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

1997/0146(COD) - 11/03/1998 - Text adopted by Parliament, 1st reading/single reading

In adopting the report by Mr Guido VICECONTE (UPE, I) on rare diseases, the European Parliament amended the programme proposed by the Commission, calling in particular for a commitment on the part of the Community to combat such diseases effectively. Although, all in all, the number of people affected by each individual rare disease was relatively small, Parliament considered that, taken together, they were quite prevalent and affected a significant percentage of the population. Accordingly it called for the programme to provide information about rare diseases (including genetic diseases and those caused by aetiological agents) to patients via self-help groups, to health professionals and to researchers. The programme should also foster a surveillance and monitoring system which would make it possible to respond rapidly and effectively when the diseases concerned appeared. Parliament also: -with regard to surveillance of rare diseases, called for action to be taken to ensure their rapid identification, assessment and treatment (it proposed, in particular, that rapid response teams be set up which could be mobilized readily in the event of an emergency); -called for the database provided for under the programme to be made widely accessible over the Internet and by means of telephone hotlines and free information pamphlets, -called for refresher courses for persons involved in dealing with rare diseases (it particularly suggested the setting-up of schools to deal with rare diseases). Lastly, Parliament: -in the field of commitology, called for the Commission to be assisted by representatives of patients or of voluntary organizations with relevant experience, -called for the appropriation for the programme for the period 1999-2003 to be increased to ECU 14 million.