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ISO 9001:2000, ATTIVITÀ DI FORMAZIONE
DI NUOVI RICERCATORI IN BIOMEDICINA

Ranica, October 15th 2004

TO WHOM IT MAY CONCERN

Re: Information Centre for Rare Diseases and Orphan Drugs in Bulgaria

Hereby, we are expressing our support for the Bulgarian Association for Promotion of Education and Science to develop successfully the project "Information Centre for Rare Diseases and Orphan Drugs in Bulgaria".

The number of specialized centres for rare diseases in Europe is limited. However, their importance and impact on the public health of the European Community is enormous. First, they provide patients, relatives and doctors with up-to-date high-quality information about the conditions of interest. Second, they systemize and create databases of hospital settings, genetic and clinical laboratories and prominent medical teams, which are occupied with a given rare disease research or study. Third, they create databases of patients with rare diseases. Fourth, these centres serve as a bridge between the patients with rare diseases and the public health care systems by advocating for the basic human right to receive contemporary and equal medical care and by lobbying for adequate rare disease and orphan drug legislation.

The existing information centers for rare diseases in Europe are not targeting the Eastern European countries (EEC), in which more than 40% from the total population of Europe are living, according to the United Nations Population Division.

The information, those centres provide is mainly in Latin-based languages - English, Italian, French, Dutch etc. Their databases contain relevant information, useful and utilizable for citizens from the Western European countries only. At the other hand, the experience and knowledge that those institutions have accumulated through the years should not remain reserved, but must be disseminated among the others, thus putting the basis of a real pan-European network on rare diseases.


The Clinical Research Center for Rare Diseases *Aldo e Cele Daccò* (a part of the Mario Negri Institute for Pharmacological Research, Italy) is one of the oldest European facilities, dedicated entirely on the rare diseases promotion and research. It operates successfully one of the first Information Centre for Rare

Diseases (ICRD) in Europe - a free of charge public service, founded in 1993 and aimed to provide up-to-date information on rare diseases with particular emphasis on aetiology, pathogenesis, genetic aspects, preventive measures, established and experimental treatments, referral research centres.

Based on the knowledge and experience of the Mario Negri Institute, we are glad to support the establishment of an Information Centre for Rare Diseases and Orphan Drugs, situated in Bulgaria and serving also the other Eastern European and ex-Soviet countries. The specific objectives of the project also include the establishment and equipment of an Office of Rare Diseases, creating multilingual WWW site on rare diseases (in Bulgarian, English and Russian languages), building registries of patients, associations, clinical trials and clinical centres, free phone services etc.

The Bulgarian Association for Promotion of Education and Science (BAPES) is a young and ambitious Bulgarian non-governmental, non-profit organization. Its founder, Dr. Rumen Stefanov has more than 3 years experience in rare diseases, being a Marie Curie fellow at the Mario Negri Institute under the Program of EC "Quality of life and management of living resources" in 2001. He is a specialist in public health and health management and holds the position of a senior assistant professor in public health at the Medical University of Plovdiv (Bulgaria). For the period June 2003 - June 2004 he has also contributed as a consultant in public health and epidemiology at the Clinical Research Center for Rare Diseases *Aldo e Cele Daccò*.

So, entirely convinced in the exclusive importance of the project at both the national and European level, as well as in the organizational capacity of the coordinators, we once again express our readiness to support the establishment of an Information Centre for Rare Diseases and Orphan Drugs in Bulgaria.



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