Título del Proyecto	Development of the European portal of rare diseases and orphan drugs - ORPHANET
Nº de expediente asignado	Agreement nº: 2010-22-06
Abstract	ORPHANET main objective is to provide the community at large with an inventory of RD, an encyclopaedia in as many languages as possible, and a directory of expert services in the participating countries. The project is to improve the update of the encyclopaedia and the update of the directory of services, to put in place a process to ensure swift management of translations, swift collection of data and validation by national health authorities before publication. The project is also to establish the governance that Orphanet deserves to ensure its mission at international level. The website will be adapted to offer national front pages in national language(s), and the possibility to disseminate information on national policy documents and national events. Each Member State will benefit from the core infrastructure already developed and will have the opportunity to offer its citizens a national portal at a marginal cost. All the collected information will serve as a source to map health care services in Europe and to build indicators.
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Enlaces:	https://www.orpha.net/consor/cgi-bin/index.php?lng=EN