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

1997/0146(COD) - 04/02/1999

A compromise on the respective demands of Council and EP was reached when the joint Parliament /Council Conciliation Committee gave the green light to two programmes for Community action to combat rare diseases. The rare disease programme covers the five-year period 1999 to 2003. There are perhaps 5000 such diseases (eg Creutzfeldt Jacob, Marfan syndrome and paramyloidosis), of which 80% are of genetic origin. Parliament persuaded Council to include in the text an acknowledgement that Community action might contribute unique added value to the treatment of problems whose scale in individual countries was too small to allow effective intervention. Council also agreed to the creation of a European information network on rare diseases, transnational collaboration between voluntary support groups, the use of high technology, information dissemination via the Internet and training for professionals (including those concerned with rapid response to the phenomenon of clusters). The programme will have a budget of EUR 6.5 million. Parliament's rapporteur is Guido VICECONTE (UFE, It), a doctor. Although Parliament's delegation would have liked more funding for the programme, it was decided to concentrate attention on the forthcoming Commission proposal for a new framework programme on public health. In a joint statement by EP, Council and Commission, the three institutions declare that, among the priorities to be addressed in this future programme, they will pay particular attention to rare diseases and will give careful consideration to the budgetary consequences. The Commission also undertook to inform the EP annually on the decisions taken to implement the programmes approved. The Conciliation Committee was chaired by Mrs Nicole FONTAINE, an EP vice-president, and, for the Public Health Council, Mr Erwin JORDAN, German State Secretary for Health. The parliamentary committee responsible is the Committee on the Environment, Public Health and Consumer Protection chaired by Ken COLLINS (PES, UK).