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Editorial

First of all, with this first newsletter of the EuroMyasthenia network, I would like to take the opportunity to thank all the participants that made possible to write down the "Myasthenia Gravis network project", and special thanks to Kostas Poulas and Socrates Tzartos who gave the idea to achieve it.

Second, I would like to thank the European Community (DG SANCO) that gave us the opportunity to think about Myasthenia Gravis as a public health problem.

With this EuroMyasthenia project, we succeed to combine scientific teams, clinicians and associations of patients. The main advantage is that the outcome of basic research will be immediately disseminated to other actors involved in the Myasthenia Gravis field, either as a patient or as a medical professional.

The first meeting will be organized at the end of the year 2006 in Paris, and the first results of the main tasks will be presented.

The EuroMyasthenia website is under construction and very soon all information regarding Myasthenia Gravis will be brought together in this website.

I wish you all a successful and productive work in a friendly atmosphere of communication.

Sonia Berrih-Aknin
Coordinator



To get info on the project please contact:

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Objectives of the project

EuroMyasthenia is a European project which objectives are to improve knowledge and information on Myasthenia rare disease.

The main aims are to:

1. Standardize biological, clinical and histological criteria
2. Develop a database at a European scale to serve as a basis for epidemiological studies all over the EU countries
3. Promote surveys among the organisations of MG patients to determine the influence of psychological and socio-economical determinants in the onset and/or aggravation of the disease
4. Promote the establishment of specific European Card for MG patients
5. Disseminate data via a web-site connected to the EU

Fundamentals of EuroMyasthenia project

Myasthenia gravis (MG) is a rare and disabling chronic neuromuscular disease.

There is a need for combining the efforts to improve the knowledge on this disease for the following reasons:

1. MG is a rare disease (prevalence about 10/100 000)
2. it is heterogeneous
3. it could be life-threatening, when the respiratory muscles are affected
4. the diagnosis is not always easy to make
5. the clinical criterion and therapeutic approaches are different among the European countries
6. there are aspects in the pathogenesis of the disease that are not yet clear
7. there is no cure for this disease
8. many of the drugs used for the treatment of MG have severe side-effects
9. some pharmaceutical molecules, such as anaesthesia agents are life-threatening for the patients.

Strategy of EuroMyasthenia

The strategy of EuroMyasthenia is to bring together 31 groups from 14 different countries, including 3 major categories:

- scientists who have made substantial contributions to the understanding of MG
- clinicians experienced with the management of MG patients
- associations of MG patients.

The members of the network will join forces to construct a database including some indicators of health as well as clinical, biological, and psychosocioeconomical factors collected by members of the network. Further analyses of this database will enable to achieve main objectives of the EU call and promote a better classification and treatment of MG patients. A better knowledge of the disease and more detailed information for the general practitioners and neurologists should avoid erroneous diagnosis, and improve treatment and health. In the long term, such coordinated action on a European level will provide a solid evidence base for healthcare management, and will enhance the efficacy of healthcare systems all over Europe .

Purpose of our newsletter

We will edit and publish this newsletter every other month to disseminate the results of our project and to provide all the partners with information regarding the MG subjects. We plan to present the participating groups and to promote the results of their research. We also plan to give information for the MG patients and their families. The newsletters will be on the EuroMyasthenia website and all the partners are requested to send any information to be published to Kostas Poulas (kpoulas@pasteur.gr). In the newsletters you will also find all the news regarding our annual project meetings and other scientific issues.

Participants

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➤ Foreseen calendar of the EuroMyasthenia project:

- **End of July 2006:** The EuroMyasthenia website will be available online
- **December 2006:** First meeting of the project is planned to be organized in Paris