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via email

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Date: 3 October 1995

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**UK HCDO MEETING: 29/9/95 - MACFARLANE TRUST REPORT**

1. A report on the Macfarlane Trust from Dr Elizabeth Mayne, one of the trustees, was read at the UK HCDO meeting.
2. Meetings were now being organised between the trustees and patients and relatives registered with the Trust.
3. There was then comment about the public attitudes survey, and overall the Trust was appreciated, other than that some people did not have very much contact with the Trust.
4. In the survey many respondents complained about poor treatment for HIV, and not being able to play a part in decision making on the best treatment available. An additional request that had been made to the Trust by some of the haemophiliacs and their families, was that the Trust should fund the private costs of in vitro fertilisation. They stated that this was available in the NHS but that they might need to wait 2 years, and so wanted to be able to have this treatment earlier.
5. The Trust had pointed out that it did not have unlimited finances, and questioned whether producing more children which would lead to greater costs for the Trust in the long term was appropriate. One of the Haemophilia Directors pointed out that the Trust would then need to support the children that they had helped to be born.
6. It was felt that individual Directors should write to the Macfarlane Trust giving their views about whether this was an appropriate use of money.

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