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

1997/0146(COD) - 29/04/1999 - Final act

PURPOSE: to establish a programme of Community action on rare diseases within the framework for action in the field of public health (1999-2003). COMMUNITY MEASURE: decision 1295/1999/EC of the European Parliament and the Council. CONTENT: the programme, which has a financial framework of EURO 6.5 million for the period 1999-2003 aims, in coordination with other Community measures, to ensure a high level of protection against rare diseases by: 1) promoting the development of, and access to, a coherent and complementary European information network on rare diseases, using the existing databases; 2) contributing to training and refresher courses for professionals in order to improve early detection, recognition, intervention and prevention in the field of rare diseases; 3) promoting transnational collaboration and networking between groups of persons directly or indirectly affected by the same rare conditions or volunteers and professionals involved; 3) providing support at Community level for the monitoring of rare diseases in the Member States and rapid response to clusters. Rare diseases are defined as diseases, including those of genetic origin, which are life-threatening or chronically debilitating of such low prevalence that special combined efforts are needed to address them so as to prevent significant morbidity or perinatal or early mortality or a considerable reduction in an individual's quality of life. Generally, the prevalance of such diseases is recognised as less than 5 per 10,000 in the Community. Nonetheless, these diseases, taken together, are quite prevalent, affect a significant percentage of the general population and pose seious difficulties for sufferers and their families. The Commission will ensure the implementation of the programme in close cooperation with the Member States and will also cooperate with institutions and organisations active in the field. The Commission will also be assisted by a committee consisting of two representatives of each Member State and chaired by a representative of the Commission. The programme will be carried out in consistency and complementarity with other Community actions in the field of public health as well as initiatives in the sphere of orphan drugs (see COD98240) and medical research. The programme will be open to participation by the associated countries of Central Europe in accordance with the conditions laid down in the Association Agreements or Additional Protocols relating thereto concerning participation in Community programmes. The programme will also be open to Cyprus and Malta, in accordance with procedures to be agreed. Subject to Article 228 of the Treaty (conclusion of international agreements), the programme will also be implemented in close cooperation with the WHO and other international organisations competent in the sphere of public health. The Commission will ensure continuous monitoring and assessment of the programme. It will submit an interim report to the European Parliament and to the Council during the programme's third year, which should take account of developments occurring within the framework for Community action in the field of publichealth. This will be followed by a final report at the end of the programme. Both of these reports will contain information on Community financing in the various fields of action and on consistency and complementarity with other actions in the field of public health. On the basis of the interim report the Commission may, if necessary, make appropriate proposals for modifications or adjustments to the programme. ENTRY INTO FORCE: 29/04/1999. It should be noted that the decision is accompanied by two declarations: 1) the first (interinstitutional) declares that the European Parliament, the Council and the Commission will pay particular attention, among the priority issues to be addressed within the framework of the future programme on public health, to rare diseases and pollution-related diseases and will duly take account of the budgetary implications; 2) the second provides and undertaking from the Commission to inform the European Parliament annually on the decisions taken to implement the programme.