An European Network of Information Centres for Rare Diseases

Fact Sheet

Project Information

EURARENET

Grant agreement ID: BMH4983415

Project closed

Start date
1 April 1998

End date
31 March 2001

Funded under
Specific research, technological development and demonstration programme in the field of biomedicine and health, 1994-1998

Total cost
No data

EU contribution
No data

Coordinated by
MARIO NEGRI INSTITUTE FOR PHARMACOLOGICAL RESEARCH
🇮🇹 Italy

Objective

Brief description:
The present project programme is aimed to establish an network of information centres on rare diseases in Europe. It has been denominated EU.RARE.NET (EUropean RARE disease NETwork). The purpose is also to establish a model for collection and dissemination of information which could be made available by the participating partners to third parties in the European Community. The project programme will be articulated in three tasks aimed to develop the following

strategies:

The first task is to establish an inventory of rare diseases in selected areas of medicine; all available information on rare diseases will be collected by the means mentioned in the methodology section.

The project programme will then develop adequate systems for the dissemination of the collected information, and means to render inforrnation available at local and European level. It will also establish a database including information about relevant experts in the different fields, centers and lay organizations.

Finally rare diseases databases will be implemented to be of use for basic and clinical researchers, health authorities, and pharmaceutical industries in planning studies interventions, development of new diagnostic and therapeutic devices.

The methods employed for the implementation of the various tasks of the projects will consist in the following steps:

Consultation of major medical literature data banks (MEDLINE, EMBASE, etc);

Exploitation of the most advanced systems (INTERNET, Mailing lists, Electronic mail) for information retrieval;

Access to general and specialized medical libraries;

Collaboration with known experts in the fields to be covered;

Collaboration with the Scientific Societies at National and European level;

Collaboration with central agencies of the European Commission with special regards with those concerned with drugs regulation and registration procedure;

Establishment of a World Web Homepage for dissemination of results; Preparation of printed material for patients and patient support groups. A crucial issue in a project concerned with evaluating and disseminating information to the public in the field of health is of course the quality of the information provided.

A quality control is therefore to be considered for the present project. An independent panel of distinguished individuals with expertise in different areas of Medicine can provide such quality control by periodically checking the information material and by supervising the entire project development.

Keywords:
Rare Diseases, orphan drugs, clinical trial, epidemiology, renal diseases, immunologic diseases, central nervous system diseases, disabilities, handicap, rare cancers

Objectives:<o establish a network of information centres on rare diseases in Europe.<o establish adequate delivery systems for collected information, and means to render information ready available at local and European level.<o establish rare diseases databases to be of use for basic and clinical researchers, health authorities, and pharmaceutical industries in planning studies interventions, development of new diagnostic and therapeutic devices.

Fields of science (EuroSciVoc)

natural sciences > biological sciences > **neurobiology**

natural sciences > computer and information sciences > **databases**

medical and health sciences > health sciences > public health > **epidemiology**

medical and health sciences > clinical medicine > **nephrology**

medical and health sciences > clinical medicine > **oncology**

Programme(s)

FP4-BIOMED 2 - Specific research, technological development and demonstration programme in the field of biomedicine and health, 1994-1998

Topic(s)

4.6.2 - Educational tools

Call for proposal

Data not available

Funding Scheme

CON - Coordination of research actions

Coordinator

MARIO NEGRI INSTITUTE FOR PHARMACOLOGICAL RESEARCH

EU contribution

No data

Total cost

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