Public health: Community action programme 1999-2003 concerning rare diseases

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The recommendation on rare diseases was adopted in the Committee. The recommendation, drafted by doctor MEPs, is on common positions of the Council relating to Commission proposals for Community action programmes for the five-year period 1999-2003. The rapporteur is Guido VICECONTE (UFE, I). The recommendation involves a programme on rare diseases (eg Creutzfeldt-Jakob, Marfan syndrome and paramyloidosis). There are perhaps 5000 such diseases, of which 80% are of genetic origin. The committee decided to retable many of the amendments it had put forward at first reading. The Council came up with a figure of only ECU 6.5 million as opposed to the ECU 14 million wanted by Mr Viceconte. However, the Council agreed with Parliament that it was necessary to fix the budget for the whole five years, whereas the Commission wished to provide funding only on an annual basis. The committee also retabled amendments to the effect that Community involvement was the only effective way of tackling a problem whose scale was too small for proper action in individual countries. Moreover, problems which at first affected only small numbers could eventually spread to the population as a whole. Hence the need for a series of measures such as an early warning system, a pooling of existing European expertise, rapid response teams and the establishment of a Community databank with the widest possible access. The rapporteur also wanted Parliament and the Council to agree that the Commission should be assisted in the management of the programmes by an advisory committee including - a ground-breaking idea - representatives of patient support or voluntary groups.