

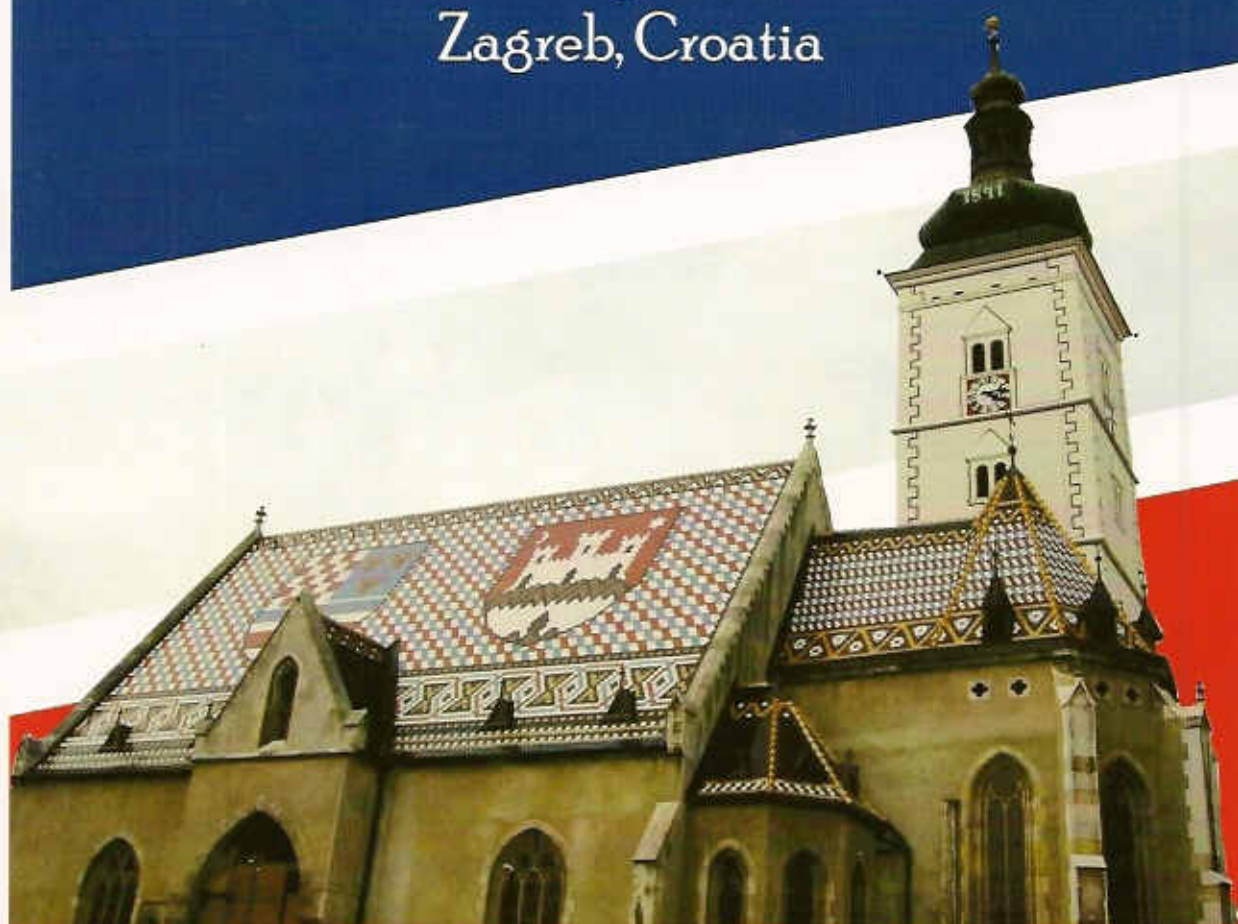
European Myasthenia Gravis

Association

Second Annual Meeting
and General Assembly

February 26, 2011

Zagreb, Croatia



EuMGA

**European Myasthenia Gravis Association
Second Annual Meeting and General Assembly
Zagreb, Croatia
February 26th, 2011**

Dear EuMGA Friends,

We are pleased to welcome you to the Second Annual Meeting and General Assembly of the European Myasthenia Gravis Association (EuMGA) in Zagreb. This venue was chosen to honour the memory of Josipa Gazibara, the inspirator and first Chairperson of EuMGA, who was also the President of the Croatian MG Association.

In organizing this meeting, our aim was to make it open and accessible to all Myasthenia Gravis Patient Organisations in Europe, members and non members of EuMGA. Our intention is that you, as representatives of MG patients in your respective countries, will have the opportunity to present and share your expertise and good practices, with an accent on the specific problems encountered or specific successes.

We are honoured to host you and we believe you will enjoy the beautiful location, as well as our discussions on common problems and needs.

Wishing you an enjoyable and fruitful meeting,

Fulvio Baggi

Chairperson

Nadia Radulescu

Cristina Vatteroni

Peter Finney

EuMGA Organizing Committee

**VENUE:
Hotel LAGUNA- Room "MIRNI SALON"
29 Kranjčevićeva Street
10000 ZAGREB, CROATIA**



The European Myasthenia Gravis Association

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EuMGA Board of Directors:

Fulvio Baggi	Chairperson
Peter Finney	Treasurer
Rudolf Janzen	Director
George Makris	Director
Nadia Radulescu	Director
Cristina Vatteroni	Director
Aila Weaver	Director

In memoriam Josipa Gazibara (1945-2010)

Josipa was born in 1945 in Jazvine, Krapina Croatia. She graduated from the Medical High School in Zagreb, then worked at the Otolaryngology Clinic KBC, Zagreb. She retired in 1985 because of her Myasthenia Gravis. Since then, she dedicated her life to charity and volunteer activities.

She graduated from St Andrew's College of Education, Glasgow and the One Week Overseas Colleagues Course at the St. Christopher's Hospice, London.

In 1990 she founded the Croatian Myasthenia Gravis Society and was elected as president.

She was the initiator and founding member of the Alpe-Adria Myasthenia Gravis Organization, bringing together MG associations from Italy, Croatia, Slovenia and Hungary.

She was the coordinator of the Section for persons with special needs, part of the Croatian-American Association for disabled persons. She was a member of the Committee of the Croatian Association for social assistance, at the Croatian Medical College.

Every summer, together with her colleagues, she organised the Annual Summer School and programme for rehabilitation and re-socialization for persons with Myasthenia Gravis, in Zaton Nin, Croatia.

Colleagues from other countries were invited there, with the intention to continue a tradition of a European summer camp for MG people in the future.

She wrote the book "Myasthenia Gravis", dedicated to persons suffering from this disease, which was very successful, being printed in two editions. She also wrote the book: "Kinetotherapeutic programme for persons with Myasthenia Gravis", which was translated into several languages.

Since 1991, Josipa Gazibara was a member of the European MG Working group (founded in 1986 in Billund), and since 2006 an active collaborating member at the Euromyasthenia Group.

At the Euromyasthenia meeting in Milan in 2006 the idea of founding the European Federation of MG Patients Associations was promoted.

Josipa Gazibara, as president of the Croatian Union of MG Societies, organised in May 2008 a European MG meeting in Copenhagen, where the basis of the European MG Association (EuMGA) was agreed. The EuMGA was registered as a UK Charity in July 2009.

In December 2009 in Paris, at the EuMGA's first general meeting, Josipa Gazibara was elected as the first chairwoman.



LIST OF PARTICIPANTS

EuMGA FULL MEMBERS

Croatia	Croatian Union of Myasthenia Gravis Societies	
	Branka Gracalic, dipl. Iur. Dubravka Čizmić, Prof.dr. Marija Šoštarko, doc.dr. Marija Žagar, prom.dr. Davorka Vranjed, vms. Biserka Hajder, Zlatko Kršil prof. Željka Kanoti, Zlatan Gazibara	branka4748@gmail.com domgh@zg.t-com.hr marija.sostarko@zg.t-com.hr mzagar2000@gmail.com
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	Aila Weaver	toimisto@suomenmg-yhdistys.fi
France	Association des Myastheniques (AMIS)	
	Claire Bellenger,	claire.bellenger@wanadoo.fr
Germany	German MGA (DMG)	
	Rudolf Janzen, Hans Rohm, Bettina Schubert	info@rwcjanzen.de bettina.schubert@dmg-online.de
Greece	Hellenic Myasthenia Gravis Association (H-MGA)	
	George Makris	makres@otenet.gr
Italy	Associazione Italiana Miastenia Grave AIM	
	Fulvio Baggi	baggi@istituto-besta.it
Italy	Associazione Italiana Miastenia Onlus MIA	
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Romania	Romanian Myasthenia Gravis Association (ANMGR)	
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ASSOCIATED MEMBERS**Denmark****Danish Myasthenia Gravis Association****Johannes Graavgard Skov**myasteni@gravgard.dk**Hungary****Myasthenia Gravis Önssegítő Betegesoport MEOSZ****Telekné Gyurina Krisztina**telek.kriszti@gmail.com**Alexandra Telek.****ASSOCIATED MEMBERS (pending approval)****Netherlands****Dutch Neuromuscular Disease Association, MG Working Group****Johan Voerman**j.w.t.voerman@hetnet.nl

PROGRAMME

Saturday February 26th, 2011

8:45 – 9:00 Wellcome

9:00 – 9:30 Josipa Gazibara – In Memoriam

Open presentations from MG Associations, Part 1

9:30 – 9:45 Croatia - Croatian Union of MG Societies- Branka Gracalic

9:45 – 10:00 Romania - Romanian MG Association (ANMGR) - Nadia Radulescu

10:00 – 10:15 Germany - German MG Association (DMG) -Bettina Schubert

10:15 – 10:30 Hungary - MG Önségitő Betegesoport (MEOSZ) -Alexandra Telck

10:30 – 10:45 Nederlands - Dutch Neuromuscular Disease Association (VSN)
(Myasthenia Working Group)-Johan Voerman

10:45 –11:15 Coffee break

11:15 – 13:00 **EuMGA General Assembly**, Reports, General discussions and Elections

13:00 – 14:30 Lunch (offered by EuMGA)

Open presentations from MG Associations, Part II

14:30 – 14:45 Italy - Associazione Italiana Miastenia Onlus MIA-Cristina Vatteroni

14:45 – 15:00 UK - Myasthenia Gravis Association of the UK (MGAUK)-Peter Finney

15:00 – 15:15 Italy - Associazione Italiana Miastenia Grave AIM -Fulvio Baggi

15:15 – 15:30 Finland - The MG Association of Finland - Aila Weaver

15:30 – 15:45 Greece - Hellenic MG Association (H-MGA) - George Makris

15:45– 16:00 Discussions posters

Denmark - Danish MG Association -Johannes Graavgard Skov

France - Association des Myastheniques (AMIS)- Claire Bellenger

CROATIA

Croatian Union of Myasthenia Gravis Societies

Speaker: Ms Branka Gracalic

Brief history of the Croatian MG Associations

In Croatia, there are today three closely collaborating MG Associations:

a) The MG Society of Croatia, which was founded in February 1990. Its headquarters are in Zagreb. Full members are patients with MG, while associate members are friends and medical professionals. The majority of its programs and activities are carried through voluntary work of its members. The Society develops programs and helps in research concerning MG; it also provides health education for patients and members of their families by informing them about MG and providing other necessary assistance.

b) The Zagreb MG Society, which was founded in 1998. This was created because most of the patients are from Zagreb.

c) The Croatian Union of MG Societies, which was established in 2006. The Union is a social, humanitarian, and nonprofit association for all the MG societies on the territory of the Republic of Croatia. The Union coordinates activities of all Croatian MG Societies and represents them in Croatia as well as abroad. Croatian Union of MG has a Medical Council and collaborates with the Center for Neuromuscular Diseases at the Department of Neurology, Medical School of Zagreb. Dr. Marija Zagar, assistant prof., is the head of the Center. She is a major supporter of the activities of the Union.

Activities and goals:

The Societies help in educating MG patients and their families, as well as the medical staff and other experts involved in medical treatment of these patients with various lectures and seminars. The members participate in various meetings organized in Croatia and abroad. Publishing activities are also very important, as well as counseling centers, their primary role being health education. The Societies publish various brochures, leaflets, newsletters, and booklets about MG and inform the public on MG through the media.

Other activities include the organization of physiotherapy programs, courses that include regular breathing exercises in order to prevent osteoporosis, and permanent counseling work to provide psychological, social, healthcare, as well as legal aid.

Summer school – Zaton

In addition, the Societies offer a traditional summer school, the summer camp in Zaton, with lots of activities. For example, education about MG, a kinetic physiotherapy course, relaxing exercises, consultations, and rich social activities such as mini-golf, bowling, walking, swimming, and others, in the fresh and healthy sea air. For rainy days, there are plenty of social games inside.

Problems:

There are two main problems that the Societies and the Union have faced throughout their activities. 1) MG patients and their problems are very often misunderstood by their family, friends, and even doctors; MG Societies and the Union act in order to help these members in need. 2) Another great problem was the lack of Mestinon, which is necessary for MG patients. The representative of the Union explained the problem to the representatives of Ministry of Health and Mestinon is now available regularly.

FINLAND

The Myasthenia Gravis Association of Finland

Speaker Ms Aila Weaver

Activities of the Myasthenia Gravis Association of Finland

The Myasthenia Gravis Association of Finland is a patient organisation which was founded in 1973. There are currently 1144 MG patients in Finland (population 5,2 mill.). The MG association has 663 members of which 599 are patients. The association is run by a 9 member board, the board is elected in the annual general meeting. All board members are currently patients.

The association aims to help MG patients to cope with the disease by providing information, peer support, rehabilitation possibilities and by looking after the availability and compensation of MG medicines. Also spreading the knowledge about MG to medical personnel and the general public is very important.

The main patient activities include face to face meetings, e.g. Annual MG-days (a weekend with specialist presentations and other activities) and local MG-group meetings (4-6 times/year in five different cities). Every second year the association organises trips to abroad for MG patients and their families (self paid). Information about MG is spread by providing MG patient guides (new guide made in 2008) and brochures, and by publishing a 32 page MG magazine four times a year . Newsletters are sent when needed (2-3/year). The internet pages are the most important information source for the latest information on MG, e.g. availability and compensation of MG medicines. Peer support is organised via 15 contact people from different parts of the country (all MG patients working voluntarily). Rehabilitation courses (2-4/year, 10-15 participants in each) for different kinds of needs are organised in different parts of the country. For newly diagnosed MG patients there are 1-2 adaptation courses annually (financed by the Social Insurance Institution of Finland).

The association's activities are mainly funded by the financial support from Finland's Slot Machine Association.

GREECE

Hellenic Myasthenia Gravis Association (H-MGA)

Speaker: Mr George Makris

A basic aim of our Association in collaboration with other Greek Associations that represent disabled people as well, is to try to confront with consistency and determination some recent governmental plans for the reduction or even the cut of very necessary drugs and therapies which are inevitable elements for our health and the quality of our life. The government must realize that "we are not responsible for our disease"

Besides, we intend to produce some leaflets with useful elements for the privileges of myasthenic people and their families, to organize better the psychological help of our members, to organize seminars for doctors and patients, as we did before, covering the subject of "myasthenia" comprehensively and not only from its neurological aspect.

GERMANY

The German Myasthenia Association

Speaker: Ms Bettina Schubert

The German Myasthenia Association (Deutsche Myasthenie Gesellschaft – DMG) was founded in 1986 and has about 3500 Members to date. Our Association's main Goal is to care for its Members and assist and support them with any Questions/ Queries they might have concerning the various Myasthenia Syndromes (Myasthenia gravis, Congenital MG, Lambert-Eaton-Syndrome). The Head Office of the German Myasthenia Association is situated in Bremen. Apart from that, the German Myasthenia Association has established 40 regional Groups throughout Germany. The head (Director) of each group acts as the contact person for that specific group, organizing meetings in regular intervals and also providing relevant and important Information through professional lectures by MG-Neurologists. The very intense Public work, which aims to create increased awareness, is supported by a 'German Myasthenia Association' Magazine, which is published four times a year, as well as the MG/LEMS-compendium, the MG-Emergency-Identification card, various Information Brochures, Doctor and Hospital Lists, Internet website and active participation in Congresses. Due to the co-operation of both the Board of Directors and the medical advisory team of the German Myasthenia Association, Research Projects regarding MG/LEMS are encouraged and financed, parallel to the compendium, and a scientific Symposium is held once a year. Since 2010 a certification by the German Myasthenia Association of 'Integrated Myasthenia Centres' has been intensely conducted, to ensure an early diagnosis and treatment in MG and LEMS patients, according to qualified clinical standards, nationwide. A register for undesirable Drug-induced side-effects has been established and will be implemented in 2011.

ITALY

The Italian MG Association - Associazione Italiana MIastenia Onlus (Associazione MIA Onlus)

Speaker: Ms Cristina Vatteroni

Our association was founded in Pisa in 1984, and today brings together patients from all over Italy and abroad. Members are mostly part of the 4000 patients which refer to the "Ambulatorio for Myasthenia Gravis Ambulatorio and Surgery of the Thymus" (in CardioThoracic Department, University Hospital of Pisa) directed dr. Roberta Ricciardi, who is also the founder of the Association and current President.

The main objectives of the Association MIA are: help patients with myasthenia and their families, spread in Italy but also in Europe knowledge about myasthenia, both among people and health Institutions, so that myasthenia could be quickly diagnosed and treated appropriately and patients can have the necessary social and health protection.

The Association MIA maintains a web site up to date, has long-experience secretarial-staff always available to inform and talk with patients and provides free Psychological Counseling. MIA makes press, radio and TV information when possible, organizes conferences and training courses for patients and health professionals, prints and disseminates publications including the best known in Italy book "Living Myasthenia - how falling in love with this disease (by Ricciardi-Fontana)". A series of conferences were organized in the homonymous tour "Living Myasthenia" in 19 cities since 2002 to 2010, also including Reiki in 2003 and Zara in 2006, Croatia.

MIA is member of EURORDIS, have been Collaborating Partner of EUROMYASTHENIA, is one of the founding member of EuMGA, in Italy participates to "The Tuscany-Forum for Rare Diseases" and "The National Consulta of Rare Diseases".

ITALY

Italian MG Association, A.I.M. (Associazione Italiana Miastenia a malattie immunodegenerative – Amici del Besta ONLUS)

Speaker: Dr. Fulvio Baggi

The non-profit Italian MG Association, A.I.M. (Associazione Italiana Miastenia a malattie immunodegenerative - Amici del Besta ONLUS) is housed at the Dept. of Neuromuscular Diseases and Neuroimmunology at the Carlo Besta Neurological Institute, in Milan, Italy. It was created in 1981 by Prof. Cornelio, a neurologist at the Carlo Besta Institute, with Prof. Micoli, a pathologist and an MG patient himself, together with several MG patients who attended the Carlo Besta Institute as outpatients. Now, A.I.M. counts around 1,200 members, including patients and family members, as well as other concerned members of the community. The members of the Board include Prof. Cornelio (President), Prof. Micoli (Honorary President), Ms. Cavallini (Vice-President) and Ms. Tromellini (Secretary). A.I.M.'s Scientific Committee is composed of Prof. Cornelio, Dr. Mantegazza, and Dr. Baggi, all of the Carlo Besta Institute, and of Prof. Evoli of Policlinico Gemelli in Roma, Dr. Luisi of Fondazione Don Carlo Gnocchi, near Florence, and Prof. Toscano of Policlinico "G. Martino" in Messina. A.I.M. has many various fund-raising activities. These include an annual concert, which has been held in the famous Duomo and other beautiful places in Milan, the next one to take place at the Conservatorio Giuseppe Verdi on January 28, 2011 with "Coro Polifonico 10" and the baroque ensemble "Il Demetrio"; car rallies; various dedicated markets throughout the year, including Christmas markets; sales of calendars and T-shirts with the A.I.M. logo etc. The raised funds are used to finance research on MG and other neurodegenerative diseases, including specific research projects, acquisition of expensive necessary equipment for the Neuromuscular Diseases Dept. at Carlo Besta Institute, and research student fellowships. But fund-raising is not A.I.M.'s only activity! Indeed, the association is very active in promoting awareness of MG in Italy. This is being accomplished through the production of a booklet, a "friendly guide" on MG, which is regularly updated with all kinds of relevant information for patients and clinicians who are not specialists and includes a list of reference centers for MG in Italy. It is distributed free of charge to patients and clinicians on request. A.I.M. organizes an information day every two years to raise the awareness of MG in medical and paramedical personnel and answer their questions. Because, except in the Piedmont region, MG is not recognized as a rare disease in Italy but is considered a chronic disease, patients must pay for much of their treatment; AIM is trying to change this situation through its action as member of "Consulta Malattie Rare" which is accredited by the Ministry of Health. AIM, together with 20 other Italian associations of patients with neurological diseases, has also initiated the creation of FIAN (...) whose goal is to develop activities to help people affected with neurodegenerative diseases in general.

At the European level, A.I.M. has been a strong supporter of the establishment of EuMGA, the Federation of European MG associations whose current chairperson is Dr. Fulvio Baggi, the official representative of A.I.M. Indeed, AIM hosted and financed the meeting of the Working Group that decided the establishment of EuMGA in March 2009. A.I.M. also organized the 2007 international research conference "Evidence-Based Myasthenia" to which patients and MG associations were also invited.

To help Italian MG patients in a more concrete way, A.I.M. has created a specific website, www.miastenia.it, which provides information but also offers patients the opportunity to communicate with MG clinical specialists through email, through a forum where a MG specialist answers questions posed by the patients through the website, or through the "Centro d'Ascolto", the "listening center", where a patient can make an appointment to speak by telephone with a MG specialist in a weekly session to raise queries, concerns etc.

Finally, a big project of A.I.M. is to establish a registry of all patients throughout Italy. This project was initiated in 2004, and is approved and financed by Provincia di Milano and Regione Lombardia; it will be the basis for epidemiological studies of MG in Italy.

ROMANIA

Romanian Myasthenia Gravis Association (ANMGR)

Speaker: Dr. Nadia Radulescu

Asociatia Nationala Miasthenia Gravis Romania was founded in November 2005 by patients suffering from this disease. Our mission is to help myasthenic patients to improve their lives through programs of patient services, public information, professional education and advocacy.

The full members are MG patients and relatives who participate actively and pay an annual fee to the association. In 2011 the association has 120 active members and offer services to over 700 MG patients. The Directory Council in Bucharest coordinates all the activities from the national office. We have 6 local chapters and contact persons in the majority of the cities. We have no staff, all the workers are volunteers.

Funding

The money comes from private sponsorships, donations from the members or other persons and through the national campaign (2%).

Activities and goals

The primary activity of our association is patient information provided by our National MG Info Centre (INFO MG-RO), the first helpline focused on a single rare disease, part of the European Rare Diseases Helplines Network - Rhapsody project EURORDIS).

INFO MG-RO offers informations on the disease, medical centres and specialists, local patients support groups and contact with other patients, about social care, medication availability, psychological support. Informations are provided by telephonic Infoline, emails, forum, or onsite visits. We provide literature on the disorder and treatment, available through the national office and the website (www.miasthenic.ro). We translated, published and disseminated the first Euromyasthenia brochure: "Myasthenia Gravis-information for patients and families" and translated and published recently the book Myasthenia Gravis and related disorders by Henry J Kaminski MD, project founded and realised 100% by our association's contribution.

Problems

Since the main issue for MG patients in Romania is the chronic shortage of specific medication Mestinon®, the association's most important goal is to help patients with medication supply. We fight with the authorities to get the legal status for drug importation and have it free of charge, build our own network for collecting information on medication's needs and have our own buffer stocks of medication from donations. The problems is still not solved. In february 2011 there is no Mestinon available in pharmacies and the situation seems to perpetuate because of the economic crisis and governmental policies

ANMGR is also a member of the Romanian Alliance for Rare Diseases, working together for implementation of the National Plan for Rare Diseases in our country.

UNITED KINGDOM

The Myasthenia Gravis Association of the UK (MGA-UK)

Speaker Mr Peter Finney

The Myasthenia Gravis Association of the UK is an English Charity which operates in England, Wales, Scotland, Northern Ireland and the Republic of Ireland.

Brief history

The Association originated in the 1960s, when small groups of patients worked with the Muscular Dystrophy Campaign. In 1976, two English patients' groups formed a separate Charity, The British Association of Myasthenics (later The Myasthenia Gravis Association). In 1995, the Charity became a Company Limited by Guarantee, at the same time changing its scope formally to include the welfare of myasthenics in the Republic of Ireland.

Governance and Membership

The Charity is governed by a Board of 12 Directors. The Directors are elected by the members of the Association. Membership is open to any adult person in UK and Ireland who is interested in the objectives of the Association. There are currently 2,321 Full (voting) members of the Association. There are no membership fees.

The Association is in regular contact with approximately 6,000 sufferers from Myasthenia Gravis, Lambert-Eaton Myasthenic Syndrome (LEMS) and Congenital Myasthenic Syndromes (CMS).

Objectives

The objectives of the association are:

To fund research into the causes, diagnosis and treatment of Myasthenia Gravis, LEMS and CMS

The education of patients, doctors and the public to improve awareness of the diseases and promote more effective medical care.

To achieve better care for myasthenics by promoting the creation of specialist medical centres and supporting local patients support groups.

Budget and Activities

The Association's Budget for its last financial year was approximately €1.26M.

The Association spends considerable funds on promoting research, and the education of scientists and neurologists. It is supporting three post-graduate medical students who are involved in relevant research at British Universities. It is also directly funding research into the genetics and diagnosis of Congenital Myasthenia and a number of other research topics.

The Association funds 5 Specialist Myasthenia Gravis Nurses at Medical Neurology Centres in UK and Ireland.

The Association publishes Medical and Social Welfare Information in a variety of media including books, videos, DVDs and CDROMS. This information is available from the Associations' website (www.mga-charity.org), which also provides an online forum and chat-room.

Operation

The association operates from its headquarters in Derby, England, with a small full-time and part-time professional staff. There are currently 49 branches in the British Isles which are each formed around a local support group. The branches are assisted by nine paid Regional Organisers, who also organize regional activities and assist the central staff in managing national events.

DENMARK

Danish Myasthenia Gravis Association

Poster presentation Mr Johannes Gravgaard and Mr Asger Frost

Rehabilitation of MG patients in Denmark

Quick Diagnosing and sufficient medical treatment is paramount for the successful rehabilitation of patient with MG. However, in order to avoid a social downfall as a consequence of the disease , many MG patients are also in need of treatment at the social, family and psychological levels.

In Denmark, we operate with a rehabilitation model for MG patients that offer support to persons with MG in in need of a more comprehensive rehabilitation effort as a supplement to the medical treatment ond in collaboration with doctors.

Anyone suffering from MG I Denmark can get a referral to the National Rehabilitation Centre for Neuro-muscular Diseases where they are offered a coherent, individual rehabilitation plan.

The plan is centred on the patient's own needs and wishes, and involves:

- information about the disease to then patient, his/her relatives and the therapists working for the local social authorities;
- collaboration with neurologists at centralized neurology departments;
- the possibility of a lifelong follow up on chronic social conditions that require new initiatives;
- cooperation with local professionals in coordinating the initiatives necessary for a successful and lasting rehabilitation process;
- training at family seminars and workshops; close collaboration with patient organizations, etc.

HUNGARY

Myasthenia Gravis Self-help groups of patients (Myasthenia Gravis Önsegítő Betegcsoport) (MEOSZ)

Speaker Ms Alexandra Telek

Our association name is Myasthenia Gravis Self-help groups of patients (Myasthenia Gravis Önsegítő Betegcsoport). It formed without support as a separate section in MEOSZ in 02. 12. 1994. Twelve enthusiastic activist founded it which is still in the works in this form and work with social workers (we have about 600 members in our group now). Our group main purpose was the next: We would like to raising people attention. Raising attention this rare hardly recognizable autoimmune disease and people who suffering this disease and their problems about health, social and family concerns. And we would like to help reinforce positive thinking, and help them to experience disease. In the first year we make a card which name is „Emergency Card” and we sent it all members. This card is very important because if the patient have an accident or they will ill the „Emergency Card” get help for the doctors or assistance. We have a list too, this name is „Medicine prohibited list”. We hold a general meeting about 3-4 times a year for our members. We invite the members in our newspapers (Myasthenia Highlights). People who can't come in this event haven't got any problem because we write „Event Summary” in he next journal. Newspaper contain medical professional articles, legal and lifestyle advices, and we help them and give advices, experiences from the others.

Membership does not involve a financial obligation. We have low membership fee but it is not binding (it is 1000 Forint (about 4 Euros)). Sometimes our group recieve donations and we are very grateful for it. Unfortunately we are unable to providefinancial support, but we are open to all the problems and difficulties affecting the community. We belong several associations, for example MEOSZ (which is a hungarian “National Association of Disabled”). RIROSZ („Hungarian Rare National Association of Diseases”). EU-RODIS (center in Brussels) („European Organisation of Rare Diseases”).

Our motto: Understanding of Care!

FRANCE

Association des Myastheniques AMIS

Poster presentation: Ms Claire Bellenger

The association AMIS is a French myasthenia association available to French-speaking communities. The website was set up in 2004 and the association was created in 2007. 140 members pay a low subscription.

Close to 1000 people have joined the website: 90% in France, 5% in Belgium, Switzerland, Luxemburg and 5% in the rest of the world. More than 1000 topics have been opened : documentaries, forms, aid approaches. More than 50 000 messages have been posted over the six years.

The association's activity is varied: welcome and hints for recently diagnosed people with myasthenia on both the website and by phone in needed, animation for the website, exchange of experiences, dialogue, placing online documentation.

Several national meetings have taken place, which are extremely positive. The organization of these meetings is very difficult because Myasthenia is very unpredictable and the people suffering from this illness are unable to know in advance whether they will be well enough to attend the meetings.

THE NEDERLANDS

Dutch Neuromuscular Disease Association (VSN)

(Myasthenia Working Group)

Speaker Mr Johan Voerman

The Dutch Neuromuscular Disease Association (VSN) was founded in 1967, originally only aimed at parents of children with an NMD. Later the focus shifted towards all people with an NMD. In 1975 the Myasthenia gravis working group was founded as the first of a series of so-called diagnosis working groups within VSN. The main work of the working group is informing our members on everything there is to know about the different myasthenias, but also to facilitate contacts among the members. VSN currently has 8,600 members, of which 765 have a myasthenia. In total there are 14 diagnosis groups.

In close co-operation with our medical advisers we have published a number of information leaflets and brochures, which all members receive when they join VSN. There are also special brochures aimed at medical and paramedical professionals.

Once every year a general meeting is organised at which the latest developments in diagnosis, treatment and research is presented by one of the leading neurologists in the Netherlands. In the afternoon there is ample opportunity to meet with each other and exchange experiences in different workshops.

VSN also has 10 regional working groups, which mainly facilitate the contacts among VSN members in the different regions. The regions organise small-scale meetings, sometimes aimed at specific diagnoses, sometimes at subjects that are interesting for several diagnoses (such as physical therapy, home adaptations, care for children with an NMD, etc.).

The Myasthenia working group currently consists of five people, four of which suffer from Myasthenia gravis and one has LEMS.

EUROPEAN MG PATIENTS ASSOCIATIONS CONTACT DETAILS

EuMGA MEMBERS:

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CYPRUS

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DENMARK

DANISH MYASTEHNIA GRAVIS ASSOCIATION –
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**HUNGARY**

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**UNITED KINGDOM****THE MYASTHENIA GRAVIS ASSOCIATION OF THE UK ((MGA-UK)**

The Myasthenia Gravis Association of the UK is an English Charity which operates in England, Wales, Scotland, Northern Ireland and the Republic of Ireland.



Address: The College Business Centre, Utttoxeter New Road

DERBY DE22 3WZ ,UK

Phone: 01332-290219

Fax: 01332-293641

Free Phone Help Lines: Within UK: 0800-919922

Within The Republic of Ireland: 1800-409672

Email: mg@mga-charity.org

Website: www.mga-charity.org

Contact person PETER FINNEY, peter@finney.me.uk

IRELAND**IRELAND MGA**

Contact person of patient organisation:

phone helpline: Within The Republic of Ireland: 1800-409672, P.O. Box 480, Ennis,

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OTHER EUROPEAN MGA ASSOCIATIONS**NEDERLANDS ASSOCIATED MEMBERS (pending approval)**

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**RARE DISEASES HELPLINES****BELGIUM**

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Rare Disease Day



**RARE
BUT EQUAL**

**RARE
DISEASE**

February
28th 2011

DAY

