Update

Disabled picket Medical Research Council

Earlier this year spina bifida people picketed the Medical Research Council in protest against trials in which 25 per cent of the high-risk women taking part will serve as untreated controls. An open letter to the MRC was distributed.

The programme has been established by the Medical Research Council to test whether multi-vitamin pills given to expectant mothers can prevent spina bifida occurring in their babies. Two thousand high-risk mothers (most of whom already have at least one spina bifida child) will take part in the programme at a number of centres throughout the country. However, says the Handicap Division of the Society for the Protection of the Unborn Child, SPUC, one in four of the women will not be given the multi-vitamin tablets: they will be given 'dummy' pills and will, therefore, be unprotected. They will then be screened and if their babies are found to be handicapped they will be offered a 'therapeutic' abortion to get rid of them.

'The trials are completely immoral and show an utter contempt for the rights and dignity of handicapped people' said 28-year-old Mrs Alison Davis, a spina bifida person, and Organiser of the Handicap Division of SPUC, which was responsible for the picket.

In the open letter to the MRC Mrs Davis said that since 1947 when Nazi doctors who had justified their medical experiments on human beings by saying that they yielded results for the good of society, were denounced at Nuremberg, medical and lay opinion had been adamant that in experiments of this kind, the interests of the subject had to come first.

'This judgement is enshrined in the Medical Research Council's statement on Responsibility in Investigations on Human Subjects, which says "the possibility or probability that a particular investigation will be of benefit to humanity or to prosperity is no defence . . . the individual has rights that the law (1) protects and nobody can infringe those rights for the public good".

'The trials currently being undertaken by the Medical Research Council to test whether multi-vitamin supplements prevent spina bifida fail to conform to these ethical standards. Indeed we believe that by proceeding with these trials the council is exploiting high-risk women, by denying them the best possible chance of having a healthy baby, and insulting the humanity of handicapped people by suggesting that spina bifida babies may be conceived by a deliberate omission of the vitamins, and then killed by abortion because of their handicap.'

The trials had already been condemned by many leading scientists and doctors working in this field of research because they were unnecessary, said Mrs Davis. A study conducted at a number of centres in Britain (over a period of six years) under the leadership of Professor Richard Smithells of Leeds University had already shown very successful results which indicated that the spina bifida recurrence rate in women given vitamin and folic acid treatment dropped to one in 150 compared to one in twenty in untreated women. Consequently numbers of research centres throughout the country had refused to take part in the trials — which had been described by some doctors as 'unacceptable'.

'However, in seeking to justify the trials the MRC has claimed that there might possibly be toxic side-effects from the pills — but there is so little evidence of this that it could not possibly justify giving high-risk women "dummy" tablets. Everybody would most certainly agree that it is essential for adequate follow-up investigations to be maintained in relation to children born to women taking multi-vitamin supplements (which should be taken only on prescription from a doctor) but there is nothing which could possibly justify the structure of the MRC trials in which women will simply be treated as statistics.

In assessing the ethics of the trials we need to ask: "Would they give Princess Diana dummy tablets?" All pregnant women should be given the best that is available and with the knowledge we have, there is no way in which anybody could claim that dummy pills could be better than multi-vitamin tablets.'

Mrs Davis also said, in the open letter to the MRC, that 'we no longer have confidence in the Medical Research Council because we believe that by backing the present multi-vitamin trials they are showing complete contempt for the humanity and rights of women, their unborn children and the handicapped community as a whole.' We therefore challenge the Medical Research Council to prove that these trials are ethical.'

References