



NEWSLETTER N° 3, March 2007

# EuroMyasthenia



## Welcome

*Dear Colleagues, it was my great pleasure to welcome all of you to our first meeting last December in Paris. The whole event was very stimulating and a good chance to discuss myasthenia as a public health problem. Presentations from each partner in the Network gave us all the opportunity to realize what progress had already been made in the project and to plan our future actions.*

**Sonia Berrih-Aknin**  
Coordinator

To get info on the project please contact:  
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The meeting was held on December 18, 2006 at the Maison Internationale (Room Gulbenkian), Cité Universitaire, Paris.

In her welcome address, **Sonia Berrih-Aknin**, our coordinator, briefly explained the objectives of the network and the specific rules of the European Union that have to be followed. She also said a few words on the budget and on the results expected from the EuroMyasthenia project.



**Renato Mantegazza** presented the main objectives of the patients' database under construction and described the rules that should be adhered to for its use. All then participated in general discussion on the EU directives for protection of patients' rights and privacy.



**Chantal Tallaksen and Angelina Maniaol**

presented their very detailed questionnaire in English, as a base for epidemiological analysis of psychosocioeconomical determinants in myasthenia gravis. Suggestions for additional endpoints were offered by participants in the ensuing general discussion .



**Nils Erik Gilhus** explained the tools that will be used for the epidemiological analysis of the available data and how this analysis can interact with the database under construction.



**Socrates Tzartos**

explained the tools that will be used for the dissemination of the results and some ideas for the evaluation of the project.



**Angela Vincent** presented the directions for standardisation of laboratory and clinical data in as many centres which provide diagnostic serology as possible, thereby increasing the number of patients that can be identified. **Alex Marx** proposed approaches for standardization of Thymic Pathology, with as main objective the optimization of therapies for specific MG subgroups.



**Konstantinos Poulas** presented the newsletter.

**Eric Franqueville**

presented the website  
[www.euromyasthenia.eu](http://www.euromyasthenia.eu)



**Almost all the participants!**

Please visit the website and contribute to it actively

- ✉ Communicate with the webmaster by E-Mail ([euromyasthenia.umar8162@u-psud.fr](mailto:euromyasthenia.umar8162@u-psud.fr))
- ✉ Post a message on the guestbook
- ✉ Post a message to react to an article
- ✉ Post news to inform the Network or the visitors of any event relative to Myasthenia Gravis.

### Interesting meetings

- *May 13-16, 2007: 11th International Conference on Myasthenia Gravis and related disorders, Chicago, USA (more info: [www.nyas.org](http://www.nyas.org))*
- *August 21-25, 2007: 13th International Congress of Immunology (ImmunoRio2007), Rio de Janeiro, Brasil*