Appendix (vii)

Report of UKHCD Working Party in HIV Infection

File

The membership of the party is made up as follows:

Chairman: Dr Christine Lee

Members: Dr Paul Giangrande
Miss Rosemary Spooner
Dr Sarah Darby
Dr Christopher Ludlam
Dr Andrew Phillips

Two meetings have been held of the Working Party on 10th February 1994 and on 3rd June 1994. The following subjects have been under discussion and in some cases task completed.

Notification of AIDS

The CDSC form has been adapted for use for the UKHCD and this is now in circulation.

CD4 counts and progression.

It was felt that some information on progression of HIV disease should be collected from the annual follow-up forms at he time of the Oxford Returns. A simple form has been drawn up with this in mind and has been circulated.

Couples wishing to have children

Guidelines for advising couples who wish to have children when the partner is HIV positive have been drawn up and circulated. A questionnaire has also been circulated to haemophilia centres to try and get data on the number of HIV positive partners who have been identified and the number who have been tested if this is available.

MRC application

Drs Sarah Darby and Andrew Phillips had prepared an application for a project grant to support the salary of two research nurses and a statistician in order to collect data nationally to look at the progression of the national epidemic of HIV disease. This study was to be on behalf of the U.K. Haemophilia Directors.

Protocol for treating HIV infection

A questionnaire was circulated to Centre directors asking them for their current protocol. These will be summarised and presented at the U.K Haemophilia Centre Directors meeting in Oxford at the end of September.

The next meeting was planned for Monday, 24th October 1994. Overall, the meetings have been very constructive and are aiming to capture data on the evolution of the national epidemic of HIV as well as providing guidelines of the continuing clinical care of these patients.

31.8.94

Guidelines for advising couples who wish to have children when the haemophilic partner is HIV positive.

1. Discuss reasons for having a child:

   - Do both wish equally to have a child?
   - What has make them decide to have a child now?
   - Are there any outside pressures for them to have children eg. grandparents, peer group?

   - What effect would it have on the relationship if they could not have children?
   - How would they resolve a difference of opinion about having a child?

2. Provide information about risks of transmission

   - increased risk with multiple exposure
   - increased risk with lower CD4 count
   - increased risk with ↑ p24 Ag (viraemia)
   - increased risk with other G.U infections

3. Possible scenarios to be presented to the couple:

(i) The partner of an HIV positive haemophilic patient could remain HIV negative and have an uninfected child. The haemophilic partner might die earlier from progression of HIV disease than would normally be expected but the mother would have a child which she might otherwise not have had.

(ii) The mother might become infected with HIV but the child could be uninfected and possibly become an orphan.

(iii) Both mother and child could become infected with HIV, resulting in all three family members being infected.

(iv) The woman could have artificial insemination with frozen semen from a screened donor so that she could experience having a child which she and her partner could share without risk of HIV infection. If the child was a girl she would not be a carrier of haemophilia.

4. Measures to make contraception safer if couple wish to proceed in spite of risks.

   - establish fertility before attempting to conceive (sperm count; ovulation)
   - continue to practise safer sex at all times except around time of ovulation. Ovulation Kit to be provided.

5. Anti-HIV test at 12 weeks of pregnancy if couple feel that seroconversion would influence them to choose termination and avoid situation outlined in scenarios (ii) & (iii) above.

6. Anti-HIV test at 38 weeks for obstetricians and midwives information but universal precautions should be followed regardless of result of test.

7. Provided the mother remains negative and practises safer sex, breast feeding is permitted but she should be informed that there have been cases of transmission of HIV through breast milk, particularly if the woman is infected during neonatal period.

8. If the mother is seropositive the infant will be positive and should be retested at 6 monthly intervals. Maternal antibody may persist up to 18 months. Close monitoring of physical health in all positive children is essential.

9. If the mother of the child remains HIV negative, there is no risk of infection for the child. If she becomes positive, the risk is dependant on maternal immunologic, virologic, and placental factors and varies between 7% and 71%.

Reference: Risk factors for perinatal HIV-I transmission according to immunologic, virologic and placental factors. Authors: Michael E St. Louis MD et al. JAMA, June 9, 1993 - Roll 269, number 22

Eleanor Goldman - 19th July 1994

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