

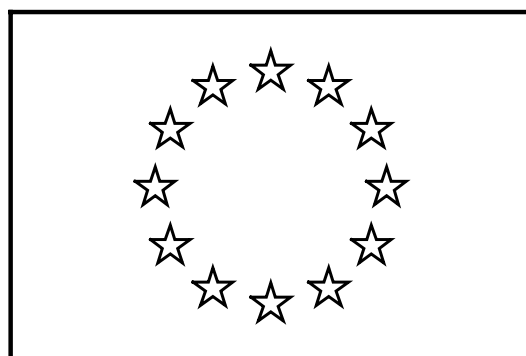


Programme of community action on rare diseases

Contract n° 2000/CVG4-808

ORPHANET : Final scientific report

February 2002



Summary

The project was to extend the content of the already existing ORPHANET database which was exclusively a French project from 1997 until 2000, to build up a truly European database. The first year was the feasibility study year and a pilot study with a few countries (4).

The European project had two parts: 1) the establishment of an on-line Encyclopaedia on rare diseases, 2) the extension of the existing database of services to other European countries.

For the encyclopaedia, the board of editors was established progressively, speciality by speciality and authors of texts nominated. The number of authors who have already written up one or more entries is 116, out of 428 who have accepted so far. For the 3,500 diseases, there are on-line: 899 summaries in French, 731 summaries in English, 327 review articles in French and 116 review articles in English.

The new European version of the website was launched on October 15, 2001. This is a true new version, with a new graphic chart and the possibility to query in six languages. The general information about rare diseases and orphan drugs in general has been dramatically expanded.

The partners were trained to use our methodology through visits, e-mails and phone calls. All the partners have identified their sources of information. The data about services are partially collected in the four new countries and updated for France. All the thesaurus were translated into Italian and German as well as the screens. The number of names of diseases with their synonyms to be translated was over 6,000.

A quality charter was defined by the partners and agreed on.

The usefulness of the database was assessed through the number of connections. In November 2001, we have had during the month 44.425 visits from 30.428 different sites from 94 different countries. The average number of pages read was 10 per visit. In addition we received an average of 65 unsolicited e-mails from patients or professionals. A methodology to handle ethically these messages was developed.

As a project leader of Orphanet, Ségolène Aymé was invited 21 times within the first year of the contract to give a lecture on Orphanet. These invitations came from the Academia, the Industry and from Agencies and took place in five different European countries.

The Orphanet project is developing according to the plans. The first year was a very busy one which permitted to explore all the difficulties for transmitting our five-year experience with data collection. The procedures are now well in place and should be easily adopted by the new partners. The experience also clearly showed to the partners that there was a great need in getting national funding to expand the local teams. Several countries are on the way of having complementary funding at the governmental level.

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