hospital Headington, Oxford OX3 7LJ	(Oxford) 64841	GRO-C
Sheffield	Royal Hallamshire Hospital, Glossop Road Sheffield, S10 2JF	(Sheffield) 26484	
Northern Ireland	Royal Victoria Hospital Grosvenor Road, Belfast BT12 6BA	(Belfast) 40503	
Scotland			
Edinburgh	The Royal Infirmary Edinburg, EH3 9YW	(Edinburgh) 2292477	GRO-C
Glasgow	Royal Infirmary Glasgow, G4 0SF	(Glasgow) 552 3535	GRO-C
Wales			
Cardiff	University Hospital of Wales, Heath Park Cardiff, CF4 1XW	(Cardiff) 755944	