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

1997/0146(COD) - 08/10/1998 - Text adopted by Parliament, 2nd reading

In adopting the recommendation for second reading by Mr Guido VICECONTE (UPE, I), the European Parliament approved the common position of the Council with numerous amendments: - it again proposed a total allocation of ECU 14 million over five years (whereas the Council had proposed an allocation of only ECU 6.5 million); - Parliament reaffirmed that a Community approach, rather than a national approach, was the only effective means of tackling a problem whose scale in individual countries was too small to allow the proper action; - it stressed that diseases which were currently rare might in future spread to the community as a whole, which made it necessary to adopt a range of measures, such as the establishment of a rapid detection and control system; pooling of knowledge acquired in Europe; extension of the programme to genetic disorders and diseases caused by aetiological agents; the setting-up of rapid response teams; the setting-up of databases accessible to all (wide dissemination of information, particularly over the Internet, telephone helplines and free information pamphlets, etc.); training of professionals; promotion of research, etc. The European Parliament also wished agreement to be reached with the Council that, in managing projects, the Commission would be assisted by an advisory committee comprising - and this would be a first - representatives of patient support groups and voluntary organisations.