

## **Rare Diseases Task Force Mandate**

### 1. Purpose of the Rare Disease Task Force

Rare diseases are life-threatening or chronically debilitating diseases which are of such low prevalence that special combined efforts are needed to address them. As a guide, low prevalence is taken as prevalence of less than 5 per 10,000 in the Community.

The aims of the RDTF are:

- to advise and assist the European Commission Public Health Directorate in promoting the optimal prevention, diagnosis and treatment of RD in Europe, in recognition of the unique added value to be gained for rare diseases through European co-ordination.
- to provide a forum for discussion and exchange of views and experience on all issues related to rare diseases.

The specific objectives are:

1. to widen access to high quality information on causes, diagnosis, screening methods, counselling, treatment and care for RD
2. to promote the availability of high quality comparable epidemiological data across Europe regarding incidence, prevalence, survival and inequalities within and between countries
3. to promote the creation of networks of centres of excellence in relation to diagnosis, treatment and outcome measurement
4. to promote the development of a classification and coding system for RD to supplement the International Classification of Diseases, in liaison with WHO
5. to promote effective surveillance, early warning and cluster response in relation to changing risk factors for RD
6. to facilitate the consideration of different models of cross-border health care and health care funding, including quality control issues
7. to promote the exchange of ideas and information regarding quality of life issues, and regarding patient preferences and choice
8. to assist in the diffusion of "good and best practice" by means of presentation and comparison of national health information

### 2. Tasks in relation to Public Health structures and processes

- a. to communicate with the Network of Competent Authorities and Working Party on Morbidity and Mortality on all of the above
- b. to ensure that RD are represented appropriately among Public Health indicators and linked into the European Public Health portal
- c. to assist the Commission in considering RD priorities for the annual work plans

- d. to help prepare the European RD Conference in Luxembourg in 2005
- e. to produce and disseminate a monthly electronic newsletter
- f. to consider the sustainability and long term funding of projects initiated under the Public Health programme
- g. to liaise with the Research Directorate General, EMEA and DG Enterprise concerning research priorities

### 3. Duration and membership

The Task Force is established for the duration of the public health programme 2003-2008. Members are current and past leaders of projects funded by public health programmes, experts nominated by members states, representatives of relevant international organisations (DG Research, DG Enterprise, EuroStat, EMEA, WHO, OECD). Additional members can be nominated on an ad-hoc basis. The total number of participants should not exceed 35 persons, of which 20 have their expenses covered by the EC services. Each member is notified of their reimbursement status.

This mandate can be modified at any time, as often as necessary; on request of its members or on request of the EC services.

### 4. Coordination and secretariat

The RDTF secretariat activities are defined in a contract with EC services.