



Summary

- Welcome
- The “Evidence Based Myasthenia Gravis” meeting
- Our newsletter
- Euromyasthenia website
- Interesting meetings

Welcome

*The present newsletter is focused on the **The “Evidence Based Myasthenia Gravis”** meeting, held in Milan last November, a meeting organised by the A.I.M. Associazione Italiana Miastenia e Malattie Immunodegenerative – Amici del Besta onlus. We would like to congratulate the organisers for this interesting and interactive event.*

We also present our project web site, hoping that it will be an active communication tool for our partnership.

Sonia Berrih-Aknin
Coordinator

To get info on the project please contact:
Mélinae Cuvelier (melinee.cuvelier@u-psud.fr) or Eric Franqueville (eric.franqueville@u-psud.fr)

The “Evidence Based Myasthenia Gravis” meeting (Milan, Italy) November 11st and 12nd, 2006.

The meeting was organised by the A.I.M. Associazione Italiana Miastenia e Malattie Immunodegenerative – Amici del Besta onlus. International speakers were invited to review current treatments for myasthenia gravis according to evidence based criteria. More than 120 participants (scientists and clinicians working in the area of Myasthenia Gravis) attended the meeting and participated with high interests to the discussion. Delegates from four Associations of MG patients (Italy, Croatia, Spain, Hungary) attended the meeting contributing with their experience from the patients' side.

Major topics presented in the first day of the meeting were:

- Evidence Based Medicine: general concepts (G. Filippini, Milan, Italy);
- Neurophysiological diagnosis (D. Sanders, North Carolina, USA);
- Immunological diagnosis (A. Vincent, Oxford, UK);
- Mediastinal imaging (D. Scaramuzza, Milan, Italy);
- Thymus pathological diagnosis (M. Barberis, Milan, Italy);
- Anticholinesterases and steroid treatment (F. Cornelio, Milan, Italy)
- Immunosuppressive agents (A. Melms, Tübingen, Germany);
- Immunomodulatory approaches (C. Antozzi, Milan, Italy);
- Thymectomy (R. Mantegazza, Milan, Italy).

The general discussion resulted in new insights and projects for a better clinical management of MG patients. On the second day of the meeting, S. Berrih-Aknin (Paris, France) and F. Baggi (Milan, Italy) presented the European Myasthenia Gravis Network and the Development of an MG-dedicated database for clinical, immunological and pathological aspects; M. Leonardi (Milan, Italy) closed the meeting presenting the results of the WHO-DAS (Disability Assessment Scale) study on the Italian MG population. During the meeting of the European MG patients' Association Representatives, all delegates agreed to promote the European Federation of Myasthenia Associations, with a provisional organization needed to move the first steps towards the official recognition of this Federation in Europe, opened to all the patient's associations.

Evidence Based Myasthenia

Palazzo delle Stelline
Sala Leonardo
Corso Magenta, 61
Milan
November, 10 - 11 2006

Our newsletter

We edit and publish this newsletter regularly to disseminate the results of our project. Next newsletter will be devoted to the results of our meeting, while the following will have information for the participating partners. The authors of the newsletter will soon start asking all the partners for their contribution.

Newsletter EuroMyasthenia, December 2006

EUROMYASTHENIA WEBSITE

We are happy to announce the birth of the **EuroMyasthenia Website**. EuroMyasthenia website is one of the specific objectives of EuroMyasthenia EC Project.

It is available from www.euromyasthenia.eu and hosted by Orphanet, another network supported by EU on rare disease.

Welcome to EUROMYASTHENIA [www.euromyasthenia.eu]

Welcome to EuroMyasthenia Public Website
- www.euromyasthenia.eu -

The objective of this site is to disseminate the research results concerning the European project EuroMyasthenia and to communicate on the Myasthenia Gravis rare disease.

In order to identify the involved partners, please click on the map.

To get information about the project and on the network activities, please click on the titles in the **Informations** and **Scientific activities** side-boxes.

To get advices about Myasthenia Gravis in your country, please visit **the FAQ section**.

December 2006

S	M	T	W	T	F	S
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03	04	05	06	07	08	09
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

Newsletter

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A website, what for?

- To increase communication between Researchers, Clinicians and Organisations of patients
- To help for dissemination of the Newsletter in relation to the "EUROMYASTHENIA" European network
- To disseminate data and to help the scientific community to get benefits from the progresses made in the various disciplines involved in the EC project. Surveys or guidelines relative to the project activities might be published on the website.

Description of the website:

EuroMyasthenia website is a portal where various web services are activated and adapted.

Articles can be displayed from the drop-down menus in the article-boxes '**Informations...**' and '**Scientific activities**'.

Side-boxes on the portal permit access to articles, to a calendar, to search keywords on the Website or to subscribe automatically to the EuroMyasthenia newsletter.

Download, FAQ and News sections are accessible from the icons on the upper part of the portal.

Interactive options on the portal allow the visitor to post News, to react to an article published on the website, to communicate with other members via tiny messages e.t.c. For these options, being registered as a member is free but obligatory.

Future development of the Website:

A questionnaire will be prepared and submitted to the partners of the network and also to the visitors, to evaluate the website.

A restricted working area dedicated to the active partners of the network will be installed. It will be used to prepare and discuss about documents relative to the project; a forum might be installed for that purpose.

Evolution of the website will also be discussed during the first meeting of EuroMyasthenia project that will take place in Paris the 18th of December 2006.

If you wish to contribute actively to the website or to give your opinion on the website do not hesitate to:

- ✉ Communicate with the webmaster by E-Mail (euromyasthenia.umr8162@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—May 16, 2007: 11th International Conference on Myasthenia Gravis and related disorders, Chicago, USA (more info: www.nyas.org)