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

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The report - on injury and suicide prevention, rare diseases and pollution-related diseases - was adopted by large majorities in the Committee. The report, all drafted by doctor MEPs, involves first readings, under the codecision procedure, of Commission proposals for Community action programmes for the five-year period 1999-2003. The report by Mr Guido VICECONTE (UFE, It) involves a programme on rare diseases (eg Creutzfeldt Jacob). There are perhaps 5000 such diseases, of which 80% are of genetic origin. The committee felt that Community involvement was the only effective way of tackling a problem whose scale was too small for proper action in individual countries. However, problems which at first affected only small numbers could eventually spread to the population as a whole. By implementing an early warning system and bringing together existing European expertise, rapid response teams could be quickly mobilized in an emergency. Supporting the Commission's proposal for a European database on rare diseases, the committee wanted this made available as widely as possible at no charge. Researchers, specialist doctors, general practitioners, NGOs, patients and their families should all be involved in the programme. The committee adopted an amendment common to all three reports (VICECONTE and TRAKATELLIS (EPP,G) on injury prevention - COD97132 and CABROL (UFE,F) on the fight against pollution related diseasess - COD97153 concerning budgetary provisions. For each programme, the Commission had specified a budget (ECU 1.3 million) for the first year only (1999), but the committee followed the rapporteurs in seeking an indicative framework of ECU 14 million for the whole of each five-year programme. The contention is that money could be recouped, eg through lower medical costs, if the programmes' aims are achieved. The Commission representative said his institution could only accept the ECU 14 million figure in the case of the Trakatellis report and then only if it came within the ceiling of the Community's financial perspective and included the existing EHLASS data collection system.