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Appendix xii

Adverse Events Working Party

The adverse event reports are prepared on a quarterly basis, and these are based on "orange card" returns sent out from the Oxford Haemophilia Centre.

The Working Party is different from all others, in that there are no regular meetings. Adverse events received are sent on to other relevant Working Parties or nominated individuals who may wish to take further information. In the period July 1996 to June 1997, 43 adverse events were reported from Centres. Details were provided in the regular quarterly reports (copies appended), but included:

- 16 new inhibitors
- 16 apparently allergic reactions to concentrates
- 3 cases of unusual bleeding in patients receiving protease inhibitors.
- 2 cases of hepatitis A.

The reports of bleeding in patients on protease inhibitors led to a publication in the journal "Haemophilia", acknowledging the role of the adverse events reporting system of UKHCDO: Protease inhibitors and unusual bleeding in haemophiliacs: T.T. Yee, P.J. Amrolia, C.A. Lee, N. Mir and P.L.F. Giangrande. *Haemophilia* (1997), 3, 219-221.

GRO-C

P.L.F. Giangrande Oxford, 3rd September, 1997

The Oxford Radcliffe Hospital A National Health Service Trust

HIV WORKING PARTY

| | Haem.A | Haem.B | vW | Total |
|--------------------------|---------|--------|-----|-------|
| HIV Tested | 3766 | 653 | 919 | 5338 |
| HIV+ | 1276 | 32 | 13 | 1321 |
| HTV+ Currently Alive | 523* | 18 | 7 | 548 |
| AIDS Cases Currently Ali | ve** 50 | 1 | 2 | 53 |
| AIDS Deaths** | 549 | 10 | 6 | 565 |
| Other HIV+ Deaths*** | 204 | 4 | | 208 |

- Includes 4 Haemophilia A patients who possibly have AIDS we are waiting for HIV94/1 forms or further details to confirm diagnosis. Also includes 38 Haemophilia A and 1 Haemophilia B patients who are usually resident overseas.
- ** Cases accepted as AIDS by both CDSC and Haemophilia Centre Directors. Three Haemophilia A patients not known to have died are usually resident overseas.
- *** Includes 17 possible AIDS cases (16 Haemophilia A and 1 Haemophilia B) we are waiting for HIV94/1 forms.

Other Coagulation Defects

3 Carriers of Haemophilia A have been reported by Directors as HIV+. None have developed AIDS.

1 Acquired Haemophilia A patient (now dead) and 1 patient with an Unclassified Coagulation Defect have been reported as HIV+.

51 Wives/partners of Haemophilia A patients have been reported as HIV+ and 8 of the wives/partners have been reported as having AIDS; 6 of the AIDS cases have died. Another 8 wives/partners have died and probably had AIDS - we are waiting for report forms.

Rosemary J.D. Spooner Oxford Haemophilia Centre

25.07.97