



USEFUL INFORMATION ON RARE DISEASES FROM AN EU PERSPECTIVE

Definition

Rare diseases, including those of genetic origin, 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.

Objective and issues from a DG SANCO perspective

Rare Diseases are one of the priorities in the new Public Health Programme. According to the 2004 DG SANCO Work Plan, the two main axes of actions are the information exchange by using existing European information networks on Rare Diseases and the development of strategies and mechanisms for information exchange and co-ordination at EU level to encourage continuity of work and trans-national co-operation. Furthermore, regarding Rare Diseases projects, DG SANCO prioritizes generalist networks, which centralize information on as many Rare Diseases as possible and not just a specific group or a single disease.

The final project reports are published on the Europa website.

Useful Commission websites

DG SANCO

www.europa.eu.int/comm/health/ph_threats/non_com/rare_diseases_en.htm

DG SANCO website about Rare Diseases

www.europa.eu.int/comm/health/ph_projects/rarediseases_project_full_listing_en.htm

DG SANCO funded projects under the former Programme on Rare Disease (1999-2003).

The total budget allocated for this Programme was 6.5 million Euros. Strengthening or creation of major established European networks such as ORPHANET, EUROCAT and EURORDIS was achieved through certain of these projects.

www.europa.eu.int/comm/health/ph_information/indicators/ev_20040120_en.htm#1

DG SANCO Task Force on Rare Diseases

www.europa.eu.int/comm/health/ph_threats/non_com/ev_pre2005_en.htm

Two day conference on Rare Diseases (pre-announcement).

The European Commission will organise in the first half of 2005 a two-day conference on the topic of rare diseases. The Conference will be held in Luxembourg, and will be organised in conjunction with the Luxembourg Presidency of the Council.

For further information please contact sanco-c2-health-information@cec.eu.int

DG RESEARCH, TECHNOLOGICAL DEVELOPMENT AND DEMONSTRATION

www.europa.eu.int/comm/research/fp6/index_en.html

6th Framework Programme (2002-2006): Life sciences, genomics and biotechnology for health

DG ENTERPRISE

www.pharmacos.eudra.org/F2/orphanmp/index.htm

Orphan medicinal products

EUROPEAN AGENCY FOR THE EVALUATION OF MEDICINAL PRODUCTS (EMEA)

www.emea.eu.int/htms/general/contacts/COMP.html

Committee for Orphan Medicinal Products (COMP)

Other useful websites

www.orpha.net

ORPHANET: European wide database on rare diseases and orphan drugs

www.eurocat.ulster.ac.uk

EUROCAT: European network of population based registries for congenital anomalies

www.eurordis.org

EURORDIS: European alliance of patient organisations