

FACTS We last wrote to you in May and we now send this leaflet to bring you up to date about the present situation. We have to report that there has been one death recorded in a person with haemophilia. This has been confirmed within the past few days. There remains one other suspected case in Cardiff. There have been no other cases relevant to haemophilia reported to the Public Health Laboratory Service.

UPDATE Media-reaction to AIDS has kept the Society's office very busy with enquiries, in addition to the standard activities created by the presence of AIDS in the United Kingdom. We thought that you would like to know some of the things we have done:

- ◊ A meeting has been held with Lord Glenarthur, Under-Secretary of State at the Department of Health, and his officials. The Society was represented by the Officers and the Co-ordinator and at the meeting we strongly emphasised our members' views about AIDS in this country.
- ◊ Regular liaison has been established with the Centre for Disease Surveillance and Control, which monitors AIDS in the United Kingdom as well as liaising with the situation in the United States. Constant contact has also been maintained with officials of our own DHSS, the Public Health Laboratory Service and members of the Society's Medical Advisory Panel.
- ◊ Close contact has been maintained with the Pharmaceutical companies involved in the importation of concentrates from America and their improved methods of blood collection have been noted.
- ◊ RESEARCH GRANTS from the Society totalling some £25,000 have been approved to enable research directly benefitting people with haemophilia, in relation to AIDS, to go ahead.
- ◊ Members of the Society attended the World Federation of Hemophilia Congress in Stockholm in late June and discussed the international AIDS situation as it affects

people with haemophilia. *The Medical Board of WFH in their report (copies available from the office, please send an s.a.e.) EMPHASISED and CONFIRMED the points made in our last letter sent in May.*

- ◊ Every meeting of the Executive Committee has been briefed about developments in detail and discussed AIDS at length.

TO SUM UP.....

- [] The Society has established and maintained close liaison with all relevant personnel and departments of government in order to keep all our members informed of developments and, of equal importance, to ensure that the Society's views are known to decision makers in the public health services.
- [] Blood collection in the USA has been improved to the satisfaction of Federal Health Authorities and our own DHSS. Assuming blood to be a transmission agent, it is not yet possible to state that imported blood products are AIDS-free (nor indeed that UK product is so), the chances are that the risk involved in imported concentrates has been reduced considerably. It is also important to remember that we have not seen the massive increases in reported cases of AIDS either in this country, nor in the USA, which were being predicted earlier in the year. *Our message remains unchanged: THE ADVANTAGES OF TREATMENT FAR OUTWEIGH ANY POSSIBLE RISK. BALANCE THE RISKS for yourself, but we would state again that the risk of AIDS is tiny compared to the risks from untreated bleeding episodes. By refusing treatment or not following your Centre Director's advice you are probably exposing yourself to even greater risk. RISK has always been a feature of haemophilia and in time this risk too will diminish, especially given the volume of research being conducted around the world.* Research in the UK has received substantial support from the Society - that is support from YOU and your local Group. Elsewhere in the world support has come from other members of the World Federation Hemophilia.