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

1997/0146(COD) - 15/04/1998 - Modified legislative proposal

In its amended proposal on the action programme on rare diseases, the Commission incorporated 16 of the 28 amendments adopted by the European Parliament at first reading. The amendments which it accepted concerned: -prevention of diseases at Community level, their treatment being too limited at Member State level, -the fact that the number of people affected by these diseases is not negligible, and that they pose serious difficulties for sufferers, -the importance of improving understanding of diseases, -the adoption of an overall policy on the subject including provision for orphan medicinal products and research, the compilation of a Community databank and the setting-up of detection and control systems, -the implementation of the programme by organizations representing sufferers and health professionals, -the extension of the programme to patients and health professionals, -clearer provisions concerning actions relating to rare-disease clusters: the actions concerned are to identify, handle and respond rapidly to such clusters, -as part of information measures, the provision of information about rare diseases to patients' families and maximum dissemination of the information gathered concerning these diseases, -as part of measures to treat clusters, having in place an effective system to monitor rare diseases, promote Community monitoring of rare diseases and make permanent organizational arrangements for providing appropriate responses for rare diseases (networking and training for their treatment). The amendments not incorporated related in particular to the budgetary provisions proposed by Parliament (increasing the allocation) and extending the scope of the programme (aetiological diseases).